Learning disabilities and behaviour that challenges: service design and delivery

Appendix B – Evidence tables

Critical appraisal and findings tables

Critical appraisal tables 3
Findings tables 200

Critical appraisal tables

Included studies were rated for internal validity (the extent to which the study can measure what it aims to measure) and external validity (the generalisability of the study findings to the population in the guideline scope) using critical appraisal checklists adapted from the NICE manual (and agreed with NICE) and the results tabulated. Different checklists were used for different study designs as appropriate (see table below). The checklist for each type of study design considered the rigorousness of execution, the strength and limitations of the study designs, and efforts to minimise bias in the findings.

Study design	**Checklist**
Systematic review	Systematic review checklist
Randomised controlled trial	Quantitative evaluation checklist
Economic evaluation	Economic evaluation checklist
Non-randomised controlled trial	Comparison evaluation checklist
Single group, pre-post test	Comparison evaluation checklist
Secondary data analysis (e.g. retrospective case note review) by time	Cross sectional survey checklist
Process evaluation	Qualitative checklist
Longitudinal	Cohort
Interviews	Qualitative checklist
Survey of views	Cross sectional survey checklist
Mixed methods	Mixed methods checklist

1. **Ahmad F et al. (2002) Partnership for developing quality care pathway initiative for people with learning disabilities: part I: development. Journal of Integrated Care Pathways 6: 9–12**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Process evaluation. **Is a qualitative approach appropriate?** Appropriate. The research question seeks to understand processes or structures, in social care this would apply to how care and support is organised. **How defensible/rigorous is the research design/methodology?** Defensible. **How well was the data collection carried out?** Appropriately the study used different methods to elicit information from the working group. **Is the context clearly described?** Clear.	**Are the data 'rich'?** Mixed. **Is the analysis reliable?** Somewhat reliable. **Are the findings convincing?** Not sure. The study describes the development phase only, not the impact or effectiveness of the care pathway. Authors say that the results from the pilot with be published in the Journal of Integrated Care Pathways, but this journal ended in 2008. **Are the conclusions adequate?** Somewhat adequate.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. No ethical concerns identified Participants were practitioners and service user representatives. Authors considered the involvement of service users in the working group but decided on a parallel working group to feed back into the group via the service user representative. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the**	**Overall internal validity score** + **Overall external validity score** + **Overall score** +

Were the participants recruited in an appropriate way? Somewhat appropriate. The response rate of the invited participants was not reported. **Were the methods reliable?** Reliable. The data was collected by more than 1 method and other studies were discussed alongside the findings of this study.		**groups covered by the guideline?** Partly. The care pathway for the group with behaviour that challenges was 1 of 3 to be developed. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Partly The exact nature of the treatment and assessment unit was not specified. **Are the study outcomes relevant to the guideline?** Partly, the study looks at the development phase of a care pathway and does not look at impact or effectiveness. **Does the study have a UK perspective?** Yes.	

2. **Alborz A (2003) Transitions: Placing a son or daughter with intellectual disability and challenging behaviour in alternative residential provision. Journal of Applied Research in Intellectual Disabilities 16: 75–88**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating

Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Two methods of data collection used. A survey and measurement of stress levels. Participants all came from the same geographic location. Due to the small number of participants (n=18) this precludes generalisation to the general population of children with intellectual disabilities who have challenging behaviour. Could have been helpful to include some quantitative data collection from administrative data that included more specific information about types of	**Are the data 'rich'?** Yes. Analysis of the transcripts employed techniques including generating 'low level categories' to describe relevant features of the data, creating definitions of and linkages between categories and making constant comparisons between cases to fully explore the complexities of the data. Two methods of analysis were used. **Is the analysis reliable?** Reliable. Consistency was assured by using a single assessor and categories/descriptions generated by analysis of a random selection of transcripts. Reliability in the analysis of data was addressed by joint review of transcripts with a study supervisor to enhance sensitivity, uncover researcher biases and assumptions and clarify interpretation of the data.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** No. Not mentioned. **Were service users involved in the study?** No. Families of service users were participants in this study. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. All service users had an intellectual disability and challenging behaviour. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	**Overall assessment of internal validity** ++ **Overall score** ++ **Overall assessment of external validity** ++

accommodation people moved to. **How well was the data collection carried out?** Somewhat appropriately. The data collection methods are quite clearly described. Most of the interviews were tape-recorded and transcribed and in the remainder responses were noted. Appears to be quite systematic from the level of detail reported in the paper. **Is the context clearly described?** Clear. The authors wanted to extend and test earlier work on the applicability of 3 transition profiles (Essex et al. 1997). Part of a larger epidemiological survey to identify the people with learning disabilities who have challenging behaviour. **Were the participants recruited in an appropriate way?** Somewhat appropriate. Two groups recruited. One group,	**Are the findings convincing?** Convincing. Extracts from the original data are included and the data is appropriately referenced. Data in the tables is reported in a clear and coherent way. Data in the tables matches with the narrative text. **Are the conclusions adequate?** Adequate. The findings are relevant to the aims of the study and you can see the clear links between data, interpretation and author conclusions. The conclusions seem plausible and coherent based on the data presented. The implications of the research for service models is clearly stated and the research builds on and extends existing studies.	**(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Sample in this study is taken from a North West regional health authority in the UK.	

follow-up of parents surveyed in 1993 study (Kiernan and Alborz 1995). The other group included parents, not previously contacted. **Were the methods reliable?** Somewhat reliable. Data was collected by more than 1 method and appear to investigate what the authors are looking into. However, no information is provided on the actual interview questions, so not possible to tell if the appropriate questions were asked. The tables used in the paper indicate that reliable methods might have been used because the data is presented is a systematic way.			

3. **Allen DG, Lowe K, Moore K et al. (2007) Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour. Journal of Intellectual Disability Research 51: 409–16**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Cross-sectional study.	**Objectives of study clearly stated?** Yes.	**Has the study dealt appropriately with any ethical concerns?** Yes.	**Overall assessment of external validity**

Does the study's research question match the review question? Yes.	**Clearly specified and appropriate research design?** Yes. **Subjects recruited in acceptable way?** Yes. **Sample representative of defined population?** Yes. **Measurements and outcomes clear?** Yes. **Measurements valid?** Yes. **Setting for data collection justified?** Partly. Only percentages given for place of residence and services received; very little details provided about cost differences and the composition of service costs in (in-area/out of area) placements. **All important outcomes and results considered?** No. Quality of life or quality of service outcomes could have been included. Lack of information about composition of costs data. **Tables/graphs adequately labelled and**	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	++ **Overall assessment of internal validity** - **Overall score** -

	understandable? Partly. Place of residence and services received only percentages given, no total number provided. **Appropriate choice and use of statistical methods?** Partly. Appropriate for the main part of the study about predicators, less so for the other aspects of the study. **In-depth description of the analysis process?** Yes. Especially for the predictive part of the study. **Are sufficient data presented to support the findings?** Partly. Discussion in the text of behaviour plans and medication, but data not fully reported. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. **Results can be generalised?** No.		

	Do conclusions match findings? Yes.		

4. **Ayres M, Roy A (2009) Supporting people with complex mental health needs to get a life! The role of the Supported Living Outreach Team. Tizard Learning Disability Review 14(1): 29–39**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Process evaluation. **Is a qualitative approach appropriate?** Somewhat appropriate. The research seeks to understand processes or to illuminate subjective experiences from practitioners. However, it would have been better to have included the views of service users as well. A quantitative approach, which partly used to measure outcomes in this study, would have provided better data to help evaluate the effectiveness of the service.	**Are the data 'rich'?** Poor. Only get the perspective of the authors who work for the service, so potential for positive bias. **Is the analysis reliable?** Somewhat reliable. Taking into account the limited perspective, some of the hurdles the team has had to face are discussed and the researchers provide reasons why it was difficult to present data for all service users on e.g. frequency of incidents of challenging behaviour. **Are the findings convincing?** Not convincing. **Are the conclusions adequate?** Inadequate. On the measures of	**Does the study's research question match the review question?** Partly. This study describes the development and functioning of a team dedicated to supporting people with learning disability and complex needs to live full lives in the community. It includes service outcomes but it is not a full effectiveness study that can tell us whether or not this model is more effective than something else. **Has the study dealt appropriately with any ethical concerns?** Yes. Process evaluation so consent wasn't required.	**Overall assessment of internal validity** - Outcome measures not reported fully and unreliable. As the authors, who work closely with the service, carried out the evaluation likelihood of positive bias and lack of perspectives included about the service. **Overall assessment of external validity** + **Overall score** -

Is the study clear in what it seeks to do? Mixed. Largely a description of a new service which includes measures that the service uses to monitor effectiveness and includes barriers and facilitators to implementing the service. However, the authors don't make clear that they also work for the team and how this might impact on the study, e.g., tendency to describe the positive aspects of the service. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. The design is somewhat appropriate to the research question. However, clear accounts or descriptions of the data collection and data analysis techniques used is not provided. The client group is well described and the way the team operates is described well. **How well was the data collection carried out?**	effectiveness and costs, not reported adequately. In relation to barriers and facilitators involved with introducing a new service, that could be generalisable to other services and community setting the conclusions are adequate.	**Were service users involved in the study?** No **Is there a clear focus on the guideline topic?** Yes. Supported living, community service. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community setting. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Views of practitioners providing a service, but views	

Inappropriately. Not clearly described. **Is the context clearly described?** Unclear. Context bias needs to be considered as you just get the observations of the authors who work in the service, so bias likely to be positive. Would have been helpful to include observations from other services that work directly with the team and from service users. **Were the participants recruited in an appropriate way?** Not sure. The current client group of the team is used and well described. However, the authors carrying out the evaluation work for the service, no indication of outside perspective. **Were the methods reliable?** Unreliable.		of service users not included in the service evaluation. **Does the study have a UK perspective?** Yes. Birmingham, UK.	

5. **Baker PA (2007) Individual and service factors affecting deinstitutionalization and community use of people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 20: 105–9**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Comparison evaluation. **Is a cohort study approach appropriate?** Inappropriate. Not prospective allocation. The comparison group is the new usual care, after the move towards de-institutionalisation. Few differences at time 2, unsurprisingly then were detected between the 2 groups. **Is the study clear in what it seeks to do?** Unclear, the study mainly considered individual level factors and less service factors relevant to this study, which might have included have included information about staff ratios, staff qualifications.	**Selection bias** **Likely direction of selection bias effect** Positive. **Allocation unrelated to confounding factors?** No **Attempts made to balance the comparison groups?** No **Groups comparable at baseline?** No. The resettlement group were significantly older and with significantly less self-injurious behaviour than the comparison group. **Was selection bias present?** High risk of bias. **Equal treatment?** Unclear Little is known about the comparability of the 2 groups or in how they differ in context, community characteristics, staffing, type of group home	**Does the study's research question match the review question?** Partly. The aim was to examine individual and service level factors, but the outcomes are mainly individual factors. **Has the study dealt appropriately with any ethical concerns?** No. There is no mention of consent or ethical approval. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. The study states that they hypothesise that behaviour that challenges would be a predictor in community participation, but it is not	**Overall assessment of internal validity** - **Overall assessment of external validity** + Medium mainly due to missing ethical approval and consent procedures. **Overall score** -

	(congregate or non-congregate) ethos etc. **Allocation – participants** No. **Allocation – practitioners** Unclear. **Performance bias appraisal** High risk of bias (also A5). **Likely direction of performance bias effect** Inflated. **Follow-up** Yes. **Drop-out numbers** Not stated **Groups comparable on intervention completion?** Unclear. Scores not reported. **Groups comparable on available data?** Unclear **Attrition bias appraisal** High risk of bias (also A5) drop-out data not known. As level of adaptive behaviour was correlated with community participation, attrition from people with more challenging behaviour would overemphasise the community participation for the remainder.	stated how many participants in each group may have displayed behaviour that challenges. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. The people who used services were moved to group homes. No further details on whether congregate or non-congregate. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Community participation. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

	Did the study have an appropriate length to follow-up? Only 6 months is a short time to assess community participation for people who have just moved out of hospital into a group home. **Did the study use a precise definition of outcome?** No. **Was the method used to determine the outcome valid and reliable?** No. Some variables are likely to be correlated with each other (BPI, SIB, Stereotypy etc.). **Were investigators kept 'blind' to participants' exposure to the intervention?** No. **Were investigators kept 'blind' to other important confounding factors?** No. **Do conclusions match findings?** Partly.		

6. **Balogh R, McMorris CA, Lunsky Y et al. (2016) Organising healthcare services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 4: CD007492**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Systematic review. **Appropriate and clearly focused question?** Yes. **Inclusion of relevant individual studies?** Yes.	**Rigorous literature search?** Yes. **Study quality assessed and reported?** Yes. **Adequate description of methodology?** Yes. **Do conclusions match findings?** Yes.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	**Overall assessment of external validity** ++ **Overall assessment of internal validity** ++ **Overall score** ++

		Are the study outcomes relevant to the guideline? Yes. **Does the study have a UK perspective?** Yes.	

7. **Bartle J, Crossland T, and Hewitt O (2016) 'Planning Live': Using a person-centred intervention to reduce admissions to and length of stay in learning disability inpatient facilities. British Journal of Learning Disabilities 44: 277–83**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Mixed methods. **Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Partly. Full information is not provided about the comparison group. **Is the integration of qualitative and quantitative data (or results) relevant to address**	**Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. Views and experiences of parents and families involved in the process; also included views of practitioners. **Is the process for analysing qualitative data relevant to address the research question?** Yes. Thematic analysis in line with Braun and Clarke (2006). **Is appropriate consideration given to how findings relate to**	**Does the study's research question match the review question?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Has the study dealt appropriately with any ethical concerns?** Partly. Not clear, however data collection seems to have been part of the planning meeting process where consent was sought; so it assumed that this consent extends to the research study as well. **Were service users involved in the study?** Yes. Not directly.	**Overall assessment of external validity** ++ **Overall assessment of internal validity** - **Overall validity score** - Not a true comparison group plus not clear from the study who was speaking: whether it was a professional's view or a family member's view, which may be important to

the research question? Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** Partly.	**the context, such as the setting, in which the data were collected?** Unclear. Don't know who the participants were and what the response rate was from total number asked to complete the feedback form. **Is appropriate consideration given to how findings relate to researchers' influence; e.g., though their interactions with participants?** Yes, feedback form, researchers' influence of less importance.	Views of families and carers included and data collected about service users. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. People with a learning disability receiving treatment for challenging behaviour or mental health difficulties in hospitals. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. Views of families and carer, not direct service users. **Does the study have a UK perspective?** Yes.	know whether the services was helpful for families.

8. **Beadle-Brown J, Hutchinson A, Whelton B (2008) A better life: The implementation and effect of person-centred active support in the Avenues Trust. Tizard Learning Disability Review 13: 15–24**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Process evaluation. **Is a cohort study approach appropriate?** Appropriate. The focus of the study is not whether person-centred active support is effective compared to not having person-centred active support, which would not be acceptable, but what are the issues in its implementation? In this case the single cohort study would be appropriate. **Is the study clear in what it seeks to do?** Clear. **Allocation unrelated to confounding factors?** Unclear. Data was collected for 29 individuals. It is not clear how representative this sample was or what the whole sample	**Do conclusions match findings?** Partly. Authors conclude that the implementation has been successful in the Avenues Trust overall, however, the trust takes care of more than 400 people with intellectual disabilities, and the study sample in this case was only 29 individuals, there is no information on whether this groups is representative of the residents of Avenues Trust homes overall.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval was gained both from the university research ethics committee and, with respect to a wider research programme of which this forms a part, from an NHS research ethics committee. Consent to observe was sought by the Avenues Trust from as many of the service users as possible, using adapted consent forms and individual explanations for each person. Where informed consent could not be obtained, the service consulted the appropriate people for each individual to obtain agreement.	**Overall internal validity score** - **Overall external validity score** ++ **Overall score** -

frame numbers were, or if there were any significant differences between participants and non-participants. It is not reported what proportion of those invited to take part agreed to take part. **Attempts made to balance the comparison groups?** Unclear. **Groups comparable at baseline?** Unclear. **Was selection bias present?** Low risk of bias. Participants tended to be as having higher support needs. **Equal treatment?** Yes. **Allocation – participants** No. **Allocation – practitioners** No. It would not be possible to blind the practitioners and managers who received the training. **Performance bias appraisal** High risk of bias from the observer effect, persons and practitioners would have been		**Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes: person-centred active support. **Are the study outcomes relevant to the guideline?** Yes. This study is primarily about the implementation and the effectiveness of delivery of good quality training in person centred active support. **Does the study have a UK perspective?** Yes.	

aware of the observer and may have adapted their behaviour, both in terms of resident behaviour and also of staff in implementing person-centred support. **Likely direction of performance bias effect** Inflated. **Follow-up** Yes. **Drop-out numbers** Four questionnaires not returned out of 36. **Groups comparable on intervention completion?** Unclear. Staff questionnaires could not be matched between follow-up and baseline because most staff had refused to provide the identification code requested at baseline. **Groups comparable on available data?** Yes. Authors state that here were few differences between the characteristics of staff at baseline and at follow-up.			

Attrition bias appraisal Low risk of bias. The majority of questionnaires were returned. **Did the study have an appropriate length to follow-up?** Yes, 1 year after implementation. **Did the study use a precise definition of outcome?** No. **Was the method used to determine the outcome valid and reliable?** No. Very short time period for observation. 2 hours 16.00 and 18.00 in the lead-up to the evening meal. Different time periods in the day may have had different levels of active support. **Were investigators kept 'blind' to participants' exposure to the intervention?** No. **Were investigators kept 'blind' to other important confounding factors?** No.			

9. **Beadle-Brown J, Mansell J, Whelton B et al. (2009) People with learning disabilities in 'out-of-area' residential placements: views of families, managers and specialists. The British Journal of Developmental Disabilities 55: 15–31**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate the study looks for reasons for placement out of are the views of the staff and family carers should capture some information not available from official records alone. **Is the study clear in what it seeks to do?** Clear.	**Are the data 'rich'?** Rich. **Is the analysis reliable?** Somewhat reliable. Again, there is little description of how the themes were reached. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Somewhat adequate. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Different interview methods were used with different participants – focus groups for the community teams, telephone interviews with care home managers and face to face interviews with family carers.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Partly. Consent was sought from participant or proxy. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Population not wholly people with learning disabilities and also challenging behaviour, but a significant proportion are likely to be, as behaviour that challenges is a factor for placement.	**Overall assessment of internal validity** + **Overall score** + **Overall assessment of external validity** +

	How well was the data collection carried out? Somewhat appropriately study says that the face to face interviews and focus groups were recorded and transcribed verbatim, the telephone interviews with the care managers may not have been. Not clear if they had the same schedule of questions. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Somewhat appropriate Participants were recruited via snowballing via the care home managers, who acted as gatekeepers to the family carers. There may have been the possibility of selection bias. **Were the methods reliable?** Somewhat reliable. The analysis is only described minimally, it is not clear whether these themes were discussed between the	**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. The study includes the views of care home managers, community teams and family carers.	

	research team, or shared with the participants.		

10. Broadhurst S, Mansell J (2007) Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities. Journal of Intellectual Disability Research 51: 293–301

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**

Methodology Qualitative evaluation. **Objectives of study clearly stated?** Yes. The context of previous research is provided and 4 hypotheses to be investigated are clearly stated. **Clearly specified and appropriate research design?** Partly. It is a non-experimental group comparison design. It is partly appropriate. The criteria for the maintained group is that placements had been successfully maintained in the community for the previous 12 months. 12 months isn't a long time to indicate stability in a placement. **Subjects recruited in acceptable way?** No. Self-selected from a mailing list of services subscribing to an information exchange network run by the Tizard Centre, University of Kent. Total of 39 managers chose to participate that served people with our population. They were	**Measurements and outcomes clear?** Partly. What and how was measured is fairly clearly described. But not all the outcomes are reported. For example, 'participation in daily living', reported no significant differences, so not reported in enough detail to tell if anything is missing. **Measurements valid?** No. Researcher-defined measures of ID and challenging behaviour were used and not standard measures or tools used in other research. Validity of these not tested. Service characteristics are not reported in enough detail to know if they are valid. **All important outcomes and results considered?** Partly. A lot of information, 92-item structured questionnaire, was collected but only a summary is reported. While the information reported appears to be the most important findings it would have been helpful to see the	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** No. Participants were asked to rate the personal characteristics of service users, for attributes such as level of intellectual disability and level of challenging behaviour and to provide information about other service users, yet no information is provided on whether any consent was sought and how this information was collected. **Were service users involved in the study?** No. Staff were asked about 'the service user who had challenged their service the most in the past 12 months'. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the**	**Overall assessment of internal validity** - **Overall assessment of external validity** + **Overall score** -

allocated into 2 groups of approximate equal size, based on criteria of whether they had experienced a placement breakdown or not, but it is not clear how the actual allocation was made. Assume the allocation was done following the collection of information, although this isn't stated. Did it just happen that the 2 groups worked out approximately of equal numbers based on the criteria for allocation into the groups? **Sample representative of defined population?** Unclear. While it is clear that only care managers of homes for people with ID and behaviour that challenges were included in the study, which is the same as our population, we don't know how many of the total care homes in the South East of England were involved in the study. Less than a 50% response rate to the questionnaire, which does not provide much confidence that the sample is representative, plus it might be that those that	questionnaire in full to be able to make a proper assessment. To see the full reporting on how often residents took part in various daily living activities or more about the training or staff. **Tables/graphs adequately labelled and understandable?** Partly. The 2 summary tables are adequately labelled, however it would have been helpful to have some additional tables included to see the results more fully. **Appropriate choice and use of statistical methods?** Partly. Differences between the 2 groups of services were explored using Mann-Whitney tests for ordinal data or chi-square for categorical data. The authors say it wasn't appropriate to use other statistical techniques, particularly due to the exploratory nature of the study.	**groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Partly. They address factors that may be associated with breakdown of residential placements for people with intellectual disabilities. **Does the study have a UK perspective?** Yes. Care homes in the South East of England.	

decided to respond were more positive about services.	**In-depth description of the analysis process**? No. **Are sufficient data presented to support the findings?** Partly. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. **Results can be generalised?** No. This is a relatively small-scale study, using previously untried measures of service characteristics which means it is not possible to demonstrate the validity of the questionnaire or to compare this sample with others. In addition, the 2 groups did not turn out to be comparable in terms of resident characteristic which makes it difficult to be sure that resident characteristics are not a contributing factor. **Do conclusions match findings?** Yes. They are consistent with other advice and guidance from the Department of Health (1993)		

	and Commission for Social Care Inspection (Wing and O'Connor 2003).		

11. Brown RI, Geider S, Primrose A et al. (2011) Family life and the impact of previous and present residential and day care support for children with major cognitive and behavioural challenges: A dilemma for services and policy. Journal of Intellectual Disability Research 55: 904–17

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. Study aims to examine parent's perceptions of impact of the day and residential services, booth before accessing the school and after. **Is the study clear in what it seeks to do?** Mixed. The original aim was to interview parents about the impact of roadworks. It might have been	**Are the data 'rich'?** Rich. Differences between participant responses marked as either Interview (I) or focus groups (F) but not anonymised codes for individual participants, so it is not possible to know if there was a wide range of views represented. **Is the analysis reliable?** Somewhat reliable. Parents may have felt more positive about the school at the time that they thought it may have	**Does the study's research question match the review question?** Yes. Types of services are full time day and residential supports services. **Has the study dealt appropriately with any ethical concerns?** Yes. Permission sought for recording interviews and focus groups. Study participants were supplied with basic information, which included the reasons for the collection of data, the nature of the interview and focus group, the observance of confidentiality (no names of	**Overall assessment of internal validity** ++ **Overall assessment of external validity** + **Overall score** +

an atypical time to ask people's experiences **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Both one-to-one interviews and focus groups were undertaken for this study. **How well was the data collection carried out?** Appropriately. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Somewhat appropriately Initially, parents were asked to participate to give their views in light of the roadworks development that was going on outside the home and this part of the study, of parents' views forms part of a larger study. Reasons for participation may have been	been under threat by the roadworks. **Are the findings convincing?** Convincing. There was agreement between the themes expressed by the one-to-one interviews and the focus groups. **Are the conclusions adequate?** Somewhat adequate. Parents often had n other experiences of services to compare it to, as many parents had not had access to any services before the school.	adults or children to be used in published documents), the right of the participant to terminate any interview or focus group or to decline to answer any questions. **Were service users involved in the study?** No. Parents of people with learning disabilities and behaviour that challenges. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Population is people with cognitive disabilities and extreme behavioural challenges. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities**	

based on their support for the school, instead of participation in research alone. **Were the methods reliable?** Reliable.		**covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Impact on family life, decision making in accessing services, quality of life. **Does the study have a UK perspective?** Yes.	

12. Browning M, Gray R, Tomlins R (2016) A community forensic team for people with intellectual disabilities. Journal of Forensic Practice 18: 274–82

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Cross-sectional study. **Does the study's research question match the review question?** Yes. **Clearly specified and appropriate research design?** Partly. The study does not	**Measurements and outcomes clear?** Yes. **Measurements valid?** Yes. **Setting for data collection justified?** Yes. **All important outcomes and results considered?** Yes.	**Has the study dealt appropriately with any ethical concerns?** Yes. Study was approved by the trust clinical governance committee as a service evaluation to inform service development. **Were service users involved in the study?** No.	**Overall assessment of external validity** ++ **Overall assessment of internal validity** + **Overall score**

compare to another comparable group, or a national baseline figure to know whether the numbers of people who committed another offence was lower than usual and it was not clear how severity was measured or if it was appropriate to think of a reduction in severity as an outcome. **Subjects recruited in acceptable way?** Yes, all referrals to a service. **Sample representative of defined population?** Partly. Limited to people referred to the service, don't know about the people who weren't referred or are not known to services.	**Appropriate choice and use of statistical methods?** Yes. **In-depth description of the analysis process?** No. **Are sufficient data presented to support the findings?** Yes. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. **Results can be generalised?** Unclear. Date was only collected for 1 service open at a specific time point. A different pattern of usage might occur over a longer time frame. **Do conclusions match findings?** Yes.	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. People with intellectual disabilities supported by a community forensic learning disability team. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community forensic team. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes **Are the study outcomes relevant to the guideline?** Yes. To help answer question about capacity. **Does the study have a UK perspective?** Yes.	+ Study relies on the accuracy and detail of reporting at the time.

13. Buxton L, Pidduck D, Marston G et al. (2004) Development of a multidisciplinary care pathway for a specialist learning disability inpatient treatment and assessment unit. Journal of Integrated Care Pathways 8: 119–26

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating

Methodology Process evaluation. **Is a qualitative approach appropriate?** Appropriate. The research question seeks to understand processes or structures. This would apply to how care and support is organised and service user or carer experience). **Is the study clear in what it seeks to do?** Mixed. There is no information on the views of the staff who implemented the care pathway, if there were any difficulties, barriers. **How well was the data collection carried out?** Somewhat appropriately. There is no feedback from the staff who implemented the care pathway of whether the approach could be acceptable and feasible into the long	**Are the data 'rich'?** Poor. Methods of gathering information on the implementation are not clear, or which views are being represented. **Is the analysis reliable?** Not sure/not reported. **Are the findings convincing?** Somewhat convincing. The benefits of establishing a multidisciplinary care pathway in specialist treatment and assessment centres is suggested in other studies. **Are the conclusions adequate?** Adequate.	**Does the study's research question match the review question?** Partly. Study looks at the development of the multidisciplinary care pathway, not the effectiveness. **Has the study dealt appropriately with any ethical concerns?** No. No ethical concerns identified **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Inpatient treatment and assessment units are relevant to this review.	**Overall internal validity score** - **Overall external validity score** ++ **Overall score** -

term. Views are authors and a descriptive. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Not sure. No recruitment of samples as such. All admissions after implementation would have been offered the care pathway. **Were the methods reliable?** Unreliable. Methods of data collection for the process evaluation were not clearly describe.		**Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

14. Carnaby S, Roberts B, Lang J et al. (2011) A flexible response: person-centred support and social inclusion for people with learning disabilities and challenging behaviour. British Journal of Learning Disabilities 39: 39–45

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating

Methodology Process evaluation. **Is a qualitative approach appropriate?** Somewhat appropriate. Process evaluation. Does not include the views and experiences of the service users for an assessment of the feasibility of this service model. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. **How well was the data collection carried out?** Not sure/inadequately reported the components of the service were well described, but it is not clear how this data was collected or documented and what was not included. **Is the context clearly described?** Clear.	**Are the data 'rich'?** Rich. **Is the analysis reliable?** Somewhat reliable. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** No. It is not clear what services were offered to people who did not meet the inclusion criteria, or were borderline **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	**Overall assessment of internal validity** + **Overall assessment of external validity** ++ **Overall score** +

Were the participants recruited in an appropriate way? Not sure. Only the highest needs were included to the service, assessed by 2 raters with a questionnaire. **Were the methods reliable?** Somewhat reliable.		**Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

15. **Chadwick O, Beecham J, Piroth N et al. (2002) Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it? Child and Adolescent Mental Health 7(2): 66–72**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. Research question seeks to find out about processes and understand service use. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. There are clear	**Are the data 'rich'?** Rich. Data is compared across 3 boroughs and contrasted. Wide number of characteristics of families used in the analysis. **Is the analysis reliable?** Reliable. **Are the findings convincing?** Convincing .Reporting is clear and coherent.	**Does the study's research question match the review question?** Yes. Respite care, who needs it? And who receives it, people's experience. **Has the study dealt appropriately with any ethical concerns?** Yes. None to be dealt with in this study. Parents were interviewed and results anonymised. **Were service users involved in the study?** No. Not directly.	**Overall assessment of internal validity** ++ **Overall score** ++ **Overall assessment of external validity** ++

accounts of the rationale/justification for the sampling, data collection and data analysis techniques used.	**Are the conclusions adequate?** Adequate. **How well was the data collection carried out?** Appropriately. More than 1 person doing the data collection, people were interviewed at home and the assessment tools used are well described. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Appropriate. **Were the methods reliable?** Reliable. Four graduate psychologists did the data collection. Inter-rater reliability based on repeat interviews carried out by different researchers after an interval of 2 to 6 months was high for the DAS (r=0.70).	The parents/carers of service users were interviewed about the services available for their children. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes, services and support for families. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Inner London.	

16. Challenging Behaviour Foundation (2015) Paving the way: How to develop effective local services for children with learning disabilities whose behaviours challenge. Chatham: Challenging Behaviour Foundation

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Somewhat appropriate. The approach is more mixed than qualitative only. Some quantitative data is used but the approach also seeks to understand processes or structures, or illuminate subjective experiences of service users. **Is the study clear in what it seeks to do?** Clear. Aims to provide examples of different elements of positive behavioural support that deliver good outcomes for children and young people and their families. **How defensible/rigorous is the research design/methodology?**	**Are the data 'rich'?** Poor. Detail and depth of data has not been demonstrate. **Is the analysis reliable?** Unreliable. **Are the findings convincing?** Not convincing. While the reporting is somewhat clear and coherent, there is not enough detail to assess the effectiveness of the services. The scant information provided on costs, with no detail on how the costs were arrived at is unconvincing. **Are the conclusions adequate?** Somewhat adequate For examples of good practice, the conclusions are adequate.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Partly. The case studies are anonymised and there is a disclaimer by the author for any errors or omissions. As this isn't a primary study, ethical approval is not needed. **Were service users involved in the study?** No. However, their experiences are described and used as case studies. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes.	**Overall internal validity score** - **Overall external validity score** ++ **Overall score** -

Somewhat defensible. A rationale is provided on why the services were chosen for the study. It should be noted that these are examples of good practice and not proper evaluations. There is consistency in the way the case studies are presented: description of the service provision; information about costs, outcomes and barriers and facilitators. On the other hand, there is not enough detail to properly assess the effectiveness of each service. **How well was the data collection carried out?** Not sure/inadequately reported. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Somewhat appropriate The author states that the services described in this paper are all underpinned by a sound evidence base and are examples of good practice.		**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Were the methods reliable? Not sure.			

17. **Chaplin E, Kelesidi K, and Emery H et al. (2010) People with learning disabilities placed out of area: the South London experience. Journal of Learning Disabilities and Offending Behaviour 1: 5–14**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Mixed methods. **Does the study's research question match the review question?** Partly. Considers the characteristics of out of area placements, thus making some observations about the resources related to local service provision and need for local care pathways. **Is a case-control approach appropriate?** Appropriate. Yes, to compare behaviour problems, need and quality of life of those being treated in and out of area, but we don't know about the differences in the services being delivered in the 2 settings to know if these	**Question appropriate and focused?** Poorly addressed. The study is trying to identify the 'needs' of the group and just uses the 'CANDID' scale to measure this and doesn't ask the service users what their needs might be or look at individual services required by the group. **Comparable populations?** Adequately addressed From within the same service. **Same exclusion criteria?** Adequately addressed. **Participation rate for each group?** Cases: 64% of service users	**Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** No. Staff providing services, were interviewed to collect data about the study participants. **Is there a clear focus on the guideline topic?** Yes People with learning disabilities who offend or have offending-type behaviours. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the**	**Overall assessment of external validity** + **Overall assessment of internal validity** - **Overall score** -

are likely to impact on the factors being measured. **Is the study clear in what it seeks to do?** Mixed.	placed out of area. Controls n=27 matched. **Comparison of participants?** Poorly addressed. Says matched where possible on the criteria of ‘adults with ICD-10 diagnosis or learning disabilities‘; ‘a clinical diagnosis of mental or behaviour disorder‘; ‘subject to CPA‘ and also where possible to age, gender and ethnicity. Difference between the 2 groups not set out clearly in the study. **Cases clearly defined?** Adequately addressed. **Distinguishing of cases from controls?** Well covered. **Measures to prevent knowledge of primary exposure?** N/A **Exposure status** N/A **Confounding factors** Not addressed. **Statistical analysis** Not clear re. CI.	**guideline?** Yes. People with learning disabilities accessing specialist mental health services on the care programme approach. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. Inner London boroughs.	

	Do conclusions match findings? Partly.		

18. **Christopher R Horsley S (2015) An evaluation of a behavioural support team for adults with a learning disability and behaviours that challenge from a multiagency perspective. British Journal of Learning Disabilities, advance online publication doi:10.1111/bld.12137**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Survey. **Objectives of the study clearly stated?** Yes. **Research design clearly specified and appropriate?** Yes. **Clear description of context**? Yes. **References made to original work if existing tool used?** Yes. **Reliability and validity of new tool reported?** Yes. **Survey population and sample frame clearly described?**	**Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Yes. **Methods appropriate for the data?** Yes. **Statistics correctly performed and interpreted?** Yes. **Response rate calculation provided?** No. **Methods for handling missing data described?** No. **Difference between non-respondents and respondents described?** No. However, as the questionnaire	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. All participants were informed of the aims of the evaluation and gave their consent to be included in the project. Participants were made aware that their feedback would be used in a written report of the evaluation, the findings of which would be shared with the team and for wider dissemination. All quotes have been anonymised and names removed to protect confidentiality.	**Overall internal validity score** + **Overall external validity score** ++ **Overall score** +

Partly. It is clear that the sample frame came from the survey population, but it isn't clear how big the population is. **Representativeness of sample is described?** Yes. **Subject of study represents full spectrum of population of interest?** Unclear. The full population isn't specified so unclear if the sample is representative. **Study large enough to achieve its objectives, sample size estimates performed?** Unclear. Sample size, as a proportion of the total population is not provide However, 19 participants from a single service in 1 geographic location would seem reasonable. **All subjects accounted for?** Yes. **Ethical approval obtained?** Yes	was completed face-to-face as a structured interview, non-response could be managed. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** Yes. Use of convenience sampling, may have produced a positive bias. Potentially, the interviewer could have been perceived to be part of the BST, meaning some participants might have been less willing to give negative responses. However, the majority of the participants had not had any previous contact with the interviewer and were encouraged to give as honest feedback as possible. Therefore, this bias is likely to have been reduced. **Results can be generalised?** No. Evaluation of a single service in 1 geographic location, plus the sample was not random and participants	**Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes **Does the study have a UK perspective?** Yes.	

The project was reviewed by the trust governance committee and was given approval as a service evaluation. **Measures for contacting non-responders?** Not stated, however participants were self-selected. **All appropriate outcomes considered?** Yes. **Response rate?** Not stated. Staff volunteered to take part, but no information provided if any participants dropped out or how many people initially contacted. **Describes what was measured, how it was measured and the outcomes?** Yes. **Measurements valid?** Yes. **Measurements reliable?** Yes. **Measurements reproducible?** Yes. **Basic data adequately described?** Yes. Results presented clearly, objectively	self-selected. There is no information to determine the proportion the sample size is of the total population being looked at. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** Partly. To verify the reliability of the coding scheme, the qualitative sections of 2 questionnaires were chosen at random to be cross-coded by an independent researcher and a Kappa coefficient (j) was generated to assess consistency between raters. This was found to be significant, indicating a substantial level of agreement, j=0.64 ($p<0.001$). **Conclusions justified?** Yes.		

and in enough detail for readers to make personal judgements? Yes. **Results internally consistent?** Yes.			

19. Davis A, Doyle M, Quayle E et al. (2015) Am I there yet? The views of people with learning disability on forensic community rehabilitation. Journal of Intellectual Disabilities and Offending Behaviour 6(3/4): 148–64

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. **How well was the data collection carried out?** Appropriately.	**Is the analysis reliable?** Reliable. Diversity of views explored. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	**Does the study's research question match the review question?** Yes. Views and experiences of people with learning disabilities and forensic needs. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical issues were particularly important in this study and the researchers took care to address them. For example, maintaining confidentiality in such a small and closely supervised population and building a	**Overall assessment of internal validity** ++ **Overall assessment of external validity** ++ **Overall score** ++

Is the context clearly described? Clear. **Were the participants recruited in an appropriate way?** Appropriate. **Were the methods reliable?** Reliable.		relationship with the participants before the interview took place in order to encourage participants to express their true views. **Were service users involved in the study?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

20. **Devapriam J, Alexander R, Gumber R et al. (2014) Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit. Journal of Intellectual Disabilities 18(3): 211–20**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating

Methodology Single group, before and after. **Did the study address a clearly focused issue?** Yes. **Was the cohort recruited in an acceptable way?** Unclear. Presume all patients admitted over a 5 months period after implementation.	**Was the exposure accurately measured to minimise bias?** Yes. **Objective measures of length of stay in hospital and numbers of admissions** Unclear. It’s not clear what the ‘lanes test’ that is shown in the pathway diagram, but presumably there are some people who are not admitted and are signposted to other services, as indicated by the diagram. It would be useful to know what numbers were signposted to other services. **Was the outcome accurately measured to minimise bias?** Yes. **Have the authors identified all-important confounding factors?** Unclear. Simple numbers of differences reported. It’s not clear if some factors were associated with outcomes. **Have they taken account of the confounding factors in**	**Can the results be applied to the local population?** Yes. **Do the results from this study fit with other available evidence?** Yes. **What are the implications of this study for practice?** Inpatient services to adopt care pathway plans to 1) facilitate discharges, 2) Increase local capacity 3) prevent out-of-area placements, this is a small scale study, however the areas of Leicester, Leicestershire and Rutland is a populous and diverse area with an increasing population and is likely to be generalisable to the UK more generally.	**Overall internal validity score** + **Overall external validity score** + **Overall score** +

	the design and/or analysis? No. **What are the results?** Reporting of results significant differences in increased admissions, decreased delayed days discharges, Average HoNOS-LD scores pre- and post- were not significant. **How precise are the results?** Measures taken were simple and likely to be accurate, if not in breadth.		

21. Douma JCH, Dekker MC, Koot HM (2006) Supporting parents of youths with intellectual disabilities and psychopathology. Journal of Intellectual Disability Research 50: 570–81

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Cross-sectional study. **Objectives of study clearly stated?** Yes. **Clearly specified and appropriate research design?** Yes.	**Measurements and outcomes clear?** Yes. **Measurements valid?** Yes. Multiple instruments used, most are fully validated. **Setting for data collection justified?** Yes.	**Does the study's research question match the review question?** Partly. Doesn't tell us fully which model is effective, it points to the specific support needs of parents and how these might be met.	**Overall assessment of external validity** - **Overall assessment of internal validity** + **Overall score**

Subjects recruited in acceptable way? Yes. Part of a larger study, where participants were randomly selected from school records. Screening questions were used to make sure there was a parental perception of emotional or behavioural problems in their child before participants could take part. **Sample representative of defined population?** Partly The population is children with an intellectual disability and additional emotional or behaviour problems.	Needs to seek views of parents and also to identify relationships between variables. **All important outcomes and results considered?** Yes **Tables/graphs adequately labelled and understandable?** Partly Some tables just the percentage is given not number. **Appropriate choice and use of statistical methods?** Yes **In-depth description of the analysis process?** Partly A lot of data in the tables, but isn't fully described. **Are sufficient data presented to support the findings?** Yes. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. **Results can be generalised?** Partly. With caution, as this is a different health and social care setting to the UK,	**Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** No. Parents/carers were the participants in this study. **Is there a clear focus on the guideline topic?** Partly. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes Community services **Does the study relate to at least 1 of the activities covered by the guideline?** Yes, Support services for families, i.e. respite care. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No.	+

	however the services described and support needs of parents appear similar to those of parents in the UK. **Do conclusions match findings?** Yes.	Study took place in the Netherlands.	

22. Evans T, Gore N (2016) Staff behaviours valued by service users: views of people whose behaviour challenges. International Journal of Positive Behavioural Support 6(2): 4–11

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Information not provided about the sampling frame or total population.	**Are the data 'rich'?** Mixed. **Is the analysis reliable?** Reliable. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	**Does the study's research question match the review question?** Yes. Views about staff skills and behaviours from people with learning disabilities and behaviours that challenge services. **Has the study dealt appropriately with any ethical concerns?** Yes 'Ethical approval was gained through the Tizard Centre ethics committee at the University of Kent. All participants were deemed to have capacity to	**Overall assessment of internal validity** - Not enough clarity about how participants were recruited and what the total population size is, which makes it difficult to know the relevance of the results. **Overall assessment of external validity** ++ **Overall score** +

How well was the data collection carried out? Appropriately **Is the context clearly described?** Unclear Not clear which type of service participants were receiving. Was is positive behaviour support or not? **Were the participants recruited in an appropriate way?** Not sure. Not enough information provided. **Were the methods reliable?** Somewhat reliable.		consent to take part. The interview questions were designed to minimise the likelihood of causing distress to participants and participants were made aware that they were able to end the interview, take a break, or withdraw from the research at any point' (p5). **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes.	

		Does the study have a UK perspective? Yes.	

23. Felce D, Perry J, Romeo R et al. (2008) Outcomes and costs of community living: semi-independent living and fully staffed group homes. American Journal on Mental Retardation 113(2): 87–101

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity**
Methodology Non-randomised, matched-group study **Is this study a prospective evaluation?** No. Participants were already living in the 2 types of accommodation. **Description of theoretical approach?** Yes. The intention was to replicate the Stancliffe and Keane (2000) methodology with the following 5 modifications: (a) he behavioural characteristics of service users living with the focus participants were matched as far as possible to those f he focus participants and were taken into account; (b)	**Was the exposure to the intervention and comparison as intended?** Yes. **Was contamination acceptably low?** Yes. The 2 groups lived independently of each other. **Did either group receive additional interventions or have services provided in a different manner?** Not reported. **Were outcomes relevant?** Yes. **Were outcome measures reliable?** Partly. Authors state that matching on shortened forms of the ABS and Aberrant Behavior	**Does the study's research question match the review question?** Partly. Behaviour that challenges was 1 of 3 characteristics the participants were matched on. In addition participants were matched on mental health status and adaptive behaviour. **Has the study dealt appropriately with any ethical concerns?** Yes. Informed consent was sought. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?**	**Overall assessment of internal validity** + Study compares 2 different services and their quality of life and cost outcomes. **Overall assessment of external validity** + **Overall score** +

all settings were to be for 4 or fewer service users; (c) the balance for-profit and not-for-profit provider agencies within each type of setting was matched; (d) total service package costs were calculated as well as those solely for the accommodation element (i.e. including costs of daytime service use and professional contact because these might be expected to differ between fully and semi-independent living settings given differences in within-setting levels of staff); and (e) some additional measures were employed, which have been used previously in re-search in the United Kingdom (e.g. by Emerson et al. 2000, 2001) **How was selection bias minimised?** Quasi-experimental. Matching groups on characteristics. **Was the allocation method followed?** Yes. **Is blinding an issue in this study?** Part blinding. Accommodation managers	Checklist in the initial screening, however, did not result in the identified participants being adequately matched on the full versions of the measures. Participants may have had important differences. **Were all outcome measurements complete?** Yes. **Were all important outcomes assessed?** Yes. **Were there similar follow-up times in exposure and comparison groups?** Not reported. **Was follow-up time meaningful?** Not reported. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** Yes. **Was intention to treat (ITT) analysis conducted?** No. **Were the estimates of effect size given or calculable?** Yes.	Yes. Types of accommodation are relevant to types of services question. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Behaviour that challenges was 1 of 3 characteristics of the people with learning disabilities. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Yes. Study measures range of quality of life outcomes with validated scales including financial management, health survey for England, Health Care Scale, Risk Scale, Index of Community Involvement, Social Network Map, Loneliness Questionnaire, Index of Participation in Domestic Life,	

distributed screening questionnaires blind to the names of the residents intending to minimise sampling bias. **Did participants reflect target group?** Yes. Participants and settings were matched on important characteristics. **Were all participants accounted for at study conclusion?** Yes. Missing data were replaced by group-specific estimated costs.	**Was the study sufficiently powered to detect an intervention effect (if one exists)?** Partly. Small matched groups (n=27). **Were the analytical methods appropriate?** Partly. Analytical methods were appropriate but not realisable in practice given the small sample size. **Was the precision of intervention effects given or calculable? Were they meaningful?** Partly. Given the small sample size, and the difficulties in matching on all characteristics, it may not have been possible to detect some important differences in outcomes. **Do conclusions match findings?** Partly. As above	Choice Questionnaire, Choice Scale, Costs data measured with Client Service Receipt Inventory. **Does the study have a UK perspective?** Yes.	

24. Gangadharan S, Bretherton K, Johnson B (2001) Pattern of referral to a child learning disability service. British Journal of Developmental Disabilities 47 part 2: 99–104

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity
Methodology Cross-sectional study. Secondary data study. **Does the study's research question match the review question?** Partly, Looks at patterns of referral to a child learning disability team. Concluding from the complex problems presented in the group that a specialised service is needed for children. It is not able to tell us if a specialised service provided better outcomes for this group than the normal service.	**Objectives of study clearly stated?** Yes. **Clearly specified and appropriate research design?** No. Unclear, plus the staff providing the service did the data collection, no independence. **Subjects recruited in acceptable way?** Yes. All the new outpatients (children) over a period of 8 months were included in the study. **Sample representative of defined population?** Yes. **Measurements and outcomes clear?** Yes. **Measurements valid?** Unclear.	**Has the study dealt appropriately with any ethical concerns?** Yes NA, secondary data analysis. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Not clear about number of participants with challenging behaviour. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes **Does the study relate to at least 1 of the activities**	**Overall assessment of external validity** + **Overall assessment of internal validity** - **Overall score** -

	Setting for data collection justified? Partly. **All important outcomes and results considered?** Partly. **Tables/graphs adequately labelled and understandable?** N/A **Appropriate choice and use of statistical methods?** Partly. **In-depth description of the analysis process?** No. **Are sufficient data presented to support the findings?** Yes. **Results discussed in relation to existing knowledge on the subject and study objectives?** Partly. **Results can be generalised?** Unclear. **Do conclusions match findings?** Partly. Poorly	**covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

	reported and difficult to identify. Not enough detail provided, some discrepancies in totals.		

25. Golding L, Emerson E, and Thornton A (2005) An evaluation of specialized community-based residential supports for people with challenging behaviour. Journal of Intellectual Disabilities 9: 145–54

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity
Methodology Comparison evaluation. **Is this study a prospective evaluation?** No. Comparison evaluation. The community based control group were already living there, the institutional group were then relocated to community base settings. **Description of theoretical approach?** Partly, authors state that they replicated procedures used in previous studies of relocation involving specialist residential services for adults with intellectual disabilities and challenging	**Was the exposure to the intervention and comparison as intended?** Yes. **Was contamination acceptably low?** Yes. **Did either group receive additional interventions or have services provided in a different manner?** Not reported. **Were outcomes relevant?** Partly. Outcomes are relevant, but measures by observation. **Were outcome measures reliable?** Partly. Measurement is by observation which is highly interpretive and over very short periods of time. Residents	**Does the study's research question match the review question?** Yes. Relocation from institutional settings to community based residential settings is relevant to this review question. **Has the study dealt appropriately with any ethical concerns?** Partly. Authors state that informed consent was sought from each participant. Where service users were unable to give informed consent, their service manager was asked to give consent on their behalf. Seeking consent from the service manager may have	**Overall assessment of internal validity** - **Overall assessment of external validity** ++ **Overall score** +

behaviour (Emerson et al. 1992; Mansell et al. 2001). **How was selection bias minimised?** Unmatched groups Significant differences between the 2 groups were reported. The community group was significantly younger than the hospital group (being relocated). The hospital group had spent significantly longer in the institution than the community based group. There were no significant differences between the 2 groups on the Aberrant Behavior Scale at either of the 2 time points. **Was the allocation method followed?** Partly. **Is blinding an issue in this study?** Blinding not possible. **Did participants reflect target group?** Partly. Very small sample size. Not clear how representative the participants are given the diversity of learning disabilities and behaviour that challenges.	themselves were not asked to reflect on their experiences. **Were all outcome measurements complete?** Partly. Authors note that behaviour that challenges can be repetitive and cyclical. Observations taken over such short periods of time may not capture this. Having observers there is likely to effect the people being observed. **Were all important outcomes assessed?** Partly, Researchers were limited to measuring only those outcomes that could be observed. **Were there similar follow-up times in exposure and comparison groups? Y**es **Was follow-up time meaningful?** Partly. See above. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** No. **Was intention to treat (ITT) analysis conducted?** No.	been inappropriate due to potential sampling bias, and possibly unintended pressure to participate. **Were service users involved in the study?** No. Data on quality of life and engagement in activities, problem behaviour was collected from researcher's observations at 3 time points for a total of 8 hours. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community based residential settings is relevant to this review question. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Relocation from institutional settings to	

Were all participants accounted for at study conclusion? Yes.	**Were the estimates of effect size given or calculable?** Partly. Reliability of the scores could be questioned as it was done by observation and interpretation of behaviours. Is this study replicable? **Was the study sufficiently powered to detect an intervention effect (if one exists)?** No. **Were the analytical methods appropriate?** Partly. **Was the precision of intervention effects given or calculable? Were they meaningful?** Partly. Outcomes were subjectively measured by a third party through non-participant observation. Definitions of the outcomes are subjective to the researchers. It is not clear whether the definition of 'meaningful activity' is shared by the participants themselves, or that 'staff contact' is necessarily welcomed by the residents.	community based settings highly relevant to this review. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

	Do conclusions match findings? Partly. See limitations above.		

26. Griffith GM and Hastings RP (2014) 'He's hard work, but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research. Journal of Applied Research in Intellectual Disabilities 27(5): 401–19

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Systematic review. **Inclusion of relevant individual studies?** Yes.	**Rigorous literature search?** Yes. **Study quality assessed and reported?** No. **Adequate description of methodology?** Yes. **Do conclusions match findings?** Yes.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes **Is the study setting the same as at least 1 of the**	**Overall internal validity score** ++ **Overall external validity score** ++ **Overall score** ++

		settings covered by the guideline? Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes.	

27. **Griffith GM, Hutchinson L and Hastings RP (2013) 'I'm not a patient, I'm a person': The experiences of individuals with intellectual disabilities and challenging behavior – a thematic synthesis of qualitative studies. Clinical Psychology, Science and Practice 20: 469–88**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Systematic review. **Appropriate and clearly focused question?** Yes. **Inclusion of relevant individual studies?** Somewhat relevant. Views of participants in residential	**Do conclusions match findings?** Yes. **Rigorous literature search?** Partly rigorous. **Study quality assessed and reported?** Yes.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** No.	**Overall internal validity score** ++ **Overall external validity score** ++ **Overall score** ++

settings. Limited services focus.	**Adequate description of methodology?** Partly adequate.	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

28. Hall I, Yacoub E, Boast N et al. (2014) Secure inpatient services: A needs assessment. Journal of Intellectual Disabilities and Offending Behaviour 5, 38–53

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating

Methodology Cross-sectional survey. **Objectives of the study clearly stated?** Yes. **Research design clearly specified and appropriate?** Partly. Few statistical tests for significance were undertaken, although this was a stated aim. **Clear description of context?** Yes.	**References made to original work if existing tool used?** Yes, study compares findings to another London needs assessment in 2007. **Reliability and validity of new tool reported?** No. **Survey population and sample frame clearly described?** Yes. **Representativeness of sample is described?** Unclear. No tests for significance were undertaken between the group that had data available and those that did not. Only gender was available for the 2 groups. There may have been other important differences, such as type/ severity of behaviour. **Subject of study represents full spectrum of population of interest?** Partly. See representativeness. **2.8 Study large enough to achieve its objectives, sample size estimates performed?** Unclear, sample size estimates were not	**Does the study's research question match the review question?** Yes. The provision of secure in patient services for people with learning disabilities and behaviour that challenges and/or offending behaviour is relevant to the capacity question. **Has the study dealt appropriately with any ethical concerns?** Yes Ethical consent was sought. However, there were some non-responses due to concerns over ensuring confidentiality in small numbers. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Partly. People with learning disabilities and behaviour that challenges and/or offending behaviour. However, the reference group of clinicians identified a number of in	**Overall assessment of external validity** + **Overall assessment of internal validity** ++ **Overall validity score** +

	reported. Approximately half the available population had data available. It is not clear how representative this sample is beyond the gender breakdown. **All subjects accounted for?** No. **Ethical approval obtained?** Yes. **All appropriate outcomes considered?** Yes. **Describes what was measured, how it was measured and the outcomes?** Yes. **Measurements valid?** Partly there was some difficulty in defining 'acute', level of security, length of time in care. **Measurements reliable?** Partly **Basic data adequately described?** Yes **Results presented clearly, objectively and in enough detail for readers to make**	patients who did not have a learning disability. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Secure settings is part of the scope. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes, the study seeks to identify service use to predict future service needs. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes. However from London, which is likely to have unique characteristics compared to the rest of the UK (e.g. costs of staff and bricks and mortar,	

	personal judgements? Partly. **Results internally consistent?** Yes. **Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Partly. No information given on whether the survey was piloted beforehand, or how the researcher collected the data. **Methods appropriate for the data?** Yes. Survey of current service provision, plus a reference group of clinicians was a suitable methods for assessing service needs. **Statistics correctly performed and interpreted?** No. Little of no statistical analysis undertaken. Basic numbers, percentages and averages. May have benefited from more suitable measures, where data is likely to be skewed, e.g.	proportion of population from ethnic backgrounds).	

	medians for length of time in secure care. **Response rate calculation provided?** No. **Methods for handling missing data described?** No. **Difference between non-respondents and respondents described?** Partly. The flow of participants show differences in gender and type of service provider. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** Yes. **Results can be generalised?** Partly. London may face particular pressures compared to the rest of the country. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** No. There is no information provided on whether the questionnaire was acceptable		

	to stakeholders, practitioners for ‘face’ validity. Or that the tool was piloted first.		

29. **Harris J (2010) The use, role and application of advanced technology in the lives of disabled people in the UK. Disability and Society 25,:427–39**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible.	**How well was the data collection carried out?** Appropriately, methods included views from people who used services, a focus group and service providers. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Appropriate. **Were the methods reliable?** Somewhat reliable study says that the authors conducted a systematic review of the literature but this is not reported here. Methods of	**Is there a clear focus on the guideline topic?** Partly, the assistive technology is to support independent living. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly, participants are adults with learning disabilities (not necessarily with behaviour that challenges) agreed by the Guideline Committee to extrapolate findings from this group. Quotes seem to be mainly from people with physical disabilities.	**Overall assessment of external validity** - **Overall assessment of internal validity** - **Overall score** -

	transcribing and understanding the themes not reported. **Are the data ‘rich’?** Mixed **Is the analysis reliable?** Somewhat reliable. **Are the findings convincing?** Somewhat convincing, although the inclusion criteria for this study was people with physical and learning disabilities, the views were predominantly from people with physical disabilities. It is likely that people with learning disabilities might face different/additional challenges in using and learning new technologies. **Are the conclusions adequate?** Somewhat adequate.	**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

30. Hassiotis A, Guinn A, Tanzarella M et al. (2015) Community-based services for people with intellectual disability and mental health problems: Literature review and survey results. London: The Royal College of Psychiatrists

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Survey (we only included the survey part of the review). **Objectives of the study clearly stated?** No. **Research design clearly specified and appropriate?** Partly. Very brief information is provided about the method, however, the survey is provided in full, which helps the reader to understand the results. **Clear description of context?** Partly. Tables and graphs are used and described in the text, but graphs do not provide specific data labels. Not clear how many people responded to each question. **References made to original work if existing tool used?**	**Describes what was measured, how it was measured and the outcomes?** Unclear. Inclusion of the survey, helps the reader to interpret the results from the narrative summary in the text. **Measurements valid?** Yes. **Measurements reliable?** No Conflicting commentary of the results presented For e.g. in the results section 'good geographical dispersion of respondents'in limitations section, 'limited geographical coverage'. **Measurements reproducible?** No. **Basic data adequately described?** Partly. Not clearly described and bar charts lack labels so can't see extract percentages.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** No, not stated. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Partly. The study focuses on community-based intellectual disability services for people with mental health, behaviour and forensic problems. It is not specifically about the population of people with learning disabilities and behaviours that challenge. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. As	**Overall internal validity score** - **Overall external validity score** - **Overall score** -

N/A **Reliability and validity of new tool reported?** No. **Survey population and sample frame clearly described?** Yes. **Representativeness of sample is described?** Partly Geographical dispersion of respondents described well. **Subject of study represents full spectrum of population of interest?** Unclear. **Study large enough to achieve its objectives, sample size estimates performed?** No. The survey was emailed to 310 members. There were 65 respondents and 53 complete responses. Response rate 20%. **All subjects accounted for?** Partly. There were 12 incomplete responses, but no detail about which questions were not answered or how many left blank.	**Results presented clearly, objectively and in enough detail for readers to make personal judgements?** No. **Results internally consistent?** No **Data suitable for analysis?** Yes **Clear description of data collection methods and analysis?** - No **Methods appropriate for the data?** Unclear **Statistics correctly performed and interpreted?** Yes. **Response rate calculation provided?** Yes, 20%. **Methods for handling missing data described?** No. **Difference between non-respondents and respondents described?** Yes. **Results discussed in relation to existing knowledge on subject and study objectives?** No.	mentioned above, part of the population. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least o1ne of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Partly, view of practitioners and not service users, families or carers. **Does the study have a UK perspective?** Yes.	

Ethical approval obtained? No. Not mentioned. **Measures for contacting non-responders?** Not described. **All appropriate outcomes considered?** Yes. **Response rate?** 20%.	**Limitations of the study stated?** Yes. **Results can be generalised?** No. Low response rate, does not provide a clear picture of service provision across the whole of England. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** No. **Conclusions justified?** Yes.		

31. Hatton C, Emerson E, Kirby S et al. (2010) Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and family impact. Journal of Applied Research in Intellectual Disabilities 23: 63–74

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. Explores perceptions of challenging behaviour, support	**Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. Interpretative phenomenological analysis used to build a rich picture of the experiences of family carers, particularly any commonalities of experience.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes, the study received full ethical approval from an NHS research ethics committee.	**Overall internal validity score** ++ **Overall external validity score** ++ **Overall score** ++

and impact of the person on the family. **How defensible/rigorous is the research design/methodology?** Defensible. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Appropriate. **Were the methods reliable?** Reliable. Process explained and multi-stage with transcripts divided between 3 members of the research team for analysis. One researcher conducting the principal analysis (IPA stages 1 and 2) and 1 other member of the research team comparing the analysis to the original transcript. A final stage of IPA was conducted by a senior member of the research team in consultation with other research team	**Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	**Were service users involved in the study?** Yes. Family carers provided their views and experiences about services and services for carers. Direct service users, i.e. people with learning disabilities and behaviour that challenges, were not included in the study. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes.	

members. The research team was also multicultural which meant any unconscious cultural assumptions made by any single analyst would be made visible, thereby improving the legitimacy of the analysis.		**Does the study have a UK perspective?** Yes.	

32. **Inchley-Mort S, Hassiotis A (2014) Complex Behaviour Service: Content analysis of stakeholder opinions. Advances in Mental Health and Intellectual Disabilities 8: 228–36**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is this study a prospective evaluation?** No. Retrospective evaluation associated with a service over 12 months. Total 24 service users in the intervention group and 22 in the control group. **Description of theoretical approach?** Yes. An observational study of clinical outcomes and social care costs associated with the	**Was the exposure to the intervention and comparison as intended?** Yes. **Was contamination acceptably low?** Yes. **Did either group receive additional interventions or have services provided in a different manner?** Yes. **Were outcomes relevant?** Yes.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval for the study was obtained from Outer West London Research Ethics Committee and written informed consent was given by the service user (where	**Overall internal validity score** + **Overall external validity score** ++ **Overall score** +

CBS over 12 months with a nested comparison of the cases seen by the CBS with cases receiving usual care and with a history of challenging behaviour. **How was selection bias minimised?** Quasi-experimental. Controls identified through the service register, who did not receive CBS (non-CBS) matched on gender, level of intellectual disability and level of challenging behaviour. However, lack of randomisation may have increased bias and the matching did not eradicate baseline differences in group characteristics. **Was the allocation method followed?** Yes **Is blinding an issue in this study?** Blinding not possible. **Did participants reflect target group?** Partly. The CBS group were identified through the CBS case load of	**Were outcome measures reliable?** Partly. Analysis was not adjusted for multiple testing and therefore significant findings need to be interpreted with caution. In all cases estimates and 95% confidence intervals are reported. Analysis was carried out in Stata V.11. In addition, 2 types of models were fitted; the first model (unadjusted, the second model (adjusted) included additional participant characteristics (living situation, level of intellectual disability, physical problems and presence of possible mental health, met and unmet needs) as predictor variables. For both models multilevel regression allowed the repeat measurements from each subject to be used in the analysis. Two-level models were used with individual measurements nested within participants. **Were all outcome measurements complete?** Not reported.	possible) while (nominated) consultees advised in cases of incapacitated adults. **Were service users involved in the study?** No. However, the study is an observational study of 46 service users. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. All service users exhibited challenging behaviour. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Partly. Primary outcome measured is	

service users n=37, but by the time the evaluation had begun, 12 months into the enhanced service implementation, 13 service users had already been discharged which explains why the study included n=24 service users. No explanation why only 22 controls in the study. It could be that as they were matched, this was the total number of people available from the registered service user population n=652 that could be appropriately matched. **Were all participants accounted for at study conclusion?** Yes.	The secondary outcomes using 3 tools: HoNOS-LD; CANDID-s and PASSAD were not reported on. However, the primary outcome using the Aberrant Behavior Checklist was reported in full (Table 2). **Were all important outcomes assessed?** Not reported. As mentioned above, the secondary outcomes using 3 tools: HoNOS-LD; CANDID-s and PASSAD were not reported on. It might have been helpful to consider the scores of the CANDID-S which is an assessment of met and unmet needs measured by the informant administered Camberwell Assessment of Needs-Developmental and Intellectual Disabilities-short version tool. **Were there similar follow-up times in exposure and comparison groups?** Yes, both baseline and 12 months.	a clinical outcome – improvement in challenging behaviour. We are interested in the social care and service model outcomes. However, the evaluation of the enhanced service model which this study addresses is relevant to the guideline. **Does the study have a UK perspective?** Yes. The study was carried out in an intellectual disability service in inner London.	

	Was follow-up time meaningful? Yes. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** Yes. **Was intention to treat (ITT) analysis conducted?** Yes. **Were the estimates of effect size given or calculable?** Yes. **Was the study sufficiently powered to detect an intervention effect (if one exists)?** Not reported. **Were the analytical methods appropriate?** Yes. Two types of models were fitted; the first model (unadjusted) contained the outcome values at baseline, time (6 months or 12 months), group (non-CBS or CBS) and the interaction between time and treatment, to allow differing treatment effects at the 2 time periods as the predictor variables. The second model		

	(adjusted) included additional participant characteristics (living situation, level of intellectual disability, physical problems and presence of possible mental health, met and unmet needs) as predictor variables. For both models multilevel regression allowed the repeat measurements from each subject to be used in the analysis. Two-level models were used with individual measurements nested within participants. **Was the precision of intervention effects given or calculable? Were they meaningful?** Yes, for the primary outcome ABC domains. **Do conclusions match findings?** Yes.		

33. James N (2013) The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: what do carers say? Journal of Intellectual Disabilities 17(1): 6–23

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Systematic review – qualitative. **Appropriate and clearly focused question?** Yes. **Inclusion of relevant individual studies?** Yes.	**Rigorous literature search?** Yes. **Study quality assessed and reported?** No. **Adequate description of methodology?** Yes. **Do conclusions match findings?** Yes.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	**Overall internal validity score** ++ **Overall external validity score** ++ **Overall score** ++

		Are the views and experiences reported relevant to the guideline? Yes. **Does the study have a UK perspective?** Yes.	

34. **Knapp M, Comas-Herrera A, Astin J et al. (2005) Intellectual disability, challenging behaviour and cost in care accommodation: What are the links? Health and Social Care in the Community 13: 297–306**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Cross-sectional study. **Does the study's research question match the review question?** Partly. **Objectives of study clearly stated?** Yes. **Clearly specified and appropriate research design?** Yes.	**Subjects recruited in acceptable way?** Partly. Data collected as part of a larger study. Organisations choose to take part; non-random and sample weighted towards more NHS providers. **Sample representative of defined population?** Yes. Included people with intellectual disabilities and behaviour that challenges. **Measurements and outcomes clear?** Yes. Methods are fairly clearly described. However, the level of learning disability and	**Has the study dealt appropriately with any ethical concerns?** Yes. No permissions needed for this type of study. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the	**Overall assessment of external validity** + **Overall assessment of internal validity** + **Overall score** +

	behaviour that challenges isn't that well described. **Measurements valid?** Partly. Information on service use was collected retrospectively for 3 months, although service with a high cost implication, such as hospital care were recorded over 12 months. We don't know if any service costs might have been included in the aggregated residential accommodation cost. Validated scales were used to collect information about level of intellectual disability and behaviour that challenges. **Setting for data collection justified?** Yes. Part of a larger study. **All important outcomes and results considered?** Partly. **Tables/graphs adequately labelled and understandable?** Partly. Adequate tables are presented and clearly labelled, but there could have been better explanation of the data	**settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

	in the tables where statistical analysis was applied. **Appropriate choice and use of statistical methods?** Yes. Justification for methods clearly explained. **In-depth description of the analysis process?** Yes. **Are sufficient data presented to support the findings?** Yes. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. Authors provide contextual detail for results. **Results can be generalised?** No. The sample in the study over-represents the NHS sector and under-represented the other sectors making it difficult to accurately general cost and service use data. **Do conclusions match findings?** Yes.		

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35. Kroese B, Rose JL (2011) Mental health services for adults with learning disabilities. London: The Judith Trust

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. Data were collected through focus group discussions as well as individual interviews. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. The study design is appropriate to the research question and a rationale is provided for using this approach. Two different qualitative methodologies were used to collect the qualitative data. Four focus groups and individual interviews.	**Are the data 'rich'?** Rich. The contexts of the data is quite well described, and a diversity of perspectives are illustrated by quotes with codes that identify which group the participant belongs to. **Is the analysis reliable?** Reliable. An audit of the initial 3 interviews was carried out in the form of independent analysis of the transcripts by 2 of the researchers who then compared and discussed in detail their emerging themes. Good agreement was found. Care was taken to ensure that the content of the emerging themes was grounded in the original data. **Are the findings convincing?** Convincing. The findings are clearly presented and appear to be	**Does the study's research question match the review question?** Partly. The study also looks at staff views about the personal qualities of people working in this field, current service provision and training/supervision programmes which aren't relevant to our review question. We have only data extracted information that is relevant to our review questions. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical issues were addressed by gaining ethical approval from NRES and the ethical committee of the University of Birmingham and adhering to ethical principles regarding informed consent and confidentiality.	**Overall internal validity score** ++ **Overall external validity score** + **Overall score** + While the external validity of the study is strong, there are some concerns about how relevant the views in the study are to our population and setting, therefore the study was rated as 'medium'.

How well was the data collection carried out? Appropriately. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Appropriate. **Were the methods reliable?** Reliable. Data was collected by more than 1 method. All focus groups were co-facilitated by 2 experienced professionals and the 2 service user groups also had a co-facilitator who was a service user. The discussions were digitally recorded and transcribed verbatim.	internally coherent. Quotes are attributed to identify different types of participants. Service user SU, residential staff RS, community staff CS. **Are the conclusions adequate?** Somewhat adequate. There isn't much adequate discussion of any limitations encountered in the study. However the findings are relevant to the aims of the study and the conclusions seem plausible and coherent.	**Were service users involved in the study?** Yes **Is there a clear focus on the guideline topic?** Partly. There is some concern about how many of the service users involved in the study experience behaviour that challenges, as this is not described in the study. However, the services that have taken part in the study (Dudley Primary Care Trust and South Staffordshire and Shropshire) both provide services of relevance to our population of interest. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. The population has learning disabilities and mental health problems, but it is unclear how much 'behaviour that challenges' is present. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Staff interviewed worked in	

		residential and community learning disability services. These are the same services that the service users are commenting on. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Partly. Views of staff aren't of prime interest, however any barriers and facilitators to service improvement identified by staff are relevant. Where staff have provided views on how the experience of staff could be improved, we haven't data extracted this. **Does the study have a UK perspective?** Yes.	

36. La Valle I (2015) Services for children with learning disabilities whose behaviours challenge: A survey of families' and professionals' experiences. Chatham: Challenging Behaviour Foundation

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Survey. **Objectives of the study clearly stated?** Yes. **Research design clearly specified and appropriate?** Partly. Web survey, but very few details about how the survey was conducted. A copy of the survey isn't included in the paper, but information is provided about dates when the survey was carried out and about the sample. **Clear description of context?** Yes. Part of the Early Intervention Project, funded by the Department of Health and carried out by the Challenging Behaviour Foundation and Council for Disabled Children.	**Basic data adequately described?** Yes. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Yes. **Results internally consistent?** Partly. A couple of the reported figures (combined %) in the text don't match raw text in the table. Only by 1–2. **Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Partly. Not much information provided, but this is only a basic survey which doesn't include any thematic analysis. Scales are used or free text responses.	**Does the study's research question match the review question?** Partly. Description of the baseline data to be collected is consistent with the research questions. It would be helpful to see the full survey, to verify this in full. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the**	**Overall internal validity score** - **Overall external validity score** + **Overall score** -

References made to original work if existing tool used? N/A **Reliability and validity of new tool reported?** N/A **Survey population and sample frame clearly described?** Yes. **Representativeness of sample is described?** Partly. For the professionals, respondents' area of work described. Limitations are highlighted. **Subject of study represents full spectrum of population of interest?** No. Only includes people drawn from the CBF mailing list, so families that are in contact with the CBF, not whole population of families. For the professionals, taken from the CBF mailing list, so not representative of the children's workforce as a whole. However, most work with children with learning disabilities, and compared with the children's workforce more generally they are likely to be	**Methods appropriate for the data?** Yes. **Statistics correctly performed and interpreted?** Partly. As mentioned above, a couple of small discrepancies in figures reported in the text, from what appears in the table. **Response rate calculation provided?** Partly. Yes, for families' survey, but not for the professionals' survey. **Methods for handling missing data described?** Yes. **Difference between non-respondents and respondents described?** Yes. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** Yes.	**settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

more aware of the issues faced by this group of children and the type of support they need. **Study large enough to achieve its objectives, sample size estimates performed?** Yes. **All subjects accounted for?** Yes. Data tables include no of respondents missing. **Ethical approval obtained?** N/A Not required for this type of survey. **Measures for contacting non-responders?** No information given, but a self-selecting survey. Response rate of 65% for this type of survey is reasonable. **All appropriate outcomes considered?** N/A **Response rate?** Parents =65%; professionals, unable to estimate as mailing list was compiled from 3 separate lists,	**Results can be generalised?** Partly. Not a representative sample of the whole population, but those in contact with the CBF. The population being studied isn't big, so the survey is a reasonable sample (n=61 families and n=128 professionals). **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** No. **Conclusions justified?** Yes.		

and people may have been included on more than 1 list. **Describes what was measured, how it was measured and the outcomes?** Partly**,** several tables and figures presented which describe the scale. As the full survey isn't included, not able to verify if anything missing. **Measurements valid?** Yes. **Measurements reliable?** Partly. **Measurements reproducible?** Yes.			

37. Lindsay WR, Holland AJ, Carson D et al. (2013) Responsivity to criminogenic need in forensic intellectual disability services. Journal of Intellectual Disability Research 57: 172–81

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Quantitative evaluation. **Does the study's research question match the review**	**Is the source population or source well described?** Yes. **Is the eligible population or area representative of the source population or area?**	**Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes.	**Internal validity score** - **Overall assessment of external validity**

question? Partly. Doesn't answer effectiveness question in full but finds in which type of service people are more likely to receive appropriate treatment.	Yes. A catchment area of around 12 million people or 20% of the UK population. **Selection of exposure (and comparison) group. How was selection bias minimised?** N/A All people treated by different types of services in 12-month period. For high secure due to low number of referrals 2 years' data was used. **Was the selection of explanatory variables based on a sound theoretical basis?** Yes. Variables of highest index offence: violence and sexual offence. **Was the contamination acceptably low?** Yes. **How well were the likely confounding factors identified and controlled?** Partially. Generic community services were chosen because of their familiarity and readiness to accept forensic referrals. Also possible that some participants were not treated because they were considered too mentally ill	**Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Not clear the level of ID in the population and behaviour that challenges that isn't sex-offence related. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Partly. One indicator of effectiveness used. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethics approval sought and approved with conditions; pilot data collection and process of getting informed consent – proved difficult so agreed to allow the gathering of anonymised data from the case files, without informed consent. **Does the study have a UK perspective?** Yes.	- **Overall validity score** - Only 1 main outcome measured.

	for psychological treatment to be appropriate. **Is the setting applicable to the UK?** Yes. **Were the outcomes measures and procedures reliable?** Partially. Somewhat reliable. Only 1 measured use: number treated for an index offence. **Were the outcomes measures complete?** Partially. Some people could have been considered too mentally ill for the psychological treatment. **Was there a similar follow-up time in exposure and comparison groups?** Yes: 12 and 24 months. **Was follow-up time meaningful?** Yes. **Was the study sufficiently powered to detect an intervention effect (if one exists)** Partially. Due to the low number of participants using secure services, different type of secure		

	service combined for the analysis. **Were multiple explanatory variables considered in the analyses?** No. **Were analytical methods appropriate?** Partially. Somewhat appropriate. Due to low numbers, Fisher's Exact was used to ascertain the significance of the differences. **Was the precision of association given or calculable? Is association meaningful?** Partially.		

38. **Mansell J, Beadle-Brown J, Whelton B et al. (2008) Effect of service structure and organization on staff care practices in small community homes for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 21: 398–413**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Comparison evaluation.	**Do conclusions match findings?** Partly. Authors acknowledge that the	**Does the study's research question match the review question?** Yes	**Overall internal validity score**

Is a cohort study approach appropriate? Appropriate. Compares homes that had training on PCAS and those who had not, as well as organisational factors. **Is the study clear in what it seeks to do?** Clear.	non-random comparison group design does not allow demonstration of causality: the differences between the groups may reflect pre-existing differences. But also that the regression analysis may have suggested important factors to consider for successful implementation of PCAS. **Allocation unrelated to confounding factors?** Unclear, it is not clear how 72 residential homes serving 359 adults with intellectual disabilities were selected, other than they were selected by the charity. There may be selection bias present if the charity felt that some homes would perform better or benefit from the training. **Attempts made to balance the comparison groups?** No It was not possible to assess the comparability of the homes prior to the start of the study. **Groups comparable at baseline?** Unclear. It was not	**Has the study dealt appropriately with any ethical concerns?** Yes, If consent (or agreement of a proxy, if it was not possible to obtain informed consent from the person) had been obtained. **Were service users involved in the study?** No - the focus of the study was staff care practices and organisation. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Small community homes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Person centred active support.	- **Overall external validity score** ++ **Overall score** -

	possible to assess the comparability of the homes prior to the start of the study. **Was selection bias present?** High risk of bias. Likely direction of selection bias effect positive results – performance bias. **Equal treatment?** Unclear. It is not clear what approach the control group may have implemented that wasn't person centred support in some way. **Allocation – participants** Unclear. For each of the homes selected to take part in the training, a broadly comparable home in the same region was selected as the control. **Allocation – practitioners** Unclear. For each of the homes selected to take part in the training, a broadly comparable home in the same region was selected as the control.	**Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

	Performance bias appraisal Unclear/unknown risk of bias. **Likely direction of performance bias effect** Unknown. **Follow-up** Yes. On average 5 months (range 3–13 months) after manager had been trained. **Drop-out numbers** Not stated, 230 full questionnaires were returned from a total of 546 questionnaires sent out (a return rate of 42%). **Groups comparable on intervention completion?** Yes. There were no statistically significant differences between services where staff questionnaires were returned and those here none were returned in terms of size of home, staff:resident ratio, resident adaptive behaviour or challenging behaviour. **Groups comparable on available data?** Unclear. Authors state that given the similarities on characteristics		

	between the intervention and control groups, multivariate analysis was undertaken using linear regression. Regression was carried out on the whole sample (n=359). **Did the study have an appropriate length to follow-up?** No. Five months seems a short period of time to see if the gains are sustained over time given the staff turnover and difficulties in implementing PCAS. **Did the study use a precise definition of outcome?** Yes. **Was the method used to determine the outcome valid and reliable?** Unclear. Not clear whether the effect is due to the training alone, as the 2 groups were combined and analysis of variance analysis conducted. Some factors seemed to be important for positive outcomes that may be unrelated to the delivery of the training, e.g. higher engagement was predicted by younger, more able white British residents, with less		

	stereotypy but with more inappropriate speech; staff who had worked in hospital and who were more knowledgeable about challenging behaviour; and where staff provided active support. This makes it difficult to know whether PCAS is ‘better’ than usual care. Or if usual care already includes some elements of PCAS. **Were investigators kept ‘blind’ to participants’ exposure to the intervention?** No. **Were investigators kept ‘blind’ to other important confounding factors?** No.		

39. Mansell J, Ritchie F, Dyer R (2010) Health service inpatient units for people with intellectual disabilities and challenging behaviour or mental health problems. Journal of Applied Research in Intellectual Disabilities 23: 552–59

Internal validity- Study aims and approach	Internal validity- performance and analysis	External validity	Overall validity rating
Methodology Survey.	**Objectives of the study clearly stated?** Yes.	**Has the study dealt appropriately with any ethical concerns?** Yes. No personal information	**Overall assessment of external validity** ++

Does the study's research question match the review question? Yes. Characteristics of service provision for both NHS and independent providers highly relevant to the capacity review question.	**Research design clearly specified and appropriate?** Partly. The survey tool was developed by the authors. **Clear description of context?** Yes. **References made to original work if existing tool used?** No **Reliability and validity of new tool reported?** Partly. Authors state that no formal assessment was made of the validity or reliability of the questionnaire because of the short time available for the audit. However, the questionnaire was developed with advice from a group of experts led by the second author, and piloted first and revised to identify items that were ambiguous or not possible to answer. **Survey population and sample frame clearly described?** Yes. **Representativeness of sample is described?** No. Specific return rates of NHS	gathered so ethical consent not necessary/sought. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Overlaps with mental health and behaviour that challenges. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Inpatient services is relevant to the scope. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	**Overall internal validity score** - Surveys are subject to threats of response bias, however the response rates were (implied) to be fairly high from a complete set of service providers. **Overall score** -

	and IH services not reported, or any differences in the characteristics or types of services of the non-returns. **Subject of study represents full spectrum of population of interest?** Unclear. Only those services identifying themselves as assessment and treatment units, low-secure or medium-secure units. **Study large enough to achieve its objectives, sample size estimates performed?** Unclear. **All subjects accounted for?** No. **Ethical approval obtained?** N/A. No identifiable information of individuals was gathered so ethical approval not necessary. **All appropriate outcomes considered?** Yes. **Describes what was measured, how it was measured and the outcomes?** Yes.		

	Measurements valid? Partly. Validity of the outcomes not tested in the questionnaire developed for the study. **Measurements reliable?** Partly. Not all of the outcomes were reported on or analysed against other characteristics, such as setting and location, size, number and characteristics of patients. **Basic data adequately described?** Yes. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Yes. **Results internally consistent?** Yes. **Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Yes. **Methods appropriate for the data?** Yes.		

	Statistics correctly performed and interpreted? Yes. **Response rate calculation provided?** No. **Methods for handling missing data described?** No. **Difference between non-respondents and respondents described?** No. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** Yes. Independent healthcare units were under-represented. The survey did not include procedures for checking the accuracy, validity or reliability of answers to the questionnaire. The survey did not attempt to gather information about the nature of the intellectual disability or other characteristics of the patients of these units. There may have been characteristics		

	of the patients that had an effect on the findings. **Results can be generalised?** Yes. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** No.		

40. Martin S, Kelly G, Kernohan WG et al. (2008) Smart home technologies for health and social care support. Cochrane Database of Systematic Reviews 4, CD006412

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Systematic review. **Appropriate and clearly focused question?** Yes. **Inclusion of relevant individual studies?** No. No studies found.	**Rigorous literature search?** Yes. **Study quality assessed and reported?** No. No studies found. **Adequate description of methodology?** Yes. **Do conclusions match findings?** Yes, yes in that there is a concern that smart home technology is increasing in use without being underpinned by rigorous	**Does the study's research question match the review question?** Partly. This is a subsection to the types of services/service models question. No studies were found for people with learning disabilities and also behaviour that challenges. Search was widened to include all people with learning disability.	**Overall assessment of external validity** + **Overall assessment of internal validity** ++ **Overall score** +

	testing for effectiveness and cost-effectiveness.	**Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Partly. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. The population has been widened to include all people with a learning disability **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. All health and social care settings. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	

		(For effectiveness questions) Are the study outcomes relevant to the guideline? Yes. **Does the study have a UK perspective?** No. International focus.	

41. McBrien J, Gregory J, Hodgetts A (2003) Offending and risky behaviour in community services for people with intellectual disabilities in one local authority. Journal of Forensic Psychiatry and Psychology 14: 280–97

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Cross-sectional study. **Does the study's research question match the review question?** Yes. Identifying the prevalence of people with learning disabilities and offending behaviour is relevant to the capacity question. **Objectives of study clearly stated?** Yes.	**Subjects recruited in acceptable way?** Yes. All services in the locality covered and consented to take part. **Sample representative of defined population?** Yes. Defined as people in contact with health and social services, rather than people clinically screened as having a learning disability.	**Has the study dealt appropriately with any ethical concerns?** Yes. Ethical committee approval was gained from the local research ethics committee. The services taking part (Plymouth City Social Services, South and West Devon Health Authority and Plymouth Community Services NHS Trust) each provided their permission.	**Overall assessment of external validity** + **Overall assessment of internal validity** + **Overall score** +

Clearly specified and appropriate research design? Yes.	**Measurements and outcomes clear?** Yes. **Measurements valid?** Partly. Small discrepancy in count of number of care staff/managers/informants in the study. **Setting for data collection justified?** Yes. **All important outcomes and results considered?** Yes. **Tables/graphs adequately labelled and understandable?** Yes. **Appropriate choice and use of statistical methods?** Partly. Differences between agencies and between individuals with and without contact with the criminal justice system (CJS) were examined using chi-square tests. However, differences between experience of the settings and the individuals not explained. **In-depth description of the analysis process?** No.	**Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Although there is often a fine line between challenging behaviour and offending. It isn't always clear if all offenses committed by people with learning disabilities can be also categorised as challenging behaviour as defined in the scope. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community services and residential homes, day centres and respite care. **Does the study relate to at least 1 of the activities covered by the guideline?** Partly. Prevalence of offending and challenging behaviour in	

	Are sufficient data presented to support the findings? Yes. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. **Results can be generalised?** Partly. For people with learning disabilities in touch with services who have had contact with CJS. **Do conclusions match findings?** Yes.	community services, not about specific activity. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Looking at prevalence of offending and risky behaviour to inform service development which isn't the same as views and experiences. **Does the study have a UK perspective?** Yes. One local authority area in a city locality in the South of England.	

42. McConkey R, Gent C, Scowcroft E (2013) Perceptions of effective support services to families with disabled children whose behaviour is severely challenging: a multi-informant study. Journal of applied research in intellectual disabilities 26: 271–83

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study.	**Is the analysis reliable?** Yes.	**Does the study's research question match the review question?** Yes.	**Overall assessment of internal validity** ++

Is a qualitative approach appropriate? Appropriate. Study is concerned with views, experiences and perceptions of various stakeholders involved with these services **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. Interviews were conducted in a private room by experienced researchers. Permission given for recording and the interview was transcribed verbatim and thematic content analysis undertaken. Some interviewees were involved in feeding back on the findings. **How well was the data collection carried out?** Somewhat appropriately. **Were the participants recruited in an appropriate**	**Are the findings convincing?** Yes. **Are the conclusions adequate?** Yes.	**Has the study dealt appropriately with any ethical concerns?** Yes. Assurances were given of confidentiality to all informants and written consents obtained. Ethical approval form the trust was not sought as this was deemed to be an evaluation of an existing service. **Were service users involved in the study**? Yes. Views were sought form parents of children who had accessed the short breaks service. Some interviewees were involved in feeding back on the findings. **Is there a clear focus on the guideline topic?** Yes. Children with learning disabilities in this study are described as severely challenging. **Is the study population the same as at least 1 of the**	**Overall score** ++ **Overall assessment of external validity** ++

way? Somewhat appropriate. Seventeen parents were randomly selected from the whole sample of people who had accessed services (99) in Edinburgh, Cardiff and Glasgow sites. **Were the methods reliable?** Reliable.		**groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

43. McGill P, Cooper V , Honeyman G (2010) Developing better commissioning for individuals with behaviour that challenges services: a scoping exercise. Canterbury: Tizard Centre

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study.	**Are the data 'rich'?** Mixed. There is not a lot of detail of the data. There is a bit of diversity of perspective and	**Does the study's research question match the review question?** Yes.	**Overall assessment of internal validity** -

Is a qualitative approach appropriate? Appropriate. **Is the study clear in what it seeks to do?** Clear **How defensible/rigorous is the research design/methodology?** Somewhat defensible. There is very little information provided about the study design/methodology to defend it. However it was carried out by the Tizard Centre, a leading academic group with a lot of relevant experience with this type of research, and this provides some assurance that the study design is appropriate, even if very little detail has been reported. **How well was the data collection carried out?** Not sure/inadequately reported. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Somewhat appropriate. The families were recruited	content was explored somewhat, however the contexts of the data are clearly described. **Is the analysis reliable?** Unreliable. There is very little information to indicate that analysis is reliable. No mention of how the interviews were coded, if the participants feedback on transcripts or if negative results were ignored. **Are the findings convincing?** Somewhat convincing. Extracts from the original data included and the data is somewhat appropriately referenced, while the experiences described above are those of only 6 families they are common among families both of children and adults (e.g. Allen et al. 2006; McGill et al. 2006; McGill et al. 2009). Plus, despite the small number of participants, 1 of the authors says ‘these experiences are not unique to the 6 families interviewed and are	**Were service users involved in the study?** Yes. The families of service users were involved in the study and gave their views about service provision for their child. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** No, not applicable. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes.	**Overall assessment of external validity** ++ **Overall score** +

and interviewed by the Challenging Behaviour Foundation, and organisation that has a lot of experience and knowledge of service users, however little detail is provided about the families, making it difficult to identify and potential biases. Not enough information is provided to make a judgement about how the commissioners were recruited, however they all come from London or the South East. **Were the methods reliable?** Somewhat reliable. The Challenging Behaviour Foundation, an organisation with a lot of experience of behaviour that challenges, interviewed the families, which would have helped to get more reliable information from the participants.	consistently raised by family carers who contact the Challenging Behaviour Foundation, often in crisis, for information and support'. For the commissioners, the barriers discussed in some detail were all endorsed by at least half the interviewees. **Are the conclusions adequate?** Adequate.	**Does the study have a UK perspective?** Yes.	

44. McGill P, Tennyson A, Cooper V (2006) Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: their perceptions of services received and expectations of the future. The British Journal of Social Work 36: 597–616

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Survey. **Objectives of the study clearly stated?** Yes. **Research design clearly specified and appropriate?** Yes. **Clear description of context?** Yes. **References made to original work if existing tool used?** Yes, only tool mentioned and used Likert scales.	**Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Yes. **Methods appropriate for the data?** Yes. **Statistics correctly performed and interpreted?** Yes. **Response rate calculation provided?** Yes. **Methods for handling missing data described?** Yes. **Difference between non-respondents and respondents described?** Yes. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Reliability and validity of new tool reported?** No.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Research participants were assured of confidentiality and all materials were kept securely and in line with the 1998 Data Protection Act. All authors were subject to departmental policies on confidentiality. Participants were given the option to complete the questionnaire anonymously. A summary of the results was sent following completion of the research to all those who had participated, and provided contact details. **Were service users involved in the study?** Yes. Parents of children in 52-week residential school placements were consulted early in the project. One parent (the third author) acted as co-supervisor of the	**Overall internal validity score** ++ **Overall external validity score** ++ **Overall score** ++

	Survey population and sample frame clearly described? Yes. **Representativeness of sample is described?** Yes. **Subject of study represents full spectrum of population of interest?** Yes. **Study large enough to achieve its objectives, sample size estimates performed?** Yes. Eleven out of 16 52-week residential schools in the UK participated in the study. **All subjects accounted for?** Yes. **Ethical approval obtained?** Yes. In line with local procedures, the researcher submitted an application for ethical approval to the Departmental Research Ethics Committee (incorporating external participants), which is charged with acting on behalf of the university ethics committee. Ethical approval was granted.	researcher and was involved at all stages of conceptualisation, design, development, analysis and dissemination. Two other parents also reviewed the pilot questionnaire and gave feedback on its ease of use, clarity, content, sensitivity and length. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes.	

	Measures for contacting non-responders? None mentioned. **All appropriate outcomes considered?** Yes. **Response rate?** The rate of questionnaire return (at 34%) was lower than in some comparable studies of parents (e.g. 53% in Male 1998) but higher than commonly found with postal questionnaires (20–30% according to Hayes 2000). While the comparability of responders and non-responders cannot be completely assured, responses came via all the schools that had agreed to participate. **Describes what was measured, how it was measured and the outcomes?** Yes. **Measurements valid?** Yes. **Measurements reliable?** Yes. **Measurements reproducible?** Yes.	**Does the study have a UK perspective?** Yes.	

	Basic data adequately described? Yes. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Yes. **Results internally consistent?** Yes. **Limitations of the study stated?** Yes. The views reported are those only of parents. These should not be interpreted as a proxy for the views of children and young people in 52-week residential schools especially in respect of direct experiences of such schools. Also, while the questionnaire sample is relatively large, it is self-selecting and caution should be exercised in concluding that the findings reflect the population of parents having children at such schools. **Results can be generalised?** Yes. The questionnaire sample included parents of children at all of the schools		

	that agreed to take part, telephone interviewees were an essentially random subsample and, as we shall see below, where comparison was possible with other studies, findings were broadly consistent with those studies. This suggests that these samples have provided information that is broadly generalisable. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** Yes. References to other relevant studies. **Conclusions justified?** Yes.		

45. McGill P, Vanono L, Clover W et al. (unpublished) Preventing the challenging behaviour of adults with complex needs in supported accommodation.

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Comparison evaluation.	**Allocation unrelated to confounding factors?** Yes.	**Does the study's research question match the review question?** Yes.	**Overall assessment of internal validity**

Is a cohort study approach appropriate? Appropriate. **Is the study clear in what it seeks to do?** Clear. Quality of social care was observed in both the experimental and control group.	**Attempts made to balance the comparison groups?** Yes. Minimisation methods to balance groups based on North of England vs. South of England, number of staff in setting, challenging behaviour, number of adults without significant challenging behaviour, adaptive behaviour, and number of residents with autism. **Equal treatment?** Unclear Difficult to ascertain whether there was strict equal treatment. Control group settings may have worked towards improving standards independently. **Allocation – participants** Yes. **Allocation – practitioners** Yes. **Performance bias appraisal** Low risk of bias. **Follow-up** Yes. Between 12–18 months.	**Has the study dealt appropriately with any ethical concerns?** Yes. The study received ethical approval from the Social Care Research Ethics Committee Governance applications were made to and agreed by 14 local authorities covering all the settings which eventually participated. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Social care in supported accommodation.	++ **Overall assessment of external validity** ++ **Overall score** ++

	Drop-out numbers Intervention drop-outs 3. Comparison drop-outs 5. **Groups comparable on intervention completion?** Yes. **Missing outcome data** Intervention, missing outcome data, not clear. Comparison, missing outcome data, not clear. **Groups comparable on available data?** Yes. **Attrition bias appraisal** Low risk of bias. **Did the study have an appropriate length to follow-up?** Unclear. The period of 12–18 months is a reasonable follow-up. More time points would be useful to see if the benefits are sustained. **Did the study use a precise definition of outcome?** Yes. **Was the method used to determine the outcome valid and reliable?** Yes.	**(For effectiveness questions) Are the study outcomes relevant to the guideline?** Partly. The main outcomes was the prevention of behaviour that challenges, which would be under the remit of the clinical guideline. However, the intervention is the improvement of social care and relevant to this review, There are other outcomes that are relevant to this review. **Does the study have a UK perspective?** Yes.	

	Were investigators kept 'blind' to participants' exposure to the intervention? Yes. **Were investigators kept 'blind' to other important confounding factors?** Unclear. **Do conclusions match findings?** Yes.		

46. McKenzie K, Paterson M (2010) Evaluating an assertive outreach team for supporting clients who present behaviour that challenges. British Journal of Learning Disabilities 38: 319–27

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Mixed methods. The service was evaluated using Maxwell's Multi-dimensional Quality Evaluation Model (Maxwell 1984). Data was obtained from the existing Assertive Outreach Team (AOT) data, which was routinely collected and collated by the service and 2 questionnaires were designed for the evaluation, 1	**Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question?** Partly. Service users' views missing. **Is the integration of qualitative and quantitative data (or results) relevant to**	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical advice was sought from the local ethics committee. Ethical approval for the project was not required as it was deemed to be a service evaluation.	**Overall internal validity score** + **Overall external validity score** + **Overall score** +

for AOT staff and the other for referrers and for services which had received input from the AOT. **Qualitative component 1** Questionnaires 1–2 **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. **Is the process for analysing qualitative data relevant to address the research question?** Yes. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Yes. **Is appropriate consideration given to how findings relate to researchers' influence; e.g., though their interactions with participants?** Yes. **Qualitative component 2**	**address the research question?** Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** Unclear.	**Were service users involved in the study?** No **Is there a clear focus on the guideline topic?** Yes **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Age range 22–65. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Outreach team. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Partly. A major limitation of the study is that effectiveness is evaluated purely in terms of a reduction in challenging behaviour. **Are the views and experiences reported relevant to the guideline?** Partly. They are views of referrers to the service and	

Which component? Existing AOT data, routinely collected by the service. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes **Is the process for analysing qualitative data relevant to address the research question?** Yes **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Partly **Is appropriate consideration given to how findings relate to researchers' influence; for example, though their interactions with participants?** Unclear **Mixed methods component** **Is the mixed-methods research design relevant to address the qualitative and quantitative research**		staff and not the views of service users. **Does the study have a UK perspective?** Yes.	

questions (or objectives), or the qualitative and quantitative aspects of the mixed-methods question? Partly, service users views missing. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** Unclear			

47. National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour. London: NAO

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative evaluation.	**Are the data 'rich'?** Poor. Considering the input from multiple stakeholders the data is poorly reported.	**Does the study's research question match the review question?** Yes. Current capacity, barriers and	**Overall assessment of internal validity** - **Overall score**

Is a qualitative approach appropriate? Somewhat appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible.	**Is the analysis reliable?** Unreliable. Not very clear who views are attributable to and how strong individual issues or findings were for the different stakeholders. **Are the findings convincing?** Somewhat convincing **Are the conclusions adequate?** Somewhat adequate. However the conclusion related to assessment and treatment does not seem to flow from the findings of the report. **How well was the data collection carried out?** Inappropriately. The data collection methods are not clearly described and no indication of how systematic the data collection and record keeping is. **Is the context clearly described?** Clear.	facilitators for transforming care. **Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	- **Overall assessment of external validity** -

	Were the participants recruited in an appropriate way? Not sure. Not enough information to make judgement. **Were the methods reliable?** Unreliable. While more than 1 data collection method used and the reason given for different methods, enough detail of the actual methods is not provided, e.g. how many people were interviewed or participated in the focus groups. There isn't much discussion around the findings alongside other findings.		

48. National Audit Office (2017) Local support for people with a learning disability. London: NAO

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Qualitative evaluation.	**Are the data 'rich'?** Poor. Considering the input from multiple stakeholders the data is poorly reported.	**Does the study's research question match the review question?** Yes.	**Overall assessment of internal validity** -

Is a qualitative approach appropriate? Somewhat appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. **How well was the data collection carried out?** Inappropriately. The data collection methods are not clearly described and no indication of how systematic the data collection and record keeping is. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Not sure. Not enough information to make judgement. **Were the methods reliable?** Unreliable. While more than 1 data collection method used and the reason given for different	**Is the analysis reliable?** Unreliable. Not very clear who views are attributable to and how strong individual issues or findings were for the different stakeholders. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Somewhat adequate. However the conclusion related to assessment and treatment does not seem to flow from the findings of the report.	Current capacity, barriers and facilitators for transforming care. **Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Yes **Are the views and experiences reported relevant to the guideline?** Yes.	**Overall assessment of external validity** + **Overall score** - Overall the quality of the audit is limited.

methods, enough detail of the actual methods is not provided, e.g. how many people were interviewed or participated in the focus groups. There isn't much discussion around the findings alongside other findings.		**Does the study have a UK perspective?** Yes.	

49. National Development Team for Inclusion (2015) Informing the service model: a report about the experiences of people with learning disabilities and families. Bath: National Development Team for Inclusion

Internal validity- Study aims and approach	**Internal validity- performance and analysis**	**External validity**	**Overall validity rating**
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Reasonable methods were used to recruit service users and families for the focus	**Are the data 'rich'?** Mixed. There is some indication in the data that diversity of perspective and content has been explored and the context of the data is described adequately. **Is the analysis reliable?** Not sure/not reported. **Are the findings convincing?** Somewhat convincing. The findings seem to be internally coherent but aren't	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Yes. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the**	**Overall internal validity score** - **Overall external validity score** ++ **Overall score** +

groups and interviews, with focus groups being held in 4 different regions. While there is some description of the characteristics of the participants, there is not a lot of detail, e.g. about age. Scant information is provided about how the data was analysed. **How well was the data collection carried out?** Not sure/inadequately reported. The data collection methods are not clearly described and results haven't been reported separately for the different data collection methods. **What was captured from the interviews and focus groups?** It is difficult to attribute who said what from the write-up. The authors provide possible solutions in the paper, but it isn't always possible to tell if the solutions spring from the data or are the authors own interpretation and thoughts.	that clearly presented and it isn't always possible to know which type of participant a comment is attributed to. There is not a lot of reference to how many people were saying something or which were the strongest themes. It is also not possible to tell which comments came from the telephone interviews and which the focus groups. **Are the conclusions adequate?** Somewhat adequate. While the findings relevant to the aims of the study, it is not always clear how the data, interpretation and conclusions are linked and if some of the conclusions have come from the authors ideas, rather than the data.	**groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

Is the context clearly described? Clear. **Were the participants recruited in an appropriate way?** Appropriate. For this type of study. **Were the methods reliable?** Unreliable. It is clear that data was collected by more than 1 method, but that appears to be the only reliable element of the method.			

50. Oxley C, Sathanandan S, Gazizova D et al. (2013) A comparative review of admissions to an intellectual disability inpatient service over a 10 year period. British Journal of Medical Practitioners 6(2): a611

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Cross-sectional study. **Objectives of study clearly stated?** Yes. Study examines changes in admission trends following policy change.	**Subjects recruited in acceptable way?** N/A **Sample representative of defined population?** Unclear. It's not possible to determine how representative the patient group is without comparisons to national data.	**Does the study's research question match the review question?** Partly. While admission trends can't answer the question on capacity directly, it can indicate barriers to access, such as reasons for delayed	**Overall assessment of external validity** ++ **Overall assessment of internal validity** - **Overall score**

Clearly specified and appropriate research design? Yes.	**Measurements and outcomes clear?** Yes. **Measurements valid?** Yes. **Setting for data collection justified?** Yes. **All important outcomes and results considered?** Partly. Outcomes and results are dependent on the quality of the data collected at the time. **Tables/graphs adequately labelled and understandable?** No. The numbers in graphs are not shown, it is difficult to make out some proportions by the axis. **Appropriate choice and use of statistical methods?** No. No statistical tests for significant differences undertaken, its default to know without this given the differences in sample sizes whether the differences were due to chance or real. **In-depth description of the analysis process?** No.	discharge and trends in the characteristics of admissions. **Has the study dealt appropriately with any ethical concerns?** Partly. The study looks at case notes for patients over 2 time periods. It does not say whether the data were anonymised. But no additional consent would be necessary for secondary data routinely collected. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. Admissions to inpatient services, including characteristics of people with learning disabilities and behaviour that challenges is relevant to this review. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. The majority of the patients admitted were due to behaviour that challenges.	-

	Are sufficient data presented to support the findings? Partly. Authors refer to other studies that look at admission trends to support their findings. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. **Results can be generalised?** Partly. To a point. The study looks at 2 time periods in 1 setting. The unit is based in a Greater London borough and is likely to experience more pressures on finding suitable accommodation with support in the community. This may be more generalisable to areas of the UK under similar pressures. **Do conclusions match findings?** Yes.	**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. Outcomes include reasons for admission and reasons for delayed discharge. **Does the study have a UK perspective?** Yes.	

51. **Pearson GS (2012) The transition experience of developmentally impaired young adults living in a structured apartment setting. Advances in Nursing Science 35: E73-89**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. Aim of research is to describe the experience from the point of view of the service user of the transition to independent living – qualitative design therefore appropriate. **Is the study clear in what it seeks to do?** Mixed. The study states that it has a focus on transition into independent living, however the questions asked of participants tend to relate more to their experience of transitioning to adulthood more generally, than their experience of living in this	**Are the data 'rich'?** Mixed. Differences between participant responses clearly described. However, author notes that the 'transition experience was likely influenced by the individual's history of placement, diagnosis ... None of these issues were systematically evaluated before conducting the interviews with participants' (pe84). **Is the analysis reliable?** Unreliable. Unclear how analysis was conducted, or any methods for cross-checking or verifying. Reporting of findings is somewhat confused. **Are the findings convincing?** Not convincing.	**Does the study's research question match the review question?** Yes. Relates to service user experience of transition to a support independent living setting. **Has the study dealt appropriately with any ethical concerns?** Yes. Ethical approval by university and local institutional review boards. Also sufficient time spent with participants to obtain their informed consent. Also phone contact by researcher with caseworkers after each interview, in case of any problems with participants. **Were service users involved in the study?** No. Service users involved as participants,	**Overall assessment of internal validity** - This study has been rated as poor because there is a mismatch between the study research aim and study design. The aim is to explore experiences of transition to an independent living setting. However, the design did not allow for finding out about where the person had lived previously and other contextual factors which would help to contextualise their experience of transition. It is unclear how interview data were recorded, and whether verbatim transcription was used. There is little information about how the analysis of the

setting and how it differs from previous experiences. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. Unclear to what extent participants are representative of this client group – researcher was unable to ascertain. **How well was the data collection carried out?** Somewhat appropriately. Unclear how interviews were recorded – appears to be based on researcher 'field notes' only rather than recordings/verbatim transcription. **Is the context clearly described?** Unclear. Little information given regarding participants' previous living arrangements – it appears that the researcher was unable to ascertain this.	The lack of congruence between the research aims and the questions asked in the interviews, as well as lack of clarity of analysis, makes it difficult to have confidence in these findings. **Are the conclusions adequate?** Somewhat adequate. **Were the participants recruited in an appropriate way?** Somewhat appropriate. Individuals initially identified by case managers, and then asked to give consent to participate. Identification by case managers has the potential for bias – case managers may have 'screened out' those who have had a negative experience of living in the setting. **Were the methods reliable?** Somewhat reliable. Only 1 form of data collection	but not in design, data-gathering or interpretation. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Adults with childhood diagnosis of pervasive developmental disorder (PDD) and additional problems relating to aggression, sexually inappropriate behaviour or sexual offending. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Supporting housing. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Relates to types of service provision. **(For views questions) Are the views and experiences**	data was conducted and the presentation of findings is somewhat unclear. **Overall assessment of external validity** + Unclear to what extent this setting – a supported independent housing scheme run by an adult mental health services providers – is similar to UK settings. **Overall score** -

However, this makes it difficult to assess experiences of transition and how current living situation may be better or worse than previous situation.	and researcher not allowed to check back interview summaries with participants.	**reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No, USA.	

52. Perry J, Allen D, Pimm C et al. (2013) Adults with intellectual disabilities and challenging behaviour: the costs and outcomes of in- and out-of-area placements. Journal of Intellectual Disability Research 57: 139–52

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity
Methodology Comparison evaluation. The approach to assessing costs followed the comprehensive costing approach recommended by Beecham and Knapp (1992). **Is this study a prospective evaluation?** No. Comparison evaluation. **Description of theoretical approach?** Partly.	**Was the exposure to the intervention and comparison as intended?** Partly. Authors point out that service provision is likely to reflect differences in needs. There may have been differences between the groups not accounted for by matching. **Was contamination acceptably low?** Yes. **Did either group receive additional interventions or have services provided in a different manner?** Not reported. **Were outcomes relevant?** Yes.	**Does the study's research question match the review question?** Yes. Out-of-area placements is of relevance to this review question. **Has the study dealt appropriately with any ethical concerns?** Partly. Informed consent was sought, or if not obtained because the person lacked capacity, consent was sought from 'personal consultees'.	**Overall assessment of internal validity** - **Overall assessment of external validity** + **Overall score** -

How was selection bias minimised? Quasi-experimental study participants matched on risk of out-of-area placement. **Was the allocation method followed?** Yes. **Is blinding an issue in this study?** Blinding not possible. It would not be possible to blind the participants to whether they were in an in-area or an out-of-area group. **Did participants reflect target group?** Yes. **Were all participants accounted for at study conclusion?** Yes.	**Were outcome measures reliable?** Partly. There were a lot of different measures for a small sample, which may have meant the sample size was not big enough to detect real differences. **Were all outcome measurements complete?** Yes. **Were all important outcomes assessed?** Partly. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** Partly **Was intention to treat (ITT) analysis conducted?** No. **Was the study sufficiently powered to detect an intervention effect (if one exists)?** No. **Were the analytical methods appropriate?** Yes. **Was the precision of intervention effects given or calculable? Were they meaningful?** No. **Do conclusions match findings?** Partly.	**Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Partly. It is not clear what types of settings are being compared that are in and out of area. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. Costs and quality of life outcomes. **Does the study have a UK perspective?** Yes.	

53. **Perry J, Beyer S (2009) The impact on objective technology of life outcomes of assistive technology in residential services for people with learning disabilities. Journal of Assistive Technologies 3: 5–14**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Single group, before and after. **Did the study address a clearly focused issue?** Yes.	**Was the cohort recruited in an acceptable way?** Unclear, it was not clear how the convenience sample was identified. **Was the exposure accurately measured to minimise bias?** Unclear. It is not clear what proportion of the residents actively used assistive technology, or passively received it, in the way of monitoring etc. **Was the outcome accurately measured to minimise bias?** Yes. Authors point out that the questionnaires may not have been able to capture all qualitative differences before and after the implementation of assistive technology.	**Can the results be applied to the review population?** Unclear. **Do the results from this study fit with other available evidence?** No. Studies tend to report positive impact on quality of life. The lack of differences could be due to: 1. small sample; 2. no control group; 3. high standard of care to begin with; 4. the group home setting (on average 7 residents per home). **What are the implications of this study for practice?** More research is needed to test the effectiveness of assistive technology on quality of life.	**Overall internal validity score** - **Overall external validity score** - **Overall score** -

	Have the authors identified all important confounding factors? No. No subgroup analysis to see if any other factors were associated with the outcome, such as setting characteristics and behaviour, or other characteristics of the participants. **Have they taken account of the confounding factors in the design and/or analysis?** Yes. Characteristics of the setting and participants were measured. **Was the follow-up complete enough?** Yes. **Was the follow-up of subjects long enough?** Unclear, authors acknowledge that the follow-up time was short. Some events that the assistive technology could have been used for and tested		

	against happen relatively infrequently. **How precise are the results?** Imprecise. Not all measures were analysed to explain any differences in outcomes. **Do you believe the results?** Unclear.		

54. **Perry J, Felce D, Allen D et al. (2011) Resettlement outcomes for people with severe challenging behaviour moving from institutional to community living. Journal of Applied Research in Intellectual Disabilities, 24(1): 1–17**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Comparison evaluation. **Is this study a prospective evaluation?** Yes, prospective. Data is collected at 4 time points. Pre- and post- move for each group. **Description of theoretical approach?** Yes. The intention had been to employ a 2-group design with	**Was the exposure to the intervention and comparison as intended?** Partly. It is clearly explained, but there were changes to the comparison, which meant direct comparisons between the hospital and resettled group could not be made and instead, changes over time measured.	**Does the study's research question match the review question?** Yes. Resettlement from a hospital setting to a community setting. **Has the study dealt appropriately with any ethical concerns?** Yes. Excellent consideration made, particularly with regards impact on participants. Clearance granted, consent and assent sought and	**Overall assessment of internal validity** + **Overall assessment of external validity** ++ **Overall score** +

about half of the participants (Group 1) being resettled earlier and half later (Group 2). Group 1 would constitute an experimental group. Group 2 would at first constitute a control group but later a second experimental group. However, delays in the accommodation being ready meant that residents moved in 3 phases, so the design had to be altered. Measurements at 4 time points were still taken and the ‘impact of change was assessed by grouping together the comparison of T1 versus T2 for Group 1 and T2 versus T3 for Group Control for exogenous factors is provided by repeated measures while participants remained in hospital, that is, Groups 2 and 3 combined between T1 and T2. Assessment of whether any post-resettlement change was maintained was achieved through comparing T3 and T4 for Groups 1 and 2 combined. Assessment of the impact of resettlement across all	**Was contamination acceptably low?** No. Staff training in positive behavioural support (PBS) and active support (AS) that started pre-move contaminated both groups. Wasn’t possible than to know if some of the changes in behaviour were due to the resettlement alone or due to the impact of the training. **Did either group receive additional interventions or have services provided in a different manner?** Partly. Unclear the impact of the training and how well it was implemented in both the hospital and community settings. **Were outcomes relevant?** Yes. The study’s outcome measures relate to the outcomes which they wanted to impact. **Were outcome measures reliable?** Yes. **Were all outcome measurements complete?**	checked before first interviews. **Were service users involved in the study?** Yes. Questioned as respondents to the subjective measures; experienced intrusion at home through being observed. The purpose of the research and impact was discussed with each individual. **Is there a clear focus on the guideline topic?** Yes. Evaluation of community living on quality of care and lifestyle outcomes compared with hospital setting. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	

participants was achieved by comparing T1 and T4' (p6). **How was selection bias minimised?** Quasi-experimental. **Was the allocation method followed?** Partly. As explained under theoretical approach, the original 2-group design had to be adapted. **Is blinding an issue in this study?** Blinding not possible It was not possible to ensure that data collectors were blind to the service differences evaluated. Nor were staff respondents. It is possible that this knowledge could have influenced their ratings. **Did participants reflect target group?** Yes. **Were all participants accounted for at study conclusion?** Yes.	Yes. However, on lifestyle satisfaction measures only a small number of participants were about to complete without bias. **Were all important outcomes assessed?** Yes **Were there similar follow-up times in exposure and comparison groups?** Yes. **Was follow-up time meaningful?** Yes. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** Yes. **Was intention to treat (ITT) analysis conducted?** Yes. **Were the estimates of effect size given or calculable?** No. Sample size was necessarily small, but potential for Type 2 areas noted by the authors. **Was the study sufficiently powered to detect an intervention effect (if 1 exists)?** No.	**(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. Quality of care and lifestyle outcomes. **Does the study have a UK perspective?** Yes. South Wales.	

	Were the analytical methods appropriate? Yes. But complicated by the 3 group design to measure change over time since the number of people in each setting was different at each time period. **Was the precision of intervention effects given or calculable? Were they meaningful?** Yes. **Do conclusions match findings?** Yes.		

55. Phillips N, Rose J (2010) Predicting placement breakdown: Individual and environmental factors associated with the success or failure of community residential placements for adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 23: 201–13

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Quantitative evaluation. **Is the source population or source well described?** Yes. Fairly well described. All from populations served geographically by 5 NHS	**Selection of exposure (and comparison) group. How was selection bias minimised?** Yes. The breakdown group represented the total breakdown population that could be identified.	**Does the study's research question match the review question?** Yes. **Were service users involved in the study?** Yes. Staff collected information about them using measures.	**Internal validity score** + **Overall assessment of external validity** ++ **Overall validity score**

trusts across the West Midlands, representing both rural and urban populations. The population was adults with intellectual disabilities and challenging behaviour, the criterion for which was set as a score of 35 or below on the behavioural items of the Disability Assessment Schedule (DAS-B). Data was collected about each individual using 3 scales/forms: demographic form, Disability Assessment Schedule and Adaptive Behaviour Scale. Information was also collected about staff, who were less well described, but the Controllability Beliefs Scale was used to collect information. **Is the eligible population or area representative of the source population or area?** Partially. While the study includes the total breakdown population that could be identified, it is still slightly smaller (n=20) than recommended by the power analysis (n=23). But the	Participants were identified by senior health and social services personnel, who gathered information from their own teams. However, some breakdowns might not been identified, as some individual may not have come into contact with intellectual disabilities services and may have entered the judicial system directly. **Was the selection of explanatory variables based on a sound theoretical basis?** Yes. Quite sound. Comparison group, an individual had to have been living in their placement for 3 years or longer. The cut-off point was chosen as an estimate of the mean length of placement of the breakdown group from initial data, and was therefore felt to represent a measure of placement stability. **How well were the likely confounding factors identified and controlled?** Yes. The authors	**Has the study dealt appropriately with any ethical concerns?** Yes. A non-experimental study. Consent was sought sensitively, using adapted information sheets and consent forms where appropriate from individuals for the researchers to approach members of staff that had worked with them. In cases where an individual was judged to be unable to give informed consent, a third party was approached (a relative, close friend or unpaid advocate) to make a decision as to whether participation would be in the individual's 'best interests'. Where consent wasn't given, 2 participants weren't included in the study. Consent was also sought from staff involved in the study. **Is there a clear focus on the guideline topic?** Yes, placement breakdown **Is the study population the same as at least 1 of the**	+

researchers say it would have been impractical to do that as it would mean extending the geographical area or extending the research window for the study, which had already been extended by 6 months to recruit a sufficient number of participants.	acknowledge that a confounding variable was introduced from the way the maintained group was identified by individuals referred to a local community or psychological services during the last 12 months. Any interventions from this service, whilst not preventing breakdown, could have impacted on the individual and environmental factors measured. **Were the outcomes measures and procedures reliable?** Partially. Three out of 4 of the scales used were tested and shown to have good internal reliability. This includes DAS-B, SABS and CBS. However the SSA (Allen 1999) is a relatively untested questionnaire. **Were the outcomes measures complete?** Yes. **Was there a similar follow-up time in exposure and comparison groups?** No. Maintained group had been	**groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes West Midlands, UK.	

	living in their setting for at least 3 years. For the breakdown group, length of placement varied, and 45% of the placements broke down within the first 10 months. **Was follow-up time meaningful?** Yes. Three years taken as a measure of stability was appropriate as the mean length for the breakdown group was 2.5 years (sd=43.7), maintained group 8.6 years (sd=47.1). **Was the study sufficiently powered to detect an intervention effect (if 1 exists)** Partially. Using Cohen's (1988) conventions for non-matched groups it was determined that approximately 23 participants would be required in each group. Participants fell short in the breakdown group, n=20, however this is the total population that could be identified from the sampling frame.		

	Were multiple explanatory variables considered in the analyses? Yes. A Stepwise (Backward Selection) binary logistic regression was conducted. There was a limit on number of variables that could be used, so only one's implicated by previous research and in the study's aims were used.		

56. Pratt K, Baird G, Gringras P (2012) Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme. Child: Care, and Health and Development 38(6): 789–97

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Mixed. Not always clear which participants are being quoted or author interpretation. Not	**Are the data 'rich'?** Poor. **How well was the data collection carried out?** Not sure/inadequately reported. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate**	**Does the study's research question match the review question?** Partly. Focus of the research question is on pre-admission to inpatient services. **Has the study dealt appropriately with any ethical concerns?**	**Overall assessment of internal validity** - **Overall score** - **Overall assessment of external validity** -

clear whether the strategies suggested were effective or acceptable to the parents of the children being admitted. **How defensible/rigorous is the research design/methodology?** Not sure/inadequately reported.	**way?** Not sure/inadequately reported. **Were the methods reliable?** Not sure/inadequately reported. **Is the analysis reliable?** Unreliable. **Are the findings convincing?** Somewhat convincing. The barriers to effective care and the hypothesis behind the intervention seem reasonable. **Are the conclusions adequate?** Somewhat adequate. Poor study methodology makes this difficult to tell whether the findings match the data.	No. Details of obtaining consent not reported. **Were service users involved in the study?** Yes. Participants were parents who had used the pre-planning checklist. Views were also sought form nursing staff. There were no views given from the children who had been admitted. Although this may not have been possible. **Is there a clear focus on the guideline topic?** Yes. This study described the interface between community and a general health setting. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. Children who were admitted had learning disabilities and autism spectrum disorder. The pre-planning admission	

		process sought to prevent behaviour that challenges by predicting and overcoming barriers. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Relates to pre-panning before admission. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. Prevention of behaviour that challenges through better, personalisation of care. **Does the study have a UK perspective?** Yes.	

57. Pritchard A, Roy A (2006) Reversing the export of people with learning disabilities and complex health needs. British Journal of Learning Disabilities 34: 88–93

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Mixed methods. **Does the study's research question match the review question?** Yes.	**Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Partly. Not well described. **Is the process for analysing qualitative data relevant to address the research question?** Unclear. Very little detail provided. **Is appropriate consideration given to how findings relate to the context, such as the setting in which the data were collected?** Partly. **Is appropriate consideration given to how findings relate to researchers' influence; e.g., through their interactions with participants?** No. **Quantitative component (incl. non-RCT; cohort**	**Is there a clear focus on the guideline topic?** Yes. Considering the issue of capacity and looking at the use of services both locally and out of area. **Has the study dealt appropriately with any ethical concerns?** No. **Were service users involved in the study?** No. Commissioners are reporting about service user needs and delivery of individual care packages. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Mainly community provision of	**Overall assessment of external validity** + **Overall assessment of internal validity** - **Overall validity score** -

	study; case-control study) Which quantitative component? Data related to service user demographics, care packages, providers and costs. **Are participants (organisations) recruited in a way that minimises selection bias?** N/A **Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?** Partly. **In the groups being compared (exposed versus non-exposed; with intervention versus without; cases versus controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?** Unclear. No clinical validation of the 2 client groups: severe learning	services but also NHS and inpatient. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. Views of commissioners included, not direct views of service users or families and carers. **Does the study have a UK perspective?** Yes. West Midlands region of the UK.	

	disabilities and complex mental health problems. **Are there complete outcome data (80% or above) and, when applicable, an acceptable response rate (60% or above) or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?** Yes. **Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question?** Partly. No information collected on the components of the care packages. This would have been helpful. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Partly. Method used for qualitative element poorly described.		

	Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)? Unclear.		

58. **Purandare K, and Wijeratne A (2015) Reflections on the use of a specialist acute assessment and treatment unit for adults with intellectual disability. Advances in Mental Health and Intellectual Disabilities 9: 132–8**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Cross-sectional study. **Objectives of study clearly stated?** Yes. Study examines changes in admission trends following policy change. **Clearly specified and appropriate research design?** Partly. Doesn't account for people who were admitted to mainstream services or private services in the area at the same time.	**Subjects recruited in acceptable way?** N/A **Sample representative of defined population?** Unclear. It is not able to say anything about people who were not admitted, for instance people who were admitted to mainstream services or private services in the area at the same time. **Measurements and outcomes clear?** Yes. **Measurements valid?** Yes.	**Does the study's research question match the review question?** Partly. While admission trends can't answer the question on capacity directly, it can indicate barriers to access, such as lack of capacity and increased catchment area for the services. **Has the study dealt appropriately with any ethical concerns?** Yes. The trust research support team was contacted regarding the need for ethical approval for the study and the authors were	**Overall assessment of external validity** ++ **Overall assessment of internal validity** - **Overall score** - Don't know anything about people who were not admitted to services and study relies on the accuracy

	Setting for data collection justified? Yes. **All important outcomes and results considered?** Partly. Outcomes and results are dependent on the quality of the data collected at the time. **Tables/graphs adequately labelled and understandable?** No. Individual referring boroughs not easily identified in figure. Some of the total numbers in graphs are not shown. **Appropriate choice and use of statistical methods?** Yes. **In-depth description of the analysis process?** No **Are sufficient data presented to support the findings?** Partly. Authors refer to other studies that look at admission trends to support their findings. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes.	advised that ethical approval was not required since the study did not use patient identifiable data. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. Admissions to inpatient services, including characteristics of people with learning disabilities and behaviour that challenges is relevant to this review. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. The majority of the patients admitted were due to behaviour that challenges. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes.	and detail of reporting at the time.

	Results can be generalised? No. One area of London; demographic data on participants not collected. **Do conclusions match findings?** Yes.	**Are the study outcomes relevant to the guideline?** Yes. Differences in length of time of admission and increases in distance from home **Does the study have a UK perspective?** Yes.	

59. **Raghavan R, Newell R, Waseem F et al. (2009) A randomized controlled trial of a specialist liaison worker model for young people with intellectual disabilities with challenging behaviour and mental health needs. Journal of Applied Research in Intellectual Disabilities 22: 256–63**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology RCT including cluster Non-blinded. **Is a cohort study approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear.	**Allocation unrelated to confounding factors?** Yes. **Attempts made to balance the comparison groups?** Yes. **Groups comparable at baseline?** No. Two more people in the control group; no Bangladeshi families in the control group. However, there were no differences on any of the	**Does the study's research question match the review question?** Yes. Comparison evaluation to find out if a liaison worker helps people access services. **Has the study dealt appropriately with any ethical concerns?** Yes. An application was submitted to the local research ethics committee for approval of the study and this was granted.	**Overall assessment of internal validity** + **Overall assessment of external validity** ++ **Overall score** +

	outcome measures at baseline. **Was selection bias present?** Low risk of bias. **Equal treatment?** Yes. **Allocation – participants** No. **Allocation – practitioners** Yes. When the initial allocation was made. **Performance bias appraisal** Unclear/unknown risk of bias Possible risk of bias in data collection as the research assistant that took the baseline measurements also carried out the intervention. It wasn't possible to record the contacts of participants in the control group and had to rely on retrospective reporting from participants. **Likely direction of performance bias effect** Inflated. Contacts data could be inflated for the intervention group.	Consent was obtained from all participants. **Were service users involved in the study?** Yes. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

	Attrition bias Likely direction of attrition bias effect. Lower level of contact data recorded. **Follow-up** Yes. Nine months later. **Drop-out numbers** Intervention drop-outs n=2. Comparison drop-outs n=2. **Groups comparable on intervention completion?** Yes. **Missing outcome data** Intervention: missing outcome data n=0 because the drop-out were at the start before the main data was collected. Comparison: missing outcome data n=2, not contactable at the end of the RCT. **Groups comparable on available data?** Yes. **Attrition bias appraisal** Low risk of bias n=2 for both groups. **Did the study have an appropriate length to follow-up?** Yes. Nine months, as the authors		

	thought this ‘length of time would be sufficient for outcomes to be visible’ (p258). **Did the study use a precise definition of outcome?** Unclear. The main outcome measure agreed upon at the start of the study was the number of contacts with services, as this best reflected the aim of the study to determine whether introduction of the specialist liaison worker could enhance access to such services. The variety of contact and outcomes of contact with services were also measured. However it isn’t clear how these were defined. **Was the method used to determine the outcome valid and reliable?** Unclear. For the intervention group data on contacts was collected by the liaison worker and also retrospectively by the participant so check for accuracy could be made.		

	Were investigators kept 'blind' to participants' exposure to the intervention? No. **Were investigators kept 'blind' to other important confounding factors?** Unclear. **Do conclusions match findings?** Yes.		

60. **Reid C, Sholl C, Gore N (2013) Seeking to prevent residential care for young people with intellectual disabilities and challenging behaviour: examples and early outcomes from the Ealing ITSBS. Tizard Learning Disability Review 18: 171–8**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Single group, before and after. **Is a cohort study approach appropriate?** Appropriate. For a pilot study of a novel approach to intensive services and short breaks. **Is the study clear in what it seeks to do?** Clear.	**Allocation unrelated to confounding factors?** Unclear. It wasn't clear if all referrals to the service were included or a sample selected. **Attempts made to balance the comparison groups?** N/A. No comparison group. Single group before and after. **Groups comparable at baseline?** Unclear.	**Does the study's research question match the review question?** Yes. Preventing residential placements is of interest to this review. **Has the study dealt appropriately with any ethical concerns?** Partly. Authors state that no ethical concerns raised as data was routinely collected. However,	**Overall assessment of internal validity** - **Overall assessment of external validity** + **Overall score** -

	Was selection bias present? Unclear/unknown risk. **Equal treatment?** N/A **Allocation – participants** Unclear. **Performance bias appraisal** High risk of bias (also A5). The stated aim of the study was to prevent residential placement. It not clear that the study has achieved that aim, as the outcomes are limited to parental concerns and behaviour. While behaviour that challenges is associated with residential placements, with no follow-up and no comparison group, it's not possible to say for certain that this intensive short breaks service achieves that. **Follow-up** Unclear. Data collection was at the end of the service, rather than a set follow-up time data collection points were collected at different times. This almost certainly reflects the different needs of the individuals, but it makes it	the parents were asked to reflect on their concerns. **Were service users involved in the study?** No. Minimally, data was routinely collected from service users. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Partly. Very limited number of outcomes to individual concerns of the parents and 1 measure of behaviour.	

	difficult to evaluate the effectiveness of the service and to replicate. **Drop-out numbers** Not stated. **Groups comparable on intervention completion?** Unclear. **Groups comparable on available data?** Yes. Single group before and after. Same group, so yes. **Attrition bias appraisal** Low risk of bias. **Did the study have an appropriate length to follow-up?** No. Difficult to establish what the appropriate time to follow-up should be to determine whether the service did prevent residential placement. Receipt of services ranged from 4 months to over 2 years. **Was the method used to determine the outcome valid and reliable?** Unclear. Very limited to 2 outcomes of	**Does the study have a UK perspective?** Yes.	

	behaviour and 3 parental concerns. **Were investigators kept 'blind' to participants' exposure to the intervention?** No. **Were investigators kept 'blind' to other important confounding factors?** No. **Do conclusions match findings?** Partly. From a small sample and no comparison group it is not certain whether the service prevented residential placement, although the results appear promising.		

61. Richings C, Cook R, Roy A (2011) Service evaluation of an integrated assessment and treatment service for people with intellectual disability with behavioural and mental health problems. Journal of Intellectual Disabilities 15: 7–19

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Comparison evaluation. **Is a cohort study approach appropriate?** Inappropriate. The 2 groups are not really	**Selection bias** Likely direction of selection bias effect: positive. **Allocation unrelated to confounding factors?**	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any**	**Overall assessment of internal validity** -

comparable – i.e. 1 single service compared to an integrated model. The comparison group is the intake group 1 year before implementation, arguably when the service was found to be wanting and in need of an overhaul, so not truly experimental. **Is the study clear in what it seeks to do?** Clear	Unclear. Referrals to the service as an inpatient only service and referrals to the service as an integrated model would likely be different, possibly in terms of level of need. **Attempts made to balance the comparison groups?** No. **Groups comparable at baseline?** Unclear. **Was selection bias present?** High risk of bias. Without comparing and perhaps matching for characteristics of the 2 groups, before and after implementation, there is a high risk of bias given the differences between the 2 services before and after implementation. **Equal treatment?** Yes. Retrospective study. Participants were not aware at the time. **Allocation – participants** Yes. **Allocation – practitioners** No.	**ethical concerns?** No. NA, retrospective study. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. A service models than includes different services working together. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	**Overall assessment of external validity** ++ **Overall score** -

	Practitioners would have been aware of the new way of working. **Performance bias appraisal** High risk of bias (also A5). Authors also note that the new service may have been met with renewed enthusiasm of staff for the short period of time being studies. **Likely direction of performance bias effect** Inflated. **Follow-up**: No. **Drop-out numbers** Not stated. No drop-outs, but scores for measures of behaviour were available for only 44% of all the participants. **Groups comparable on intervention completion?** Unclear. Baseline characteristics not stated, so unclear. **Groups comparable on available data?** Unclear. See above.		

	Attrition bias appraisal Unclear/unknown risk of bias. **Did the study have an appropriate length to follow-up?** Unclear Authors note that some problems, such as delayed discharge, are cumulative, and increase over time, **Did the study use a precise definition of outcome?** Yes, **Was the method used to determine the outcome valid and reliable?** Yes. **Were investigators kept 'blind' to participants' exposure to the intervention?** No. **Do conclusions match findings?** Yes.		

62. Robert M, Leblanc L, Boyer T (2015) When satisfaction is not directly related to the support services received: understanding parents' varied experiences with specialised services for children with developmental disabilities. British Journal of Learning Disabilities 43: 168–77

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating

Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate. **Is the study clear in what it seeks to do?** Clear. **How defensible/rigorous is the research design/methodology?** Defensible. **How well was the data collection carried out?** Appropriately. **Is the context clearly described?** Clear. **Were the participants recruited in an appropriate way?** Somewhat appropriate. The parents were recruited, on a voluntary basis by a team of professionals who provide specialised support to children. Recruitment took place over a 15-month period, until we reached a total of 15	**Are the data 'rich'?** Rich. **Is the analysis reliable?** Reliable. **Are the findings convincing?** Convincing. **Are the conclusions adequate?** Adequate.	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** No, not mentioned. No mention of getting consent from the interview participants. **Were service users involved in the study?** Yes. Parents of children with developmental disabilities were involved in this study. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. The children of participants in the study are described as being diagnosed with autism spectrum disorder or intellectual disabilities, but there is no additional mention of the characteristic of behaviour that challenges.	**Overall internal validity score** + **Overall external validity score** - **Overall score** -

parents of children with developmental disabilities. **Were the methods reliable?** Somewhat reliable. Interviews of 60 minute duration were recorded and transcribed verbatim to make them more accessible and easier to analyse. Semi-structured question guide used to ensure a range of issues covered. Open-ended interview gave parents the opportunity to use their own words, what was important to them. Data analysis performed by first author and second author reviewed the analysis process, including the codes and categories. Differing interpretations were resolved through discussion between the 2 authors. A third author reviewed summaries of the thematic analysis process to identify errors and discrepancies.		**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** No, City of Quebec, Canada.	

63. **Robertson J, Emerson E, Pinkney L et al. (2004) Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. American Journal on Mental Retardation 109: 332–44**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Quantitative evaluation. **Is this study a prospective evaluation?** No. Participants are already located at the 2 settings. **Description of theoretical approach?** Partly. Results comparing congregate to non-congregate settings for people with learning disabilities and the most severe behaviour that challenges have been mixed to date. This study set out to see if there were important differences between the 2 groups. **How was selection bias minimised?** Quasi-experimental groups in the 2 settings were matched on important characteristics.	**Was the exposure to the intervention and comparison as intended?** Not reported. **Was contamination acceptably low?** Yes **Did either group receive additional interventions or have services provided in a different manner?** Not reported. **Were outcomes relevant?** Partly. **Were outcome measures reliable?** Partly. Dependent on recall of a staff member. **Were all outcome measurements complete?** Yes **Were all important outcomes assessed?** Partly.	**Does the study's research question match the review question?** Partly. Study compares 2 different setting, 1 with a minority learning disability and behaviour that challenges services (LDBCS) and 1 a majority LDBCS. Samples are matched against the LDBCS. **Has the study dealt appropriately with any ethical concerns?** Partly. Interviews were conducted with a member of staff on the participant's behalf. It is not clear if informed consent was sought, either from the person themselves or a family member. There are issues around who can give informed consent when a person may not be able to communicate. **Were service users involved in the study?** No.	**Overall assessment of internal validity** + **Overall assessment of external validity** + **Overall score** +

Was the allocation method followed? NA **Is blinding an issue in this study?** No blinding. Provider organisations to nominate settings that they considered to be either congregate or non-congregate. It could be that these sites selected may have been more obviously one or the other, but the study does not identify those that were thought to be non-congregate but in practice were congregate. **Did participants reflect target group?** Yes. **Were all participants accounted for at study conclusion?** Yes.	**Were there similar follow-up times in exposure and comparison groups?** Yes **Was follow-up time meaningful?** Partly. Two points in time separated by a period of approximately 10 months. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** Yes. **Was intention to treat (ITT) analysis conducted?** No. **Were the estimates of effect size given or calculable?** No. **Was the study sufficiently powered to detect an intervention effect (if 1 exists)?** No. Authors note that behaviour that challenges can be persistent and cyclical. A 10-month follow-up may be too short a time to compare the effect of congregate and non-congregate settings on behaviour.	**Is there a clear focus on the guideline topic?** Partly. Conceivably the policy landscape has changed since publication of this study. Current UK policy is non-congregate settings wherever possible. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. This study's participants were at the more severe end of the scale for behaviour that challenges as measured by 5 or more items rated as a severe problem or a total score of 31 or more on the Aberrant Behaviour Checklist Irritability and Hyperactivity subscales (Aman et al. 1995) and a score of 20 or less on the Adaptive Behavior Scale (ABS) Language subscale (Nihira et al. 993) plus a score of less than 3 for use of sentences (equivalent to not using complex sentences). **Is the study setting the same as at least 1 of the**	

	Were the analytical methods appropriate? Partly. There are difficulties in involving the views of people who may not be able to speak for themselves and rely on the interpretation and recall of another party on their behalf. **Was the precision of intervention effects given or calculable? Were they meaningful?** Partly. **Do conclusions match findings?** Partly. Given the limitations of the study.	**settings covered by the guideline?** Partly. Current UK policy is towards non-congregate settings. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. Costs outcomes include resource use, such as staff ratios, accommodation costs, support provided to participants. Quality of life measures include: choice, family contact, social networks, participant activity, risk and injuries. **Does the study have a UK perspective?** Yes.	

64. Royal College of Psychiatrists (2013) People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services. London: PCPsych

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Mixed methods. **Does the study's research question match the review question?** Yes.	**Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Yes. The expert witnesses describe the characteristics of the different bed categories. **Is the process for analysing qualitative data relevant to address the research question?** Unclear. No methods of qualitative analysis are described. **Is appropriate consideration given to how findings relate to the context, such as the setting in which the data were collected?** No. **Is appropriate consideration given to how findings relate to researchers' influence e.g., through their**	**Is there a clear focus on the guideline topic?** Yes. **Has the study dealt appropriately with any ethical concerns?** Partly. It's not clear how the participants were recruited and what method of gaining informed consent. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the**	**Overall assessment of external validity** + **Overall assessment of internal validity** - **Overall validity score** -

	interactions with participants? No. **Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question?** Yes. As this is a study describing the characteristics of the different categories of inpatient services, the selection of clinical experts and family carers of service users is valid. There was little in the way of reporting the methods of data collection or analysis. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative**	**guideline?** Partly. It is not clear always where the data is coming from, professional/expert opinion, or service user experiences **Does the study have a UK perspective?** Yes.	

	and quantitative data (or results)? No. As the reporting of the methods, including methods of analysis from professionals and family careers, it's not possible to assess the strengths and limitations of the methods used.		

65. Seaward S, Rees C (2001) Responding to people with a learning disability who offend. Nursing Standard 15: 36–9

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Survey. **Objectives of the study clearly stated?** Yes. **Research design clearly specified and appropriate?** Yes. **Clear description of context?** Yes.	**References made to original work if existing tool used?** No. **Reliability and validity of new tool reported?** Partly. The questionnaire was piloted first before the main post-out and revised. Not sure what revisions were made or the reasons for this.	**Does the study's research question match the review question?** Yes. Identifying the prevalence of people with learning disabilities and offending behaviour is relevant to the capacity question. **Has the study dealt appropriately with any ethical concerns?** No. There may be ethical issues of sharing information about non-	**Overall assessment of external validity** + **Overall assessment of internal validity** - **Overall validity score** -

	Survey population and sample frame clearly described? No. **Representativeness of sample is described?** Partly. Response rate for a survey was high. Not clear how the staff were selected to receive the survey, or how representative they were for the areas' services. **Subject of study represents full spectrum of population of interest?** Yes. **Study large enough to achieve its objectives, sample size estimates performed?** Yes, partly. The aim was to estimate the prevalence of people with learning disabilities who have, or were thought to have, committed offences. Even though the sample is small, the proportions of offences and	prosecuted allegations of offences. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Ethical approval obtained?** No. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Offending behaviour and challenging behaviour overlap, but it isn't always clear if all offences committed by people with learning disabilities can be also categorised as challenging behaviour as defined in the scope. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes.	

	characteristics seem similar to those reported elsewhere. **All subjects accounted for?** Partly, subjects accounted for depend on staff knowledge and recall. **Describes what was measured, how it was measured and the outcomes?** Partly. Not all of the characteristics asked in the survey were reported. **Measurements valid?** Partly. Measurements are simple counts and percentages, no further analysis done. **Measurements reliable?** Partly. **Basic data adequately described?** Partly. Not all characteristics were reported. **Results presented clearly, objectively and in enough**	**Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	

	detail for readers to make personal judgements? Partly. More in-depth analysis of the characteristics of the subjects may not have been possible given the small sample size. **Results internally consistent?** Yes. **Data suitable for analysis?** Partly. Very small sample size. **Clear description of data collection methods and analysis?** Partly. **Methods appropriate for the data?** Partly. Limited by small sample size. **Statistics correctly performed and interpreted?** No. **Response rate calculation provided?** Yes. **Methods for handling missing data described?** No.		

	Difference between non-respondents and respondents described? No. **Results discussed in relation to existing knowledge on subject and study objectives?** Partly. Little comparison with other prevalence studies to see how their results may have compared, or triangulation with other regional or sector data on prevalence. **Limitations of the study stated?** Yes. **Results can be generalised?** Partly. The results may not necessarily be generalised, but the methods of data collection could be. **Appropriate attempts made to establish ‘reliability’ and ‘validity’ of analysis?** Yes.		

66. **Sergeant EV, Brown G (2004) Housing people with complex needs: Finding an alternative to traditional service models. Housing and Care and Support 7: 25–30**

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Qualitative study. **Is a qualitative approach appropriate?** Somewhat appropriate. Methods of recording the views of stakeholders not clear. If all the stakeholders were represented. If there were other stakeholders would could have usefully contributed. **Is the study clear in what it seeks to do?** Mixed. Study says that it reports on findings, but no outcomes other than the process of developing the housing plans were presented. **How defensible/rigorous is the research design/methodology?** Somewhat defensible. A qualitative design is	**Were the participants recruited in an appropriate way?** Not sure. No information on how stakeholders were recruited. **Were the methods reliable?** Unreliable. The data was not collected by more than 1 method, but the authors do discuss their findings alongside other studies. **How well was the data collection carried out?** Not sure/inadequately reported. **Are the data 'rich'?** Poor **Is the analysis reliable?** Unreliable. Methods of analysis not reported. **Are the findings convincing?** Somewhat convincing.	**Does the study's research question match the review question?** Yes. Models of housing service delivery. **Has the study dealt appropriately with any ethical concerns?** No No ethical concerns identified. **Were service users involved in the study?** No. No service users involved in the study. However the preferences of accommodation were recorded, but it is not clear where this information came from. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes.	**Overall assessment of internal validity** - The study provides a useful discussion on how agencies may involve stakeholders to develop alternative housing services. Other research supports the need for such personalised packages of care. This study was unable to say whether ultimately the project was successful in meeting the needs and preferences. There was no information on implementation. **Overall assessment of external validity** + **Overall score** -

appropriate for this process evaluation. **Is the context clearly described?** Clear.	The study reports on the development of an alternative models to housing, but is unable to show whether this was effective or not for the group of people that were under a delayed discharge or in a long stay home. **Are the conclusions adequate?** Inadequate. There was a mention made of assistive technology but did not go into what type, or whether it had been adopted or if it was effective.	**Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Community-based services. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Partly. This is a process evaluation involving a stakeholder consultation exercise in developing housing options better suited to the needs and preferences of people with learning disabilities and behaviour that challenges. There was no service user involvement in this consultation. **Does the study have a UK perspective?** Yes. Based on a single city in Scotland.	

67. Shared Lives Plus and KeyRing (2012) Closing the Winterbournes. Liverpool: Shared Lives Plus

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Process evaluation **Did the study address a clearly focused issue?** N Briefing that outlines how 2 successful approaches work.	**Was the cohort recruited in an acceptable way?** Unclear. Only case examples from 1 user of each service is used. **Was the exposure accurately measured to minimise bias?** No. **Was the outcome accurately measured to minimise bias?** No. **Have the authors identified all important confounding factors?** No. **Have they taken account of the confounding factors in the design and/or analysis?** No. **Was the follow-up complete enough?** No follow-up. **Was the follow-up of subjects long enough?** No. **What are the results?** The authors identified a number of things were needed	**Can the results be applied to the review population?** Unclear. It isn't always clear if the people the report is talking about have learning disabilities and behaviour that challenges. **Do the results from this study fit with other available evidence?** Yes. **What are the implications of this study for practice?** In this report the authors described what they found were successful approaches to help people move out of assessment and referral units in the UK and move into – or become regular visitors to – family homes.	**Overall internal validity score** - **Overall external validity score** - **Overall score** -

	for the scheme to work. They also identified things that either got in the way or helped moving into the community. **How precise are the results?** A lot of the time the report makes suggestions for the future, but it is not clear whether these have been tested and found to work in practice.		

68. Slevin E (2004) Learning disabilities: a survey of community nurses for people with prevalence of challenging behaviour and contact demands. Journal of Clinical Nursing 13: 571–9

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Survey. **Objectives of the study clearly stated?** Yes. **Research design clearly specified and appropriate?** Yes. **Clear description of context?** Partly. One issue pointed out in the aims is that there is	**Reliability and validity of new tool reported?** Yes. Piloted, tested and refined following feedback from the pilot. **Survey population and sample frame clearly described?** Yes. **Representativeness of sample is described?** Partly. As the survey is for 1 reason only, it's not clear how	**Does the study's research question match the review question?** Yes. **Has the study dealt appropriately with any ethical concerns?** Partly. Study says ethical issues were addressed by assurances of confidentiality being given to the nurses and seeking their informed consent. They were also informed that details	**Overall assessment of internal validity** + **Overall assessment of external validity** + **Overall validity score** +

geographical variation in caseloads by region, however this survey looked only at 1 region. There are no details given about this region of the UK to know how representative it is. **References made to original work if existing tool used?** N/A	representative the sample is nationally. **Subject of study represents full spectrum of population of interest?** Yes. **Study large enough to achieve its objectives, sample size estimates performed?** Partly. It is not possible to determine what sample size would be adequate to be representative without comparing to some baseline figure. **All subjects accounted for?** Unclear. **Ethical approval obtained?** No. Permission to contact the nurses was granted by regional managers. **All appropriate outcomes considered?** No. Not all outcomes were reported. It was not the aim of the study to undertake any further statistical analysis. **Describes what was measured, how it was measured and the outcomes?** Partly.	regarding any clients would be totally anonymous to the researcher. However, some small numbers could mean that individual nurses might be able to be identified. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. This includes the views and experiences of professionals. The study is quite old (2004). The views about prevalence are unlikely to change, but not clear what impact this has on staffing numbers, time	

	Not all outcomes were reported on, nor how any of the outcomes may have been correlated with each other. No explanation or analysis of the findings. **Measurements valid?** Yes. **Measurements reliable?** Partly. Dependent on the understanding of the nurses of challenging behaviour, which the researchers made some effort to ensure consistency with the piloting and revising the questionnaire. Also dependent on recall of the nurses. **Basic data adequately described?** Yes. Simple counts and percentages. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Yes. **Results internally consistent?** Yes. **Data suitable for analysis?** Yes.	resources and caseloads per nurse. **Does the study have a UK perspective?** Yes.	

	Clear description of data collection methods and analysis? Partly. Simple counts and percentages, no further analysis. **Methods appropriate for the data?** Partly. **Statistics correctly performed and interpreted?** Unclear. No statistical analysis undertaken. **Response rate calculation provided?** Yes. **Methods for handling missing data described?** Unclear. No methods for dealing with missing data. **Difference between non-respondents and respondents described?** No. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** Partly.		

	Only that this was a small scale survey. **Results can be generalised?** Unclear. Little is known about the region in which this study took place. Geographical variation was already stated as an issue in being able to measure prevalence and caseloads for nurses. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** Yes. Survey tool was piloted and assessed for face validity by CLDT nurses.		

69. **Slevin E, Sines D (2005) The role of community nurses for people with learning disabilities: working with people who challenge. International Journal of Nursing Studies 42: 415–27**

Internal validity, study aims and approach	**Internal validity, performance and analysis**	**External validity**	**Overall validity rating**
Methodology Qualitative study. **Is a qualitative approach appropriate?** Appropriate.	**Were the participants recruited in an appropriate way?** Appropriate. **Were the methods reliable?** Reliable.	**Does the study's research question match the review question?** Yes. Study aims to explore the meanings, experiences and	**Overall assessment of internal validity** + **Overall score**

Is the study clear in what it seeks to do? Clear. **How defensible/rigorous is the research design/methodology?** Defensible. Use of grounded theory to allow the perspectives of the nurse participants to generate the themes. More than 1 researcher was involved in developing themes and reaching consistency in coding from the transcribed data. **How well was the data collection carried out?** Appropriately. Nurse participants were sampled from all health and social services (HSS) trusts in the UK as well as for their range of experiences and perspectives. **Is the context clearly described?** Clear.	**Are the data 'rich'?** Mixed. It was not always clear who was speaking, the direct quotes are not attributed to a speaker. It is not possible to tell whether there was a range of voices represented, or if there were any differences between learning disability and behaviour that challenges specialists and learning disability generalists **Is the analysis reliable?** Somewhat reliable. **Are the findings convincing?** Somewhat convincing. **Are the conclusions adequate?** Adequate.	values of community nurses in the roles. **Has the study dealt appropriately with any ethical concerns?** Yes. Informed consent was obtained and participants could withdraw at any time. Client case notes were anonymised. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Partly. This study relates to the views and experiences of practitioners working with families. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Three nurses worked solely with children with learning disabilities and behaviour that challenged, while the	+ **Overall assessment of external validity** +

		remainder 19 nurses had mixed caseloads with over a quarter of their caseload having behaviour that challenged. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does study relate to at least 1 of the activities covered by the guideline?** Yes. **(For views questions) Are the views and experiences reported relevant to the guideline?** Partly. The main theme identified was ‘Promoting amelioration of detrimental effects of challenging behaviour and thus empowering clients and carers’ but other themes relevant to this guideline, such as the relationship with families and brokering and	

		accessing services, were also identified. **Does the study have a UK perspective?** Yes.	

70. Toogood S, Saville M, McLennan K et al. (2015) Providing positive behavioural support services: specialist challenging behaviour support teams. International Journal of Positive Behavioural Support 5: 6–15

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Single group, before and after. **Did the study address a clearly focussed issue?** No. This study looks at the development of the positive behaviour support teams, its design, structure and operation, but doesn't address a clearly focused issue.	**Was the cohort recruited in an acceptable way?** Unclear. Not relevant, an existing service is examined participants weren't needed to be recruited. **Was the exposure accurately measured to minimise bias?** NA **Was the outcome accurately measured to minimise bias?** No. **Have the authors identified all-important confounding factors**? Unclear. **Have they taken account of the confounding factors in**	**Can the results be applied to the review population?** Yes. **Do the results from this study fit with other available evidence?** Unclear, but seems to fit with Christopher (2015) and Inchley-Mort (2014). **What are the implications of this study for practice?** There may be many factors why this service could be successful in 1 area, but not another, such as the community-based capacity, leadership and commitment, multidisciplinary working	**Overall internal validity score** - **Overall external validity score** - **Overall score** -

	the design and/or analysis? Yes. **Was the follow-up complete enough?** Unclear. **Was the follow-up of subjects long enough?** No. **Reporting of results** 'As a multiple stakeholder approach, PBS delivery is likely to require focused collaborations between the focus person, persons who know the focus person and setting well, and persons who possess high-level technical skills.' **How precise are the results?** Not precise. **Do you believe the results?** Unclear.	relationships and organisational cultures. Results should be treated with caution on their own and should be considered with other studies that measure effectiveness other process evaluations that have similar findings and components.	

71. Vaughan PJ (2003) Secure care and treatment needs of individuals with learning disability and severe challenging behaviour. British Journal of Learning Disabilities 31: 113–17

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Survey.	**Objectives of the study clearly stated?** Yes.	**Has the study dealt appropriately with any ethical concerns?** No.	**Overall assessment of internal validity**

Does the study's research question match the review question? Yes. Inpatient secure provision for people with learning disabilities and severe behaviour that challenges is highly relevant to this review question on capacity.	**Research design clearly specified and appropriate?** Yes. **Clear description of context?** Yes. **References made to original work if existing tool used?** No. However, the study builds on previous work by the same author on mapping of services in the same area. **Reliability and validity of new tool reported?** No No piloting of the tool reported. No inter-rater reliability, or face internal or validity testing reported. **Survey population and sample frame clearly described?** Yes. **Representativeness of sample is described?** Yes, very high response rate of 96%. **Subject of study represents full spectrum of population of interest?** Yes. **Study large enough to achieve its objectives,**	Given the small numbers returned from each area, it may be possible to identify individuals, however little personal information was collected or cross-tabulated. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. **Does the study have a UK perspective?** Yes.	- **Overall assessment of external validity** + However the study is over 10 years old i.e. pre-Mansell DH report 'Services for people with learning disabilities and challenging behaviour or mental health needs 2007'. **Overall validity score** -

	sample size estimates performed? Yes. **All subjects accounted for?** Partly. **Ethical approval obtained?** No ethical permission was necessary given that it was a description of service use, however small numbers and the rare nature of the characteristics may have made some individuals identifiable. **All appropriate outcomes considered?** Yes. **Describes what was measured, how it was measured and the outcomes?** Yes. **Measurements valid?** Yes. **Measurements reliable?** Yes. **Basic data adequately described?** Yes. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** Yes.		

	Results internally consistent? Yes. **Data suitable for analysis?** Yes. **Clear description of data collection methods and analysis?** Yes. **Methods appropriate for the data?** Yes. **Statistics correctly performed and interpreted?** No statistical analysis performed other than simple counts. **Response rate calculation provided?** Yes. **Methods for handling missing data described?** No. **Difference between non-respondents and respondents described?** Unclear. **Results discussed in relation to existing knowledge on subject and study objectives?** Yes. **Limitations of the study stated?** No.		

	Results can be generalised? Partly. Care would have to be taken to see what policy changes have taken place since 2003 (e.g. Mansell, DoH report 2007) and if this has translated into change in practice. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** No.		

72. Watson JM, McDonnell V, Bhaumik S (2005) Valuing People: Evaluating Referral Systems. A Study of a Multidisciplinary Single Point of Referral System to Dedicated Adult Learning Disability Health Services in Leicester, UK. The British Journal of Development Disabilities 51(101), 155-70

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Mixed methods. Literature review, interviews with practitioners, retrospective case note review. **Does the study's research question match the review question?** Yes. Models of service delivery	**Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** Partly. Views of the people implementing the new referral process. But their views do not seem to be reported. It seems that this part was to gather	**Is there a clear focus on the guideline topic?** Yes. **Has the study dealt appropriately with any ethical concerns?** No. NA, retrospective case notes for referrals. **Were service users involved in the study?** No.	**Overall assessment of external validity** + **Overall assessment of internal validity** - **Overall validity score** -

focused on the system connecting services and connecting people to services.	current service status information. **Is the process for analysing qualitative data relevant to address the research question?** Unclear. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** Partly. It was not always possible to find participant information to compare from before the single point of referral (SPR) was implemented. Authors note that the referrals may not have been representative. **Quantitative component (incl. non-RCT; cohort study; case-control study)** Which quantitative component? Postal questionnaire to professionals. **In the groups being compared (exposed versus non-exposed; with intervention vs. without;**	**Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. One third of people referred to the services also at times displayed behaviour that challenges. **Is the study setting the same as at least 1 of the settings covered by the guideline?** Yes. Covers all settings where services are available. No settings were excluded. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. Whole service operation. **Are the study outcomes relevant to the guideline?** Yes. **Are the views and experiences reported relevant to the guideline?** Partly. Only responses from the postal questionnaire were reported, although interviews	

	cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups? Partly. Authors note the limitations of having 2 systems running concurrently, professionals not being aware of the new services and lack of data from before implementation to make matched comparisons. **Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?** Yes. Although a small number of providers were contacted, 90% responded. **Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and**	were also conducted with the referral process coordinators. **Does the study have a UK perspective?** Yes.	

	quantitative aspects of the mixed methods question? No. The mixed methods design may be appropriate but was not well executed. The qualitative element was not reported, the postal questionnaire was limited and baseline information was not available for comparisons. Baseline data of the new system replied on recall of the participants who were using the new system. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** Yes. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** No.		

73. Wheeler JR, Holland AJ, Bambrick M et al. (2009) Community services and people with intellectual disabilities who engage in anti-social or offending behaviour: referral rates, characteristics, and pathways. Journal of Forensic Psychiatry and Psychology 20(5): 717–40

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Secondary data study. Retrospective observational case note study. **Does the study's research question match the review question?** Yes. The services for people with learning disability and behaviour that challenges as antisocial or offending behaviour is relevant to this review. **Is a case-control approach appropriate?** Appropriate identifying participants from community samples may be a more accurate reflection of people with learning disabilities who also offend, compared to identifying people with learning disabilities who offend from criminal justice samples, given that not all	**Question appropriate and focused?** Adequately addressed. **Comparable populations?** Adequately addressed. There are difficulties in definition at the borderlines, such as definitions of antisocial behaviour, severity of behaviour and learning disability and criminal culpability. **Same exclusion criteria?** Well covered. **Participation rate for each group?** Cases 49, 20%. Controls 188 79%. **Comparison of participants?** Well covered. Participants were compared on gender, age, (at time of referral), level of learning disability, psychiatric	**Has the study dealt appropriately with any ethical concerns?** Yes. Data is anonymised case note information. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. **Is the study population the same as at least 1 of the groups covered by the guideline?** Partly. Not all of the people being serviced by intellectual disability (ID) service had a learning disability as defined by this scope, however there were people who were on the borderline of the definition. **Is the study setting the same as at least 1 of the**	**Overall assessment of external validity** + **Overall assessment of internal validity** + **Overall score** +

people with learning disabilities whose challenging behaviour is antisocial or criminal are reported. **Is the study clear in what it seeks to do?** Clear.	diagnosis, psychosocial history, behaviour which led to referral, previous recorded behaviour. **Cases clearly defined?** Adequately addressed. Whether had criminal justice system (CJS) contact or not (the control) would depend on any contact, even if the issue had been resolved informally being recorded. **Distinguishing of cases from controls?** Adequately addressed. **Measures to prevent knowledge of primary exposure?** N/A **Exposure status** Not reported. **Confounding factors** Adequately addressed authors acknowledge that figures from the community teams were inaccurate. It's not clear what impact this may have had. Authors choose sensible midpoints and averages and compare figures to wider literature.	**settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes, study looks at how people experience different services over time. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Partly, Study isn't looking at effectiveness or quality of services. But how people experience them over time. **Does the study have a UK perspective?** Yes. However, the study is still 7 years old. Effective working between the CJS and mental health and community services may have improved.	

	Statistical analysis No CI provided. **Do conclusions match findings?** Partly.		

74. Wong YL, Bhutia R, Tayar K et al. (2015) A five decade retrospective review of admission trends in a NHS intellectual disability hospital. Advances in Mental Health and Intellectual Disabilities 9(3): 108–15

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology Retrospective case notes review **Does the study's research question match the review question?** Partly. Study question relates to the current capacity of this particular hospital over time. It is not able to track whether lack of capacity in this case it offset by use of services elsewhere.	**Objectives of study clearly stated?** Yes. **Clearly specified and appropriate research design?** Yes. **Subjects recruited in acceptable way?** N/A. Retrospective observational study. **Sample representative of defined population?** Yes. **Measurements and outcomes clear?** Yes. **Measurements valid?** Partly. The measurements are over a long period of time in 1	**Has the study dealt appropriately with any ethical concerns?** No. Retrospective observational study, from hospital admission records. **Were service users involved in the study?** No. **Is there a clear focus on the guideline topic?** Yes. Trends in hospital admission is relevant to this question. **Is the study population the same as at least 1 of the groups covered by the guideline?** Yes. **Is the study setting the same as at least 1 of the**	**Overall assessment of internal validity** - **Overall assessment of external validity** + The hospital change of tier status is likely to have impacted on the characteristics of the people admitted to the hospital. **Overall score** -

	hospital, and which changed status in that time. Validity is limited by the representativeness of not only that hospital, but the community services in the area that the hospital links to, and changes over time. **Setting for data collection justified?** Yes. **All important outcomes and results considered?** Partly. **Tables/graphs adequately labelled and understandable?** Yes. **Appropriate choice and use of statistical methods?** Partly. Trends are measured in % and changes in % only. No statistical tests for significance. **In-depth description of the analysis process?** Partly. Limited statistical analysis undertaken. **Are sufficient data presented to support the findings?** Partly. Some limitation to the internal	**settings covered by the guideline?** Yes. **Does the study relate to at least 1 of the activities covered by the guideline?** Yes. **(For effectiveness questions) Are the study outcomes relevant to the guideline?** Yes. Rates of hospital admissions and the characteristics of patients admitted over time is relevant to this review question. **Does the study have a UK perspective?** Yes.	

	and external validity, being focused on only 1 hospital in 1 area over a long period of time. It is not clear how changes in hospital policies after Winterbourne have directly impacted on admission rates, a stated aim of the study. **Results discussed in relation to existing knowledge on the subject and study objectives?** Yes. **Results can be generalised?** Partly. The study would have benefited from some comparison to national baseline data. Not clear if admission to the hospital is broadly similar to other hospitals in similar areas. The change in tier status is also likely to have impacted on the characteristics of the people admitted over that time, but this was not tested. **Do conclusions match findings?** Partly.		

75. Xenitidis K, Gratsa A, Bouras N et al. (2004) Psychiatric inpatient care for adults with intellectual disabilities: generic or specialist units?. Journal of Intellectual Disabilities Research 48(1): 11–18

Internal validity, study aims and approach	Internal validity, performance and analysis	External validity	Overall validity rating
Methodology 2-group before-and-after study **Did the study address a clearly focused issue?** Yes. To evaluate the effectiveness of a specialist unit for people with a learning disability and mental health problems (MHP) and to compare admissions to the specialist unit and the general psychiatric unit.	**Was the cohort recruited in an acceptable way?** Yes. **Was the exposure accurately measured to minimise bias?** No. A number of people were admitted to both units, this possibility doesn't seem to have been considered in the study design. **Was the outcome accurately measured to minimise bias?** No. Outcome measures used in the study are not entirely independent from each other and are not all standard measures used with people with a learning disability and mental health problems. **Have the authors identified all important confounding factors?** Yes. Limited number of beds in the specialist unit and possibility of	**Can the results be applied to the review population?** Yes. **Do the results from this study fit with other available evidence?** Yes. Length of stay and out-of-area discharge. **What are the implications of this study for practice?** Specialist unit care is likely to be longer due to the complex problems of people being treated. Indicators are that specialist care can help prevent people being from moving out of area when they return to the community.	**Overall internal validity score** - **Overall external validity score** + **Overall score** - Outcomes in the comparison group not measured and small number of beds in specialist unit could have meant some referrals more appropriate for the specialist unit had to be directed to the generic units.

	patients being transferred from 1 unit to the other – treated in both. **Have they taken account of the confounding factors in the design and/or analysis?** No. Not with the group that was admitted to both services. **Was the follow-up complete enough?** No. Clinical outcomes measured on discharge only. **Was the follow-up of subjects long enough?** No. **What are the results?** Out of area discharge, a major outcome, not fully reported, difficult to know how accurate it is. **How precise are the results?** Results related to characteristics more precise; but other outcome measures, such as length of stay and out-of-area are poorly reported.		

Findings tables

1. Ahmad F et al. (2002) Partnership for developing quality care pathway initiative for people with learning disabilities: part I: development. Journal of Integrated Care Pathways 6: 9–12

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim In this paper we detail the development phase of the initiative and bring together common themes in the development of 3 separate care pathways for epilepsy, challenging behaviour and hearing impairment. **Service aims** The Partnership for Developing Quality (PDQ) care pathways initiative for people with learning disabilities identified 3 key areas for care pathway development: epilepsy, challenging behaviour and hearing impairment. **Country**	**Participants** **Professionals/practitioners** Community nurses, specialist nurses, local service managers, therapists, psychiatrists, social services, patient representatives, adults with learning disabilities and behaviour that challenges. User groups liaised with the service user representative back to the working group. **Sample size** Not mentioned **Treatment of groups** N/A (not more than 1 group). **What is the sampling frame (if any) from which participants are chosen?**	**Summary of findings** Summary of key factors in the care pathway development process : - Support from a cross-regional clinical governance body - Relevance to the timing and content of national policy - Multi-professional stakeholder recruitment - Appointment of facilitators for each care pathway - Care pathways training for working groups - Use of a generic process map template - Mission statement - Literature review and search for previous relevant care - First stage of care pathway to include	**Overall score** +

UK. **Methodology** Process evaluation. **Mechanism for change** Care pathway. **List/ add services of interest (read notes)** Inpatient services, category not specified. **Source of funding** Health authority. The Partnership for Developing Quality is funded by the West Midlands Regional Levy Board. **Content/components of service** **Assessment reports and intervention plans** **Protocols** All 3 working groups produced mission statements or their respective pathways. At the core of each mission statement was person-centred planning and reflection of recent national policy documents.	Implicit (please specify). The PDQ sent a letter to professionals working with people with learning disabilities in the West Midlands region, describing the care pathways initiative. Those who expressed an interest were invited to the initiative launch in November 2000. **How do the groups differ?** N/A (not more than 1 group). **What methods were used to collect the data?** Expert testimony: a working group professionals working with people with learning disabilities in the West Midlands region.	a coordinator - Large variation recording sections - 'Scoping' of documentation - Establishing diverse pilot sites – evaluating existing pre-pilot service - Identification of a pilot evaluation tool documents. **Facilitators identified** Organisational commitment. Multi-agency-interdisciplinary involvement. Single coordinator. **Study limitations** This study looked at the development phase of 3 care pathways, the challenging behaviour pathway was 1 of these, and it is not clear whether there are challenges to implementation or development of pathways for the review population only.	

Information use/sharing This was reinforced by a coordinator's checklist, to help the coordinator ensure that a particular individual negotiated the pathway successfully and that all documentation, including recording of variances, was completed. **Coordinator** Groups suggested that an individual care pathway coordinator increases the likelihood of the care pathway (and attached documentation) being completed. **Time to follow-up** No follow-up. A pilot study was planned.			

2. **Alborz A (2003) Transitions: Placing a son or daughter with intellectual disability and challenging behaviour in alternative residential provision. Journal of Applied Research in Intellectual Disabilities 16: 75–88**

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim	**Participants**	**Clinical outcomes**	**Overall score**

Looks at the factors that affect the move to alternative accommodation of a group of people with intellectual disabilities and challenging behaviour. **Country** UK. **Methodology** Qualitative study. **Source of funding**: Not reported. **Time to follow-up** No follow-up.	Carers/family members: interviews were mostly with mothers alone (n=13), n=5 involved both parents and n=1 included a grandmother. Children with learning disabilities and behaviour that challenges. Participants in the study were aged between 11 and 35 years, so included some children. Adults with learning disabilities and behaviour that challenges **Sample characteristics** Adults. **Age** Service users: aged between 11 and 35 years (mean 23.5; sd=5.18). Mothers: ranged from 44 to 63 (mean 51; sd=5.18). **Gender**: n=13 males (72%), n=5 females (28%). This differs (male =66%) from the gender distribution of the population of people with intellectual disabilities and identified as having challenging behaviour in other studies (Alborz 2001; Qureshi et al. 1989). **Ethnicity** N=17 White British; n=1 Asian. **Level of need**	**Physical health** The researchers were interested to know whether the mothers of those who had moved had been suffering higher levels of stress than those of people who remained at home. However, no significant difference was found in pre-move stress level scores (Malaise – Rutter et al. 1970) between a subgroup of mothers whose son or daughter had moved (mean 7; sd=3.55; range 2–11) and a control group whose sons and daughters remained at home (mean 8; sd=3.46; range 5–14). Indeed, the majority of mothers in both groups scored highly enough on the Malaise Inventory (i.e. a score of 6 or more) to signal that they might be suffering psychological distress. **Qualitative themes** **Access to support** There were 7 main factors that described the circumstances under which a move to alternative residential provision took place. One was about access to services. Some parents acknowledged that lack of services had an impact on their situation such that they could not cope in the long run, or needed to seek education or treatment elsewhere. **Choice and control**	++

	Participants' intellectual ability is described as follows: n=4 good; n=6 fair; n=5 poor; n=3 low. Participants physical limitations described as: n=11 none; n=4 moderate; n=3 severe. The characteristics of the population in this study are in-line with the larger study (n=439) that showed that higher levels of physical limitations were significantly correlated with lower levels of intellectual disability (r=0.53; p=0.000) as would be expected. **Relationship** Interviews were with families of people with a learning disability and behaviour that challenges. Mothers (n=13). N=5 involved both parents and n=1 included a grandmother. N=15 2 parent families n=3 lone-parent families. **Residence** The people in the study had moved home between 1 week and 6 years (mean 2.51 years) before the interview. **Characteristics of behaviour**	There were 7 main factors that described the circumstances under which a move to alternative residential provision took place. Two related to aspects of choice and control. Parents either decided that their son or daughter needed to lead a separate life, to end dependence on them and to lead a near 'normal' lifestyle for their age; or, the son or daughter with intellectual disability was bored/frustrated or ready to move. **Family life** There were 7 main factors that described the circumstances under which a move to alternative residential provision took place. Two related to factors of family life. First, parents were experiencing severe challenging behaviour at home, impacting directly on their lives which was hard to cope with. Second, additional difficulties in the family, such as divorce or mental/physical illness of spouse or siblings not directly involved in caring for the person with a learning disability. Overall, the data showed that the primary impetus in the decision to seek an alternative to family care, for 14 of the 18 families (78%), was that life at home was very difficult. For the remaining 4 families home life was not an issue.	

	All participants were people with intellectual disabilities showing challenging behaviour. **Sample size** N=18. **Sampling frame** Explicitly stated – 1988 epidemiological survey to identify people with learning disabilities who have challenging behaviour (n=695). This was a total population survey in a representative sample of 7 health authority districts that were part of the then North West Regional Health Authority. The sample of families interviewed were taken from this larger set. **Treatment of groups** N/A (not more than 1 group). However, there were 2 interview groups taken 2 years apart, 10 family interviews took place in 1993 and 8 in 1995. **How do the groups differ?** N/A (not more than 1 group). **What is the sampling frame (if any) from which participants are chosen?**	**The future** Four moves (22%) were categorised as ‘normal launching’, i.e. the son or daughter was leaving home at an age typical of that for the general population and for reasons of greater independence and/or separate adult lifestyle and is similar to the proportion found by Essex et al. (18%). No families appeared to fit the ‘postponed launching’ profile (Essex et al. 1997). This type of explanation emphasised moves from home at an older age than one would find in the general population (say aged 30 or more), as a preventative strategy or ‘anticipatory planning’ (Nolan et al. 1996) against the time when parental health may fail (Essex et al. 1997). This was partly due to the age range of the group. **Health and wellbeing** There were 7 main factors that described the circumstances under which a move to alternative residential provision took place. One was about health and wellbeing. Some parents described feeling ‘worn out’ or at the ‘end of their tether’. They might also have physical limitations themselves that were making caring difficult. **Stress and strain** There were 7 main factors that described the circumstances under which a move to	

	1988 epidemiological survey to identify people with learning disabilities who have challenging behaviour (n=695). This was a total population survey in a representative sample of 7 health authority districts that were part of the then North West Regional Health Authority. The sample of families interviewed were taken from this larger set.	alternative residential provision took place. One related specifically to stress and strain. Explanations acknowledged challenging behaviour as a factor in the decision to seek change because of its 'chronic nature' or the distress caused by witnessing its effect on their son or daughter. **Transition** There were 7 main factors that described the circumstances under which a move to alternative residential provision took place. These have been individually described under the appropriate heading but include: 1. Independence (n=6) 2. Bored – ready to move (n=3) 3. Severe challenging behaviour (n=11) 4. Lack of services, including respite (n=7) 5. Family problems (n=5) 6. Challenging behaviour – wearing (n=9) 7. Parent exhaustion or ill health (n=8) All parents of people with poor or low intellectual ability mentioned challenging behaviour as a contributory factor, as did most parents of people with fair intellectual ability. More parents of people with poor intellectual ability mentioned lack of services than other groups. Analysis of the range of 'last straw' explanations revealed 3 broad categories of primary impetus for placement as	

		follows: 1. Forensic (n=6) – involved intervention by the police or may have done so were action not taken 2. Family (n=5) – involving problems within the family not directly attributable to the person with intellectual disability or parental ill health 3. Service (n=3) – related to a lack of service provision, or lack of suitable services locally. **Costs?** None **Facilitators identified** **Family support** The researchers suggest, based on the findings from this study that if a number of family supports were put in place this could provide support to the family to facilitate transition and to help a person stay longer in a family home. Suggested supports include: - Provision of assistance to reduce the effects of challenging behaviour may go some way to boosting the family's ability to cope in the longer term. - Some families may need support to recognize their son or daughter's aspirations for 'independence' before this is perhaps expressed through behavioural	

		challenge. - Parents of people with poorer intellectual ability may need support to recognize the effect that caring may have on their own wellbeing, and to monitor other family difficulties. - A whole family approach to support may help to alleviate difficulties not directly connected to the son or daughter with intellectual disability, and enable them to remain in the family home longer, if they wish. - Improved access/less exclusion to day or respite services. **Summary of findings** Few people moved due to ‘normative’ family life cycle changes. The majority left because of family difficulties (‘stress process’). This research suggests that people (particularly young men) with intellectual disabilities and challenging behaviour enter statutory care earlier than their counterparts, and people with different levels of intellectual and physical disabilities follow different transition routes. The factors associated with a move were not straightforward but appeared to vary, to some extent, with the intellectual and physical ability level of the person concerned. Where a person is incapable of ‘independence’ in self-care, social	

		interactions and daily living skills, the data here suggest that moving as a normal part of growing up may be rare. There was evidence that some people who moved as an outcome of ‘stress on the family’, may have been expressing their wish for ‘independence’ or a separate adult lifestyle through challenging behaviour. Challenging behaviour, although rarely the reason cited for the instigation of a move, was nevertheless a major contributor to the circumstances that led many to placement. The findings from the study suggest that if better family supports were put in place, this could facilitate transition to alternative care before a crisis point is reached. **Study limitations** 1. The study relies on retrospective accounts, some 6 years ago, which may be hard to recall for some people in the study. However, no parents reported difficulty with recall and a comparison of reports from the minority of parents whose son or daughter had moved more than 4 years previously with those who had moved within the last year showed no noticeable lack of detail. 2. The sample is taken from the North West Regional Health Authority in the UK, so the experiences may not generalise to the	

		general population of people with learning disabilities and behaviour that challenges.	

3. Allen DG, Lowe K, Moore K et al. (2007) Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour. Journal of Intellectual Disability Research 51: 409–16

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Investigate the predictors, costs and characteristics of out-of-area placements for people with learning disabilities and behaviour that challenges. **Mechanism for change** Proactive, not reactive approach Identifying predictors for out-of-area placement can be used to highlight deficiencies in local services and individuals at increased risk of exclusion from local services. **Service aims** Provide services supporting children and adults with ID. **Methodology**	**Participants** Carers/family members. Primary carers were interviewed to obtain information about service users and the services they received. Administrators, commissioners, managers. Services were screened to identify children and adults with challenging behaviour meeting objective criteria. **Sample size** Intervention number n=97 (11%) were placed out of area. **Sample size** N=1458 service users, n=107 of whom were placed out of area. Data was collected for n=901	**Service use** **Out of area** Of service users, 7–11%were placed out of area. For the total population (n=1458) of people with learning disability and challenging behaviour identified in the study, 7% were placed out of area, in the sample (full data available) (n=901) 11% were placed out of area. Out-of-area placement could successfully be predicted for 90.8% of the sample by a history of formal detention under the Mental Health Act, the presence of mental health problems, a formal diagnosis of autism, total score on the Adaptive Behaviour Scale, behaviour that led to physical injury to the participant themselves (repeated incidents and usual consequence) and their exclusion from service settings (p413). **Staff contact/assistance**	**Overall score** -

Cross-sectional study.	people, n=97 of whom were placed out of area. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).	Frequency of contact (% receiving 4 or more contacts per year). In area: frequency of contact was greatest with social work (37%) and care manager (29.7%) and lowest for psychology (14.7%) and advocacy (4.7%). Out of area: frequency of contact was greatest with psychology (35%), psychiatry (36%) and social work (36%) and least with advocacy (11.3%) and speech and language (17.5%). **Qualitative themes** **Access to support** Access to and frequency of contact with psychology support and care management was noticeably higher out of area. Input from psychiatrists was slighter higher out of area; access to advocacy services was extremely low irrespective of placement. Speech and language therapy support was superior within area, and social worker contact was unaffected by placement status. **Choice and control** In relation to place of residence. For people in area the most common placements were within family (26.9%) and staffed home settings (55.1%) and within staff housing (33.6%) and ‘other’ (52%) (Mostly larger-scale, more institutional) types of accommodation out of area.	

		Personalisation of care Behaviour plan: 36% of those in area and 63% out of area were reported to have a behaviour plan, with the vast majority said to be concerned with more than a single behaviour category. The greatest proportion of plans were focused on aggression in both groups. 22% in area and 37% out of area were reviewed on at least a monthly basis, although the majority were reviewed far less frequently in both, and a small proportion had not been reviewed at all. **Cost information** The combined health, social service and educational costs for supporting all 107 out of area placements was £11.2.million at 2002–03 prices. The mean placement cost was £96,000. At the same point in time, the cost of providing local, specialist continuing NHS residential care in 5 person community bungalows was £97,000 (p414). **Summary of findings** Out of area placement can be accurately predicted by: mental health status - higher ability level - diagnosis of autism - challenging behaviour (that led to physical injury to the participant themselves and their exclusion from service settings). These variables can be regarded as risk factors for out of area placements and they are likely to	

		‘reflect specific deficiencies in the capacity and competency of local services to meet the needs of challenging individuals’ (p414). Given the rationale that people are placed out of area because services aren’t available locally or they are better at supporting challenging individuals and that placements tend to be high cost, it is surprising that more than 37% of those placed out of area had no behavioural support plan, almost 50% had no access to psychology, and more than 40% no access to psychiatry. In addition, the out of area services were generally provided in larger scale, more institutional settings. **Implementation issues** With the finding that out of area services were more likely to be provided in larger-scale, more institutional settings it suggests that not planning effectively for the needs of people who challenge services is resulting in a de facto policy of rebuilding of these institutions within the private sector. **Study limitations** The authors say that the results have ‘considerable face validity’ in that they highlight key areas of known service deficiency within this locality of South Wales. However, it cannot be assumed that these results will generalise to other areas of the UK, particularly as the decision to place out	

		of area will be the product of a wide range of variables. The study doesn't tell us much about the quality of services received in area and out of area and very little about the differences in costs. The researchers suggest that future research in this area needs to adopt a far broader range of measures of service quality.	

4. Ayres M, Roy A (2009) Supporting people with complex mental health needs to get a life! The role of the Supported Living Outreach Team. Tizard Learning Disability Review 14(1): 29–39

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim This study reports on the development and service delivery of the Supported Living Outreach Team (SLOT), set up by South Birmingham PCT in 2001. The study describes why the team was formed and how it works. The study also measures the effectiveness of the team and reports on service outcomes. The study also reports on the hurdles and	**Participants** Professionals/practitioners: The team providing the service consists of: a clinical nurse manager, 5 clinical team leaders, 2 nurses and 3 support workers. All clinicians are registered learning disability (RNLD) nurses, some having further expertise in behaviour therapy, mental health, autism and person-centred facilitation.	**Clinical outcomes** **Behaviour that challenges** The authors state 'there have been significant reductions in the number of assaults, damage to property, self-injurious behaviour and forensic risk across the client group'. However, they also say that 'due to the different timescales for service opening and the great variation in complexity that the team supports, it is difficult to show this on one graph'. They report on 1 case, for illustrative purposes, of a service user with severe learning disability, autism and a history of severe aggression, destructiveness and self-injury, showing the change in behaviour over a 7-year period. Frequency of incidents of challenging behaviour reduced over a 7 year period from	**Overall score** -

barriers it has had to overcome in supporting people with learning disability and complex, severe, mental health needs to live safely in their local communities. **Service aims** The team’s role is to work in partnership with domiciliary care providers and housing providers to develop supported living services to enable these individuals to live in their local area (p30). **Country** UK. **Source of funding** Not reported. However, the 2 authors of the paper appear to work in or with the team being evaluated. Martin Ayres, clinical nurse manager, Supported Living Outreach Team, South Birmingham PCT, Ashok Roy, consultant psychiatrist, South Birmingham PCT.	Adults with learning disabilities and behaviour that challenges. **Sample characteristics** Adults Age: range 21 to 49. Gender: the team supports n=18 males, n=8 females. **Level of need** The team accepts referrals only for those people who have exhausted all local provision and face placement out of county, or prolonged hospital stays, due to the complexity and severity of their needs. n=11 on the autistic spectrum n=3 bipolar mood disorder n=2 schizophrenia n=3 personality disorder n=2 attention deficit hyperactivity disorder. n=3 epilepsy n=2 cerebral palsy. Out of 26 people service users: n=6 are new services being set up n=10 services still requiring	over 70 per year to under 10 per year. However, it is worth noting in the illustration that incidents of ‘self-injury’ rose dramatically in the sixth year to over 70 incidents in the year, up from under 10 in the previous year. No explanation is provided on why this might have happened. The authors also report on the decrease in the use of PRN medication. They say ‘for nearly all our clients, reduction in problem behaviours has also been reflected in reduction in the use of PRN medication to manage incidents and the use of antipsychotic medication to manage behaviour (an additional cost saving)’ (p36). Once again, they say it is difficult to show results, so provide for illustration results for 2 service users over 3 years in a graph (figure 2). For client 1, frequency of PRN medication reduces from over 25 usages in year 1 to under 15 usages in year 3. For client 2, frequency of PRN medication reduces from just over 15 usages in year 1 to 0 in years 2 and 3. **Person-centred outcomes** **Choice and control** The authors report an ‘increase in the independent living skills for many of our clients’. These are measured by development and review of support plans based on the person’s PCP. **Relationships** The authors say ‘In supported living, clients have stronger links with their immediate families and are active members of their local communities, which they access safely each day’.	

Methodology Process evaluation. **Services of interest** Supported independent living/ single tenancy. Community support. Peripatetic specialist challenging. Behaviour (intensive) support. **Content/ components of service** Crisis prevention and management Case management. **Time to follow-up** No follow-up.	intensive input for a clinical team leader n=10 being monitored by a community nurse Service users received 2700 hours a week of support. **Characteristics of behaviour** N=23 had been referred for physical aggression n=15 for property damage n=14 had self-injurious behaviour. Other reasons for referral included inappropriate sexual activity (n=4), fire setting (n=2) and theft (n=2). For full details of client group see Table 1. 'The team works with people who Emerson et al (1997) define as having challenging behaviour' (p3). **Sample size** N=26. **What is the sampling frame (if any) from which participants are chosen?** Implicit. Current service	**Cost information** The current (2008/09) cost of the team is £490,000 per annum. Changes in cost of service The average annual team cost reduced from £124,500 in 2004/05 to £87,921 in 2007/08. A cost saving of 36%. Examples of cost savings are provided for n=4 service users over the same period. Average cost savings for these 4 service users for 32%. 'As the levels of risk have fallen, so too has the need for high levels of support for some clients with severe reputations. As a result of these reductions we have achieved an average 34% reduction in costs across schemes. Costs are based on the £12.77 hourly rate of support set by the City Council. This has amounted to a total approximate saving of £430,000 since the team was formed in 2001' (p36). **Service use** **Risk of emergency admissions** 'The level of support provided has prevented breakdown of placements for clients in crisis, the result of which breakdown might otherwise be admission to hospital, an out-of-city placement or involvement with the criminal justice system' (p36). **Staff contact/assistance** Analysis of the nature of support over 2 years revealed an increase of indirect support and a decrease of direct support. **Changes in nature of input between 2006 and 2007**	

<table>
<tr>
<td></td>
<td>users of the Supported Living Outreach Team.
Treatment of groups
N/A (not more than 1 group).
How do the groups differ?
N/A (not more than 1 group).</td>
<td>
<table>
<tr><th>Input</th><th>2006 hours</th><th>2007 hours</th><th>Change hours</th><th>Change/2006 hours %</th></tr>
<tr><td>Home visits</td><td>78</td><td>32</td><td>-46</td><td>-59%</td></tr>
<tr><td>Staffing support</td><td>334</td><td>190</td><td>-144</td><td>-43</td></tr>
<tr><td>Telephone support</td><td>410</td><td>695</td><td>+285</td><td>+70</td></tr>
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The service also ‘constantly questions the purpose of support and who benefits’ (p36). For some clients, high levels of support can be disabling. In these cases the service, develops people’s own skills in independent living and self-management of behaviour. This leads naturally to reductions in support. ‘As the levels of risk have fallen, so too has the need for high levels of support for some clients with severe reputations. As a result of these reductions we have achieved an average 34% reduction in costs across schemes’ (p36).
Facilitators identified
Commissioning
A large number of service users have a history of severe property damage. In order to persuade landlords and housing associations to offer tenancy agreements to individuals with such histories, a property damages fund of £10,000 per annum was set up by the service commissioner to cover such costs. SLOT has</td>
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		responsibility for overseeing the fund. Landlords are reassured and it helps enable the service users to secure local housing at affordable rents. **Collaborative team working** Developing flexible teams around highly complex individuals. The initial approach was to develop small, dedicated teams for individual clients to ensure that staff developed strong relationships with the person they supported and to ensure consistency of approach. This did not take into account the stress this placed on the staff and on the 'clients would often complain of being tired of having the same people supporting them. Some clients developed dependencies on particular members of staff, and when they left clients had difficulties in adjusting to and accepting new people to support them' (p38). This has resulted in doubling the staff team for certain individuals, so that staff do not work fulltime on a service, but are split between 2 services. This allows replacement of staff at short notice with minimal disruption to the service. Debriefing are carried out with both staff and clients following any incident and follow-up put in place if required to make sure that any lessons that need to be learnt following an incident are implemented quickly, and ensures that staff members receive the appropriate levels of support at times when they require it. **Multi-agency interdisciplinary involvement** 'The success of the team has been based on the effective partnership arrangements with independent sector providers and the local community team. It has been preferable to manage crises in an individual's own home,	

		with familiar, dedicated staff, than in a traditional inpatient unit with a significant number of unsettled admissions being cared for by a team not known to them. Since the team was formed, it has had to provide intensive assessment and support to 8 of its individual packages of care to prevent re-admission to hospital’ (p38). **Ways of working** ‘The team has had to work very closely at developing strong relationships with neighbours, local councillors, anti-social behaviour teams and vulnerable persons officers, in order to allay concerns in the local neighbourhoods and to develop new ways of working with local agencies to manage the behaviours that the clients may exhibit. 2 people have had to be moved in 7 years due to an irretrievable breakdown in community relations, but both people have settled successfully into their new homes with minimal disruption to the local neighbourhood’ (p38). **Summary of findings** The SLOT have been able to operate a local integrated service with the following outcomes: - Significant decrease in levels of risk and reductions in challenging/forensic behaviour - Decrease in the use of as required (PRN) medication – increase in independent livings skills for many service users - Prevented breakdown of placements for clients in crisis, resulting in fewer out-of-area placements and admissions to hospital	

		- Earlier local discharge of existing inpatients - Decrease in hours of support - Costs savings – average 34% across schemes. During the first 7 years of the service, several issues have emerged that the service has learnt from and point to some things that can help the service work better, such as: 1. Setting up a property damages fund to offer support and reassurance to landlords so that service users can still secure local housing 2. Developing good relationships and ways of working with neighbours, local councillors, antisocial behaviour teams to address any concerns in local neighbourhoods. 3. Developing flexible teams around highly complex individuals 4. ‘Admission proof’ services – developing effective partnership arrangements with independent sector providers and the local community team, so where possible, manage crises in an individual’s home, with familiar, dedicated staff. **Study limitations** Outcomes aren’t reported fully or in enough detail, to say confidently what the positive outcomes of this model of service has been for service users. The authors of the study also appear to work for the service they have evaluated, but they haven’t acknowledged this in the paper, but provides potential for a positive bias in the way	

		they have reported the findings. However, the authors do acknowledge that the models needs further evaluation.	

5. Baker PA (2007) Individual and service factors affecting deinstitutionalization and community use of people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 20: 105–9

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim To evaluate the effect of the closure of a small intellectual disability hospital on the community use of those people involved. In addition, the study sought to identify those factors that might influence the community use of people with intellectual disabilities. **Service aims** Implicit. Resettlement into the community from residential hospital. Resettlement from hospital increase the range and frequency of leisure and community contacts	**Participants** Adults with learning disabilities and behaviour that challenges **Sample characteristics** **Age** Hospital (resettlement group) average age 50.6 (14.9) Community (comparison group) average age 39.8 (10.2) ** **p<0.01 levels of significance (2-tailed). **Gender** Hospital (resettlement group) men 13, women 13, community (comparison group) men, 13 women 13. **Level of need**	**Person-centred outcomes** **Participation in daily life** A significant main effect of time F (1, 58) =58.19; p<0.01, and a significant interaction between groups (i.e. resettlement group versus comparison group) and time F (1, 58) =24.57; p=<0.01 on Guernsey Community Participation and Leisure Assessment (GCPLA) Range scores. The community scores for the resettlement group and the comparison group at t1 and t2 were analysed This indicated a significant main effect of time F (1, 58) =32.86; p<0.01 and a significant interaction between groups (i.e. resettlement group versus comparison group) and time F (1, 58) =12.03; p=0.01. **Barriers identified**	**Overall score**: -

Country UK. **Services of interest** Fully staffed group home. **Methodology** Comparison evaluation **Time to follow-up** No follow-up During the 6 months prior to the resettlement of the first group of hospital residents (t1), all participants were assessed on a range of measures. Each participant in the resettlement group was reassessed 6 months after moving. All participants in the comparison group were reassessed during the 18-month period between the first and last group moving out of hospital (t2).	Adaptive Behaviour Scale ABS (mean) hospital (resettlement group) 62 (44.7), community (comparison group) 69.1 (37.7), behaviour problems Inventory BPI (mean) hospital (resettlement group) 11.8 (20.9) community (comparison group) 15.6 (23.7) self-injurious behaviour SIB(mean) hospital (resettlement group) 1.2 (3.1)* *$p<0.05$ community (comparison group) 6.5 (13.5) aggression (mean) hospital (resettlement group) 0.3 (0.7) community (comparison group)1.6 (5.8) stereotypy (mean) hospital (resettlement group) 9.5 (20.5) community (comparison group) 9.4 (15.4). **Treatment of groups** No prospective allocation-use of pre-existing differences to create comparison groups. **How do the groups differ?** Explicitly stated. The hospital (resettlement group) was significantly older than the comparisons group and significantly lower on the Self-injurious Behaviour Scale.	**Living in an institution** Was a predictable barrier to community participation. **Facilitators identified** **Adaptive behaviour** Was a reliable predictor in community participation **Proactive support** Having individually written community access goals encompassing specificity of activity/contact as well as specific conditions and time frame for attainment were the most reliable predictors of participation in community and leisure activities. **Summary of findings** The main effect on GCPLA range scores in the resettlement group appears to be confined to increases in community activities and contacts following movement from hospital with no discernible change in home-based leisure activity during the same period. No significant relationship existed between BPI scores and GCPLA Range. The data presented here would suggest that the move from hospital to the community group home settings corresponded with greater access to a wider range of community activities for the	

	Sample size Comparison numbers: n=34; intervention number n=26. **Sampling frame** Explicitly stated. The study sample involved 60 individuals with a severe/profound intellectual disability who were residing in NHS-provided residential services.	people involved. Similar increases did not occur in the comparison group. the most reliable predictors of participation in community and leisure activities: - not living in an institution - having relatively higher levels of adaptive behaviour and - having individually written community access goals. Encompassing specificity of activity/contact as well as specific conditions and time frame for attainment.38% of the variance in GCPLA range scores. This study has demonstrated a relationship between the robustness of the individual planning goals and the person's use of leisure and community activities. **Implementation issues** None reported. **Study limitations** The absence of a relationship between the challenging behaviour and community and leisure use is somewhat surprising. However, this finding should be considered with caution as it is possible that any relationship that might have been present would have been affected by the correlation between the BPI and the other independent variables. The limiting	

		influence of factors such as the collection of data from individual service in 1 geographical area, and the use of multivariate analysis with simple rating scales, and small sample sizes, needs to be kept in mind.	

6. Balogh R, McMorris CA, Lunsky Y et al. (2016) Organising healthcare services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 4: CD007492

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The authors were interested in finding out if providing intensive community support services is better than providing health services to people with learning disabilities in the usual way (i.e. GP or community learning disability team in England). **Service aims** To improve the care of mental and physical health	**Participants** Adults with learning disabilities and behaviour that challenges. People who had an intellectual disability and mental health problems. Two out of 7 of the studies specifically mention the population having challenging behaviour. **Sample characteristics** **Adults** **Age**: Most participants in the 30–60 age range.	**Costs** **Economic evaluation** Full or partial: 3 studies assessed the costs associated with the interventions. This was very limited with low to very low certainty evidence for the different interventions. **Summary of findings** **Intensive community support** It is uncertain whether increasing the frequency and intensity of services decreases behavioural problems. Increasing the intensity of a service probably makes little difference to the	**Overall score** ++

problems of adult persons with an intellectual disability. **Country** UK: 5 of the trials in a UK setting. US: 1 trial in a US setting Netherlands: 1 trial in Netherlands setting. **Source of funding** Not reported. **Methodology** Systematic review. **Mechanism for change** N/A **Source of funding** Not reported.	**Disability:** Most participants had mild to moderate intellectual disability and mental illness. **Gender:** Average across all studies 56% male. **Characteristics of behaviour** One study included people with ID who experienced significant bereavement; 2 studies mention people with ID and challenging behaviour. **Sample size** n=347. Comparison numbers: n=181. Intervention number: n=166. **Systematic reviews** Participants in number of studies n=347 total in 7 trials. **Services of interest** • Specialist health team. • Learning disability intensive support team. • Peripatetic specialist challenging behaviour (intensive) support.	burden on carers and little to no difference to costs. **Assertive community outreach** It is uncertain whether outreach treatment compared to hospital treatment decreases behavioural problems or decreases the burden on carers. It is also uncertain whether outreach treatment decreases costs. **Community-based specialist behaviour therapy** There was evidence that this type of support may slightly decrease behavioural problems and may make no or little difference to costs. **Study limitations** The severity of behaviour problems in the studies ranged from bereavement (Dowling 2006) to severe psychotic illness (Hassiotis 2001). This means that some of the findings in those 2 specific studies may not be relevant to our population. The standard quality of care might be quite different in some countries. For example, community learning disability teams (Martin 2005; Oliver 2005) are a common feature of the English health system, and generally provide a good standard of care, whereas in the US study	

		(Coelho 1993) community learning disability teams were not in place at the time so different levels of standard care are being compared. This means the effect shown in other health systems may not be detected.	

7. Bartle J, Crossland T, Hewitt O (2016) ‘Planning Live’: using a person-centred intervention to reduce admissions to and length of stay in learning disability inpatient facilities. British Journal of Learning Disabilities 44: 277–83

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study aimed to answer 3 research questions: 1. Does a ‘Planning Live’ meeting reduce the number of inpatient admissions to the service? 2. Does a ‘Planning Live’ meeting reduce the length of inpatient admissions? 3. Is a ‘Planning Live’ meeting experienced as helpful by those who attend? **Service aims** ‘Planning Live’ process aims are to bring together	**Participants** Professionals/practitioners Carers/family members Adults with learning disabilities and behaviour that challenges **Sample characteristics** **Adults** **Age** Mean n=39 years; range 18–75 years. **Gender** N=53 male; n=49 female. **Ethnicity**	**Satisfaction with care** How helpful were the ‘Planning Live’ meetings process: Mean score for the group n=57 4.46 (sd=0.68) professionals n=34 4.34 (sd=0.78) family members n=10 4=7 (sd 0.48) carers n=11 4.72 (sd= 0.47). **Qualitative themes** **Family contact** ‘Being about to get everybody involved in supporting the person together, especially family’ (p281). **Information**	**Overall score** -

knowledge about a person, to identify gaps in understanding, to stimulate further questions and to formulate an action plan to support the person and those in their wider system. The aim of the 'planning live' process is to reduce the number of inpatient admissions and the length of inpatient admissions. **Country** UK. **Source of funding** Not reported. **Methodology** Mixed-methods. **What is the sampling frame (if any) from which participants are chosen?** All people who had a 'Planning Live' meeting from when they were introduced in April 2013 to March 2015. **Comparison**	84% white British; 6.8% Asian British; 2% Afro-Caribbean, mixed race British and white (any other background). **Residence** 37% supported living 33% residential care home 26% family home 3% different arrangement. **Sample size** N=102 (people who had a 'planning live' meeting between April 2013 and March 2015. N=57 participants who had attended a planning live meeting. **Services** Community Assessment and Treatment team (CATT). **Content/ components of service** Care, support and enablement framework Crisis prevention and management Person centred support.	Families also said that it helped to have information about the meetings in advance so that they could be properly prepared and know what to expect. People found it helpful to have a perspective of someone 'outside' of the system 'Input from professionals who had known client historically … gaining an independent view' (p282). **Inclusion/isolation** This theme was about the practical aspects of holding the meetings. One of the points raised that it wasn't always possible to have the person themselves as part of the meeting, though it was acknowledged that this was often because the person was unwell. 'It was a shame the person was unable to attend/contribute (although this would have been very difficult at the time)' (p282). **Personalisation of care** A positive approach. A theme of positive approach was identified, people appreciated a more holistic way of seeing the person, and focusing on what the person can do. 'Liked to focus being on what the person can do, positive attributes and building on these'. 'Facilitation focussed on what can be	

Admissions and discharges in the period before (1 April 2011 to 31 March 2013). **Details of data collection instruments or tool(s)** Researcher designed questionnaire. Feedback form that asked quantitative and qualitative questions. **Mechanism for change** Services working with the person and their family. The study about using planning meetings to help reduce admissions to and length of stay in inpatient facilities, found that having as many people as possible involved in supporting the person attend the meetings helped create a more positive approach and holistic way of seeing the person. **Source of funding** Not reported. **Time to follow-up** No follow-up.		done rather than what was not done; avoided a negative focus on what should have or could have been done in previous placements' (p282). **Working together** '… Several people from various disciplines shared ideas, experiences and a holistic approach was valuable' (p281). **Costs?** No. **Service use** **Inpatient service use** Intervention: n=42 (admissions between 1 Apr 2013 and 31 Mar 2013) comparison: n=30 (admissions between 1 April 2011 and 31 March 2013). Following the 102 meetings, 5 people had a planned admission to an inpatient unit, and 52 people did not require an inpatient admission; 51% of people who had been referred for an inpatient admission did not go on to have such an admission following the 'Planning Live' meeting. **Length of hospital stay** Comparison: medium length of stay 143.5 days (interquartile range 203.5 days); intervention: medium length of stay 66 days (interquartile range 209.75 days); Mann-Whitney U-test (U=457, z=-1.97, p=0.02) and was found to be significantly	

		lower at the p<0.05 level after the introduction of ‘planning live’ meetings. **Facilitators identified** Family involvement in care planning Multi-agency interdisciplinary involvement. **Summary of findings** The study found that for people who had to come into hospital, they had a shorter stay and could go home more quickly, but there was also a significant increase in the numbers of people who were admitted as an inpatient. **Study limitations** Differences between the before and after groups could possibly be explained by a general trend to avoiding in patient admission. Without a comparison group it is difficult to say for certain that the differences between the before and after group could only be the due to the effects of this new service. However, the study found an increase in admissions overall compared to the before group. This maybe because of local factors effecting community services and a knock on effect for demand for inpatient admission in this particular area, at that particular time but authors also point out that similar services that aim to reduce in patient admission by	

		person-centred planning, or providing specialist services in the person home instead of in hospital have had similar mixed results. The feedback was generally positive, but it was not clear from the study who was speaking: whether it was a professional's view or a family member's view, which may be important to know whether the services was helpful for families.	

8. **Beadle-Brown J, Hutchinson A, Whelton B (2008) A better life: the implementation and effect of person-centred active support in the Avenues Trust. Tizard Learning Disability Review 13: 15–24**

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim Engagement in meaningful activities and relationships is important for social inclusion, personal development and choice and autonomy. This paper provides a description of the implementation of person-centred active support in the Avenues Trust. It gives an illustration of the effect of the introduction of person-centred active support on the lives of the individuals living in 6 pilot	**Participants** Professionals/practitioners; adults with learning disabilities and behaviour that challenges. **Age** Mean age 44 years (range 20–61). **Level of need** Very high support needs.	**Social care outcomes** **Social interaction or support** A 300% increase in the amount of facilitative assistance provided by staff. A significant increase in the quality of staff support as measured by the Active Support Measure. Mean percentage score on active support increased significantly ($p<0.001$) from 33% (range 17–54) to 64% (range 25 to 93), a 94% increase in active support. Significant increases in the ratings for individual	**Overall score** -

services, as well as on the experiences of staff working in those services (p16). **Service aims** Improving the quality of life of all the people served by implementing active support throughout the organisation (p16). **Country** UK. **Source of funding** Not reported. Authors work for the Avenues Trust where the Active support was implemented) and Tizard trust, which evaluated the programme. **Methodology** Process evaluation.	**Sample size** Total 29. **Services of interest** Person-centred active support (PCAS). **Components of service** Clear targets – including ensuring that all service users would have an active person-centred plan by 2009. **Clear roles and responsibilities** Coordinator. Any queries or concerns were addressed in relatives meetings or by direct contact with the PCAS coordinator. **Regular review** A project group meets every 3 months to discuss progress. **Training** Four levels of training were provided as part of the pilot implementation project. Training for front-line staff: 1-day classroom workshop. 1.5–2 days of hands-on training in the	planning, activity planning, and support for resident activity. **Engagement in meaningful activities** The average percentage of time people spent engaged in any meaningful activity nearly doubled ($p<0.001$). **Behaviour that challenges** A 53% decrease in self-injurious behaviour from 0.36 to 0.17% of the time. There was a reduction in stereotypic and repetitive behaviours from 21 to 16% and there was a reduction in challenging behaviour (in particular stereotypic behaviour) as measured by the Aberrant Behaviour Checklist. **Staff satisfaction** Staff reported higher levels of satisfaction, higher quality of management and more practice leadership from their managers than the teams at baseline had reported. The percentage of staff reporting that their manager usually modelled good practice increased from 42% to 78%. Percentage reporting that managers usually gave feedback almost doubled from 48% to 81%. At follow-up 96% of staff reported that they were at least quite satisfied overall (increasing from	

	services, with on-the-spot feedback, modelling and then written feedback to the team. Training for home managers, service managers and senior managers: how to provide practice leadership. Training for the director of operations, regional managers, service managers and some house managers as trainers in person-centred active support. Training in observation to support monitoring of the implementation of active support over time. Senior managers, including the director of operations, regional managers, service managers and some house managers.	77% at baseline). In addition, propensity to leave in the following 12 months decreased from 34 to 10% of staff. **Choice and control** Opportunities for choice increased significantly (p<0.05). **Participation in daily life** Significant increase in participation in daily life (p<0.01). **Facilitators identified** **Organisational commitment** Involving those in corporate and operational roles helped create a shared understanding of its importance at all levels of the organisation. Training trainers within the organisation ensures a greater degree of ownership and helps to get the message to services which have yet to be trained. Person-centred active support be aligned with other person-centred approaches such as person-centred planning, positive behaviour support and total communication. **Summary of findings** It is clear that the introduction of person-centred active support in the Avenues Trust has been very	

		successful overall and has made positive changes to the lives of those in the services. However, the average data does hide some variation; implementation is better in some services than in others and for some people than others. **Implementation issues** The process of implementing person-centred active support and embedding it in the fabric of an organisation is complex and requires a huge commitment on all levels. It needs to be reviewed and adapted frequently to ensure maintenance and continued development (p23).	

9. **Beadle-Brown J, Mansell J, Whelton B et al. (2009) People with learning disabilities in 'out-of-area' residential placements: views of families, managers and specialists. The British Journal of Developmental Disabilities 55: 15–31**

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The study aims to answer the following questions: Do family members and care managers' report difficulties in finding a suitable placement? Are there difficulties in contact for family	**Participants** Professionals/practitioners 30 home managers, 17 care managers or reviewing officers. Carers/family members: 15 family carers. Adults with learning disabilities	**Qualitative themes** **Barriers** For 6 of the 26 people, the reason for placement was closure of an institution or other residential placement. Members of all the community teams raised problems with	**Overall score** +

members and in contact and communication between care managers and the person themselves, the home manager and professionals in the receiving area? How is the quality of out-of-area placements viewed by family members, care managers and professionals in the receiving area? Are there advantages to such placements? (p17). **Country** UK. **Methodology** Qualitative study. **Source of funding** Not reported.	and behaviour that challenges. Semi-structured interviews were also carried out with the service user where this was possible and where consent was received. **Sample characteristics** **Age** Mean age of 40 years (range 18–69). **Disability** They were in general moderately to severely intellectually disabled with average percentage scores on the Short Adaptive Behaviour Scale of 55% (range 26.5 – 91.2). **Gender** 53% were male. **Ethnicity** 77% were white British. **Residence** 73% of people were placed by authorities in London with the average distance from the home to the placing authority being 60 miles but with a range	access to care managers being much more difficult when people were placed by authorities' out-of-area. One team reported that they are using. **Accountability** Selected quotes: 'nobody wants to take responsibility, not even to turn up to the reviews. So some people don't even have annual reviews and that feels really wrong, that somebody is placed, particularly if they have got some ongoing needs, and yet as soon as it starts going wrong you can't contact the person that's placed to get them to come down and assist' (occupational therapist) (p24); 'my worst-case scenario was someone where I felt their needs weren't being met and between the time of my first making contact to attending a review … about 6 weeks later, was that there were 5 different care managers I had been informed had been allocated and then when we did turn up to the review, nobody came, and she rang saying "I have decided to leave the post, so I'm not coming"' (psychologist) (p24). Raising issues or complaining is stifled due to the fear of losing the placement: 'There's lots of things I'd like to say but I'm frightened to because sometimes what I've said has been misinterpreted and it has come back that I've been having a dig at	

	from less than 25 miles to 200 miles; 90% of people had been in their current home for over 3 years; 21% for more than 10 years. **Characteristics of behaviour** Total 22 people (73%) were identified by the service as showing challenging behaviour, of which 14 (64%) of those rated as having challenging behaviour) showed aggressive and/or destructive behaviour **Sample size** Total 48 service managers and service users, 18 refusing to take part. For 4 of these, it was the service user themselves who refused. **How do the groups differ?** N/A (not more than 1 group).	them … A couple of times they've thought that maybe this wasn't the right place for him, after these incidents. But what do you do. I can't physically look after him at home all the time while we look for another place. There's the funding and all that business … I don't know what the situation is, we haven't said anything' (family member) (p24). All the community learning disability teams felt that the quality of care in out-of-area placements was often poor and that there was insufficient monitoring of placements by the placing authority's care manager. 'Because there isn't the support from the placing authority in a lot of cases, unless it's crisis driven, things are let slide that shouldn't be let slide. That they are placed with quite significant complex needs and quite often clearly specified needs that are then not provided for … Which I think puts both the client and others at risk, significant risk' (psychologist) (p25). When monitoring did occur, it was suggested that individual needs were often subordinate to cost and the effort of changing services. 'They just think it's cheaper actually … they don't even think it through' (Everyone in 1 team) (p25). **Access to support** One issue, raised by care managers, home managers and family members, was the	

		difficulty of finding suitable placements locally. Six out of the 9 care managers who could give a reason for the placement being made out-of-area noted that the main reason was the shortage of suitable services locally. ‘I think it was the only option, I don’t think there was anything in London that was specialised in that area. The first choice is always to try to place someone in their area but then because of specific needs, certainly with people with dual diagnosis or very challenging behaviour, services within the borough are very limited and sometimes you need specialist services that are only available out of borough then we would place out of borough’ (Care manager) (p22). Eight of the 26 people for whom managers could give a reason for placement, had moved to them for specialist input, in 1 case this was in an emergency. ‘When a lot of the long stay institutions got closed down, wherever the services were that paid the lowest, that is where they got shipped to … I think it is just funding, because the cost of the service was relatively cheap in comparison to others’ (home manager) (p22). ‘We went around everywhere, so many places and every time I came out of there I went “no”. We saw this home in the newspaper and we called them and they put his name on the list – he was 13 then. We used to have	

		to go up to [his earlier placement] which was 250 miles each way and when this came up, it was only 70 miles' (family member) (p22). **Choice and control** For some people there seemed to have been little choice in where they moved. Those who played a leading role in finding the placement generally were happy with the placement. 'A lot of say, if we didn't like it we could have said. We were given the choice, not made to feel that this was the only placement she could go to' (family member) (p22). For some people lack of say was related to pressure of time: '... And then suddenly I was called the next day (after being told the previous day that he definitely wouldn't be moved away) to be told that he had to go there. Having being reassured earlier that he wouldn't be … I couldn't do anything about it. Oh I was told that I could have the money … if I could look after him myself … What a crazy idea … I couldn't look after him, I was working' (family member) (p22). **Environment** The physical environment was described (by the community; learning disability support teams) as institutional. 'The homes are usually smelly, big horrible, sprawling	

		frightening, just horrible, grey, and dirty, depressing environments. It takes you back years' (speech and language therapist) (p26). **Family life** 'Her sister usually visits twice a year, but not so far this year, and she puts that down to funding. She does have a point, she struggles to get travel warrants from social services and that's wrong. She has to contact them and say that she's coming down to see her sister and they will give her a travel warrant but they won't give them for her children and she can't come without her children, they obviously haven't got a lot of money' (home manager) (p23). **Information** Home managers reported that of the 24 people that had some contact with their family, 6 families attended the last review meeting, 5 did not and in 13 cases the manager did not know whether the family attended the last review (p23). 'We've just had to reschedule, this is the third different date we've got now. It's not because of us, it was actually the care manager couldn't make it and I've had to reschedule to suit them and not us' (family member) (p23). None of the teams felt that they had access to accurate information, claiming that	

		assessments were either not completed by people competent to do so, or if they had been completed they did not get access to them (p24). **Impact on carers** ‘Oh I was told that I could have the money … if I could look after him myself … What a crazy idea … I couldn’t look after him, I was working’ (Family member) (p22). **Navigating care services** ‘We don’t just accept it when people say “oh no that’s far too much money, we won’t pay that, this is our ceiling” ... because we know you don’t have to and we know that there are other finances available. But I feel very much for people because I think that everything we have got we have had to fight for. They make you jump through hoops for it …’ (family member) (p23). ‘It’s just really hard to get hold of people, everyone’s in meetings, they have the same problem getting hold of me really … as you well know! It’s just trying to catch people at the right time, it’s not anything other than that. We all experience the same thing really. Too much to do, not enough time, but she will generally get back to me. She always phones back if I have left a message’ (home manager) (p23).	

		Resources The homes were charging a substantial fee but it was the community learning disability team, not the home, which was meeting the client’s needs. All the teams felt out-of-area placements meant lack of resources for local clients. All the teams felt out-of-area placements meant lack of resources for local clients. ‘The team want … to be very proactive … and we just can’t because the out-of-area clients are so challenging they take up the majority of the time. When they go into crisis, they go into a major crisis. People from [2 London boroughs] … don’t place your quiet little old lady; they place the most severe or challenging’ (team manager) (p26). **Safety** ‘Because there isn’t the support from the placing authority in a lot of cases, unless it’s crisis driven, things are let slide that shouldn’t be let slide. That they are placed with quite significant complex needs and quite often clearly specified needs that are then not provided for … Which I think puts both the client and others at risk, significant risk’ (psychologist) (p26). ‘There was an adult protection case that I was involved in recently and really the motivation for the care manager was just to keep the placement going because she didn’t want	

		the person back' (speech and language therapist) (p26). **Satisfaction** Of the families interviewed 14 of 15 said that they thought that their relative was happy living in the home. '. They have long term staff which is good. They have had, like every care home, times when they were run down and short staffed, but this has not lasted for any length of time. In general I am happy with the service' (family member) (p25). **Staff skills** Families said that staff supported service users well (8 people; 53%). Other examples were that staff were good at teaching new skills, that the person was well looked after in terms of physical care, that the service was good at involving families and they were good at providing activities (p25). Family members gave an example of staff turnover as a way of improving care: 'a more stable full staff team. She finds it upsetting when staff leave. We have had huge problems previously when several staff were fired due to negligence … Still lots of problems, bad feeling and backstabbing going on. [They need a] more experienced staff team. Most are very young and don't know the best way of	

		handling her' (family member) (p25). Team members felt that staff did not have the skills required to support people with such complex needs. 'We've thought, goodness me, this must be picked up by care standards inspection, and very often it isn't. It's just astounding … these things have just been passed, whatever the word is, allowed to continue, when things looked to me very clearly very impoverished, the environment, the quality of the work, the way that staffing levels are permitted. One staff to 5 people and these are very high need complex residents with learning disability and it's permissible. We are told that is perfectly acceptable. But it's these out of area homes that use that, that work to that standard. Minimum standard' (senior nurse practitioner) (p26). **Summary of findings** Out-of-area placements may make it harder for people to maintain family links and for care managers to monitor quality. Placements, especially those for people with more complex needs, were difficult to find and secure. This study offers further evidence that the continued focus on stemming out-of-area placements and developing good quality local placements is justified.	

		Barriers identified **Study limitations** The study focuses on the experiences of families and staff in 1 local authority, in the South East of England. Authors say that consent for participation was sought from service users, but there were no views expressed in the results form service users, gender of service users was purposively sampled to ensure a high enough number, but no further analysis undertaken by demographic characteristics and findings.	

10. Broadhurst S, and Mansell J (2007) Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities. Journal of Intellectual Disability Research 51: 293–301

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study aimed to find out whether placements for people with intellectual disabilities whose behaviour challenges service which had broken down were different from those which had not. In	**Participants** Administrators, commissioners, managers: participants were managers of care homes for people with IDs in the South East of England. **Sample characteristics** **Age**	**Clinical outcomes** **Behaviour that challenges** The placement breakdown group had on average a lower level of ID than the placement maintained group, but this was not statistically significant. (U=138.0, z=1.583, p=0.114). There was no significant differences between the groups on difficulty, intensity or frequency of challenging	**Overall score** -

particular, it investigated 4 hypotheses: 1. That residents whose placement had failed because of challenging behaviour would not have different characteristics than those whose placements had been maintained 2. That services where a placement had broken down would have received less advice and help from external professionals such as psychologists, nurses and therapists than services where placements had been maintained. 3. That services where a placement had broken down would provide less management support to staff in terms of training, supervision and team meetings. 4. That services where a placement had broken down would make less use of written guidelines and procedures for working with residents in areas	Age of service users is not specified. Age of participants (care home managers) is not specified. **Disability** Level of intellectual disability. Placement breakdown % placement maintained % mild 26.3 5.0 moderate 36.8 35.0 severe 31.6 60.0 profound 5.3 0 additional disabilities and conditions placement breakdown % placement maintained % autism 47.4 45.0 named syndrome 10.5 5.0 mental illness 26.3 25.0 sensory disability 5.3 5.0 physical disability 5.3 5.0 dual diagnosis 36.8 20.0. **Level of need** In order to be classed as displaying challenging behaviour for the purposes of this study, the service user needed to be rated as posing at least a potential management difficulty. **Characteristics of behaviour** Challenging behaviour (potential or major management difficulty). Type of behaviour Placement breakdown % placement maintained % self-injurious	behaviour. Difficulty U=121.5, z=2.065, p=0.027. Frequency U=111.5, z=2.128, p=0.022. Duration U=99.5, z=2.550, p=0.009 Intensity U=106.5, z=2.290, p=0.015. There were no significant differences between the groups in terms of self-injury, aggression, damage to property, antisocial behaviour or other challenging behaviours, nor for the number of different challenging behaviours shown. **Person-centred outcomes** **Participation in daily life** ‘There were no significant differences between groups in how often the resident took part in various daily living activities (e.g. food and drink preparation), whether there was a written activity plan for the individual each day, and how much choice the person had’ (p297). **Costs?** None. **Service use** **Organisation and staffing** Homes in the placement maintained group had better written guidelines for staff in how to support individuals (fuller, used in practice, regularly reviewed) in respect of supporting activity, pursuing developmental goals and managing challenging behaviour	

such as personal care, individual goals and behaviour management (p294). **Service aims** Not stated. **Country** UK. **Services of interest** Fully staffed group home: participants were ‘managers of care homes for people with IDs in the SE of England’. No other detail is provided about what type of ‘care homes’ people lived in. They may not have all been fully-staffed group homes. **Components of service** Placement development: it is more about placement breakdown, rather than development. By identifying what factors that have contributed to a placement breakdown, the flipside is the types of things that could help sustain a placement or develop it.	behaviour 42.1 45.0 aggression 84.2 80.0 property damage 57.9 45.0 inappropriate sexual behaviour 68.5 30.0 antisocial behaviour 52.7 75.0 other 26.4 30.0. **Sample size** N=39 managers of care homes with residents that had challenging behaviour. Comparison numbers: control group n=20 (placement maintained group); Intervention number n=19 (placement breakdown group). **Sampling frame** Questionnaires were sent to all 100 managers on a list of services subscribing to an information-exchange network run by the Tizard Centre, University of Kent. Total of 44 managers chose to participate, of whom 39 served people with challenging behaviour and are those included in the study. **Treatment of groups** Prospective allocation into more than 1 group: people were divided into 2 groups based on whether or	(U=103.5, z=2.542, p=0.006, 1-tailed test); 55% of the placements in maintained group were scored in the top category (good) compared with 16% of the breakdown group. ‘There was no significant difference in how much in-service training had been received by staff, in staff: client ratio, hours worked and how quickly staff were replaced when they left employment. The placement maintained group had significantly better support provided by management (U=99.0, z=2.844, p=0.002, 1-tailed test) in terms of frequency of supervision and team meetings and provision of training and coaching’ (p297). There was no significant difference in how much in-service training had been received by staff, in staff: client ratio, hours worked and how quickly staff were replaced when they left employment. The placement maintained group had significantly better support provided by management (U=99.0, z=2.844, p=0.002, 1-tailed test) in terms of frequency of supervision and team meetings and provision of training and coaching (p297). **Staff contact/assistance** The placement maintained group reported more external support (range of professional disciplines providing advice and support in	

Source of funding Not reported. **Methodology** Qualitative evaluation. **Time to follow-up** No follow-up.	not they had experienced a placement breakdown. **How do the groups differ** Explicitly stated. Placement breakdown group: people with challenging behaviour who either experienced an irretrievable change in address or were waiting for another placement to be found. Placement maintained group: people with challenging behaviour who were still living at the same address and who were not waiting for an alternative placement to be found.	respect of the individual resident identified, whether staff found the advice easy or difficult to follow and whether respite facilities were available during crises) (U=106.0, z=2.419, p=0.008, 1-tailed test). Double the proportion of services in the placement maintained group scored at the top level of this scale, compared with the breakdown group. The placement maintained group reported more external support (range of professional disciplines providing advice and support in respect of the individual resident identified, whether staff found the advice easy or difficult to follow and whether respite facilities were available during crises) (U=106.0, z=2.419, p=0.008, 1-tailed test). Double the proportion of services in the placement maintained group scored at the top level of this scale, compared with the breakdown group. **Summary of findings** More residents in the breakdown group had inappropriate sexual behaviours and also showed lower average levels of ID, but there were no other differences. Services in the breakdown group had more limited procedural guidance for staff, weaker training, supervision and team meetings and less external professional support, in the	

		form of psychology, psychiatry, speech and language therapy, nursing, etc. The findings suggest that those selecting and funding residential placements for people with intellectual disabilities and behaviour that challenges should 'attend to the technical competence of the placement (in terms of its use of procedural guidance, training and professional advice) and to the extent of support for staff (in terms of training, supervision and team meetings)' (p299). The researchers suggest that further research is needed to explore the service characteristics in more detail, particularly the content and quality of written guidance and the kind of external professional support required. **Implementation issues** None identified. **Study limitations** There are a number of concerns about this study. First, it is a relatively small-scale study, using previously untried measures of service characteristics, Second, there is no data on the representativeness of the respondents for us to make an assessment about whether the results are generalisable to the whole population. Third, the 2 groups are not comparable in terms of resident	

		characteristics which makes it difficult to know if resident characteristics are a contributing factor to placement breakdown or not. Fourth, we don’t know about the history of the maintained group, making it impossible to know whether they had previously experienced placement breakdown. Fifth, untested scales, developed by the researchers were used so we don’t know, e.g., if the estimates of level of ID equate to established measures of ability. Finally, given that the questionnaire was specifically designed for the purpose of this study, it is not possible to directly compare this sample with other studies. Given these limitations, the results in this study should therefore be interpreted with caution. However, they do confirm earlier suggestions (e.g. Allen 1999; Intagliata and Willer 1982; Mansell et al. 1994) that placement characteristics may be an important determinant of community placement success for people with IDs and challenging behaviour.	

11. Brown RI, Geider S, Primrose A et al. (2011) Family life and the impact of previous and present residential and day care support for children with major cognitive and behavioural challenges: A dilemma for services and policy. Journal of Intellectual Disability Research 55: 904–17

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Measuring the need for and effectiveness of support services on parents and other carers of people with behaviour that challenges. Specifically the impact on family life pre-admission and post-admission to a residential home/day care centre and changes to the child's behaviour during this process. The full study was carried out due to the need for a description of the possible effects of major road developments on the lives of the children in residential and day care at CSA. **Country** Scotland. **Methodology**	**Participants** Carers/family members. **Sample characteristics** Adults. **Age** The children's average age was 12.7 years with a range of 6 to19 years. **Level of need** Page 4: Anxiety, depression. Sleep problems, food and other allergies of eczema, epilepsy, asthma and obesity, children also had a variety of functional difficulties. Most children (21) had speech and language impairments, gross and fine motor skills impairments, emotional and behavioural difficulties. The majority (21) of children had sensory hyper-sensitivities.	**Qualitative themes** **Access to support** Families spoke about no respite available. **Family life** 'What difference has it made, is that I do what other people do now. I eat meals, I go for walks, I go out, I go to the – Oh I can go shopping! I can go shopping when I feel like it!' (parent, interview) (p912). 'So this [the child's destructive behaviour] had an effect on his brothers. He has 2 brothers … obviously they were being disrupted and their pattern and quality of life has been quite severely impacted upon' (parent, interview) (p912). **The future** Many parents were now able to express a more positive outlook, with hope for the	**Overall score** +

Qualitative study. **Services of interest** **Day care services** Total 23 day pupils. **Residential school** Total 60 were residential. Twenty of the residential pupils were weekly boarders and 40 full residential in term time.	**Relationship** Family members of people with behaviour that challenges. **Residence** All participants had lived in the same household as a person with behaviour that challenges. **Socioeconomic position** Page 5: the social economic status of the families was judged through low, medium, high with approximately equal numbers in each of the 3 categories. **Sample size** The families of 23 children agreed to take part in the study.	future for themselves, their family and their child with special needs. Some parents noted their recognition and acceptance that their child would never be truly part of a wider society (p912). **Impact on carers** 'When you're at full-time work you can't do night shift and then go do a day shift' (parent, interview) (p912). **Inclusion/ Isolation** 'Sibling's] friends have grown up knowing that they have to be out of the house by 9 o'clock because they don't want to disturb [child with special needs] in case there's problems getting him off to sleep' (parent, interview) (p911). 'No social life; no respite; restricted outings for family; restricted visitors to home'; (p909; 'The [sibling's] friends have grown up being accustomed to finding the (room) doors locked' (parent, interview). 'My wife's parents, nothing to do with who they are, didn't understand the problem' (focus group) (p912). Family freedom and choices were thus significantly impacted upon, with	

		disruption and restrictions affecting day-to-day functioning and social interactions whether in the home or community. **Love and respect** ‘Due to improvements in the child’s behaviour, parents felt they were now often able to appreciate the time that they had with their child with a disability. Now when he comes home at the weekend we can enjoy having him home because you know that’s the time you spend with him’ (parent, interview) (p913). ‘Because she’s happier, it’s nicer to be around her. One could have a bit of fun, which we couldn’t do before’ (parent, interview) (p913) **Stress and strain** ‘I was stressed. But I was! I definitely was. But when you’re living in it, I don’t think you realise that’ (parent, interview) (p913). **Summary of findings** Parents generally noted improved positive behaviour in their child and no deterioration in any behaviour – 2 parents reported no change in behaviour. Improvements included the child being	

		calmer, happier, having an improved ability to cope, more predictable, less aggressive, and more confident. Half of parents reported improved independence in their child. Around half of parents reported improved communication by, and with, their child. There was an emphasis on services being effective because they were supporting the whole family. Parents were able to be more optimistic about the child's future and their own. However, the study notes that this was dependent on the belief that the service would remain available. The study notes that degree of relief and optimism may have been affected by the strain families were feeling before the service was made available to them. The study notes limitations in terms of being retrospective in terms of discussing past stress when the child lived exclusively at home.	

12. Browning M, Gray R, Tomlins R (2016) A community forensic team for people with intellectual disabilities. Journal of Forensic Practice 18: 274–-2

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The study aimed to find out more about the characteristics of adults with learning disabilities who were supported by a Community Forensic Learning Disability Team (CFT) and the types of services delivered. **Service aims** CFT provides multi-disciplinary input (psychiatry, nursing, psychology, speech and language therapy, occupational therapy) to people with intellectual disabilities who have committed or are at risk of committing serious offences. **Country** UK. **Source of funding**	**Participants** Adults with learning disabilities and behaviour that challenges. **Sample size** N=70. **Sample characteristics** **Age** Mean age of 37.1 years (range 18–58, sd=12.017). **Disability** 74.3% had a mild intellectual disability. **Gender** N=66 (94.3%) male. **Health status** 75.7% had at least 1 mental health problem, physical health problem or development disorder with almost half (48.6%) having more than 1. Autistic spectrum disorder 38.6% physical health problems 32.9% problematic	**Clinical outcomes** **Behaviour that challenges** Following referral to CFT, over half of service users had engaged in no further offending behaviours (51.4%). **Costs?** No. **Summary of findings** Following referral to CFT, over half of service users had engaged in no further offending behaviours (51.4%). Assault was the most common re-offence, followed by sexual offences, destruction/vandalism and threatening/offensive behaviour Those engaging in fire-setting behaviours reduced after referral from 14.3 to 1.4%. There was a decrease in the number of people committing contact sexual offences and sexual offences against under 16s. Fewer individuals received any criminal convictions because of their behaviour (54.3% at index offence vs. 7.2% after referral). There was a slight	**Overall score** +

No funding. **Methodology**: Cohort (single group). **What is the sampling frame (if any) from which participants are chosen?** All service users open to the CFT during June 2013. **Details of data collection Instruments or tool** Researcher designed questionnaire. **Mechanism for change** Multidisciplinary collaboration. **Time to follow-up** Two years, so it may be that rates reduce as people get older.	drug or alcohol use 28.6% personality disorder 21.4%. **Ethnicity** White 62.8% Asian 18.6% black Afro-Caribbean 10% mixed 5.7% unknown 2.9%. **Residence** At time of referral to CFT secure units 44.3% living in the community 44.3% forensic step-down unit 7.1% no service users were in prison. **Characteristics of behaviour** Index offence sexual offence 52.9% contact sexual offence 44.3% assault 20% fire-setting 14.3%. In total, 54.3% of service users were charged/convicted for their offence. Alcohol and/or drug use played a part in the main recorded offence of 12 (17.1%) service users, e.g. they were intoxicated when committing the offence. **Other** 48.6% had been victims of physical or sexual abuse or neglect in their childhood; 22.9% had experience more than 1 form of abuse/neglect.	increase in people committing offences, where police were involved but no charge was brought, from 17.1% to 24.3%. CFT there was a reduction in people in secure units (which are out of area) from 44.3 to 27.1%. **Study limitations** The retrospective case notes review relies on the accuracy and detail that was recorded at the time. The study does not compare to another comparable group, or a national baseline figure to know whether the numbers of people who committed another offence was lower than usual and it was not clear how severity was measured or if it was appropriate to think of a reduction in severity as an outcome. Recidivism rates for people who set fires suggest that this rate is comparable for other populations too. A review of recidivism rates (Brett 2004) identifies recidivism rates ranging from 4% (Soothill and Pope 1973) to 60% (Rice and Harris 1991) across 24 studies that differ widely in their operational definition of recidivism, their methodology, setting and sample population. (Dickens et al. 2009). However the reduction in people in secure units who were now being	

	Services of interest Specialist Forensic community Intellectual disability services Support from the CFT is generally provided on a long-term basis, with service users being open to the team for an average of almost 2.5 years. **Content/ components of service** Occupational therapist Speech and language therapist Psychologist/psychiatrist Function-based support Total 30% of service users received offence specific interventions such as adapted sexual offender treatment programmes (Craig et al. 2012); fire-setter treatment programmes (TSTP)(Boer 2012); anger management; and thinking skills (Lindsay et al. 2011).	supervised and looked after by the community forensic team is likely to be representative of that community. This shows that the service could shift care for people with forensic needs who might have been referred to an inpatient secure unit into the community. The increase in the proportions of re-offences where the police were involved but no charges brought may indicate the forensic team had better links with local criminal justice agencies and there was a greater willingness to divert away from CJS into forensic care into the community where there was service involvement associated with the individual. The proportion of people using this service who had experienced abuse themselves is also found in offenders who don't have learning disabilities. People with a dual diagnosis of problems with drugs and/or alcohol was also relatively common, but links to drug and alcohol services was not indicated in this service.	

13. Buxton L, Pidduck D, Marston G et al. (2004) Development of a multidisciplinary care pathway for a specialist learning disability inpatient treatment and assessment unit. Journal of Integrated Care Pathways 8: 119–26

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This article describes the development of such a pathway for a 5-bedded unit in the UK. **Mechanism for change** **Care pathway** The development of the pathway was felt to be necessary to ensure that the process of assessment and treatment was carried out as efficiently as possible, given the large number of health and social care professionals involved in the task. The pathway was needed to reflect the individual clients' specific needs, their legal rights and to help with the process of audit and quality control. **Services working with other services** Identify all the various members of the multidisciplinary team and	**Participants** Not clear. **Sample size** Not mentioned. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).	**Qualitative themes** **Mechanisms** The decision was made that the assessment and treatment process should ideally be no longer than 12 weeks in length other than in exceptional circumstances. **Facilitators** Documentation were developed to support the pathway include a pre-admission assessment document, where the history of the presenting condition is recorded and a preliminary risk assessment carried out prior to admission. **Summary of findings** There is now a clear end point to the admission and assessment process, which identifies where lack of suitable residential accommodation is preventing discharge, rather than the assessment and treatment process carrying on until a suitable community placement is found. **Study limitations**	**Overall score** -

the wider health and social care community involved in the process of assessment and treatment. When developing the new pathway mention of a focus group of the various stakeholders to ensure commitment to the project from an early stage. Areas of documentation that were developed to support the pathway include a pre-admission assessment document, where the history of the presenting condition is recorded and a preliminary risk assessment carried out prior to admission. **Service aims** The development of the pathway was felt to be necessary given the findings of a previous audit and to ensure that the process of assessment and treatment was carried out as efficiently as possible, given the large number of health and social care professionals involved in the task. It was also felt that a pathway was needed to reflect the individual clients'		Study describes the development of the care pathway process and is relevant to this review. The study does not report on the impact of adopting the care pathway or how scalable the process would be.	

specific needs, their legal rights and to help with the process of audit and quality control. **Country** UK. **Methodology** Process evaluation. **Source of funding** Not reported.			

14. **Carnaby S, Roberts B, Lang J et al. (2011) A flexible response: person-centred support and social inclusion for people with learning disabilities and challenging behaviour. British Journal of Learning Disabilities 39: 39–45**

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim The authors describes an innovative, interagency model of provision that has attempted to keep social inclusion as the key objective when developing person-centred support. **Service aims** Explicit. The Flexible Response Service (FRS) aims to operate by bringing together 3 key influences.	**Participants** Professionals/practitioners. **Sample characteristics** **Sample size** Not mentioned **Level of need** Currently unable to tolerate group situations or activities, require ongoing (and intensive) clinical input, often have a	**Barriers identified** **Organisational structures/ cultures** Sharing risk assessments, strategies and interventions in a way that leads to consistent working remains a challenge as different organisational cultures come together around 1 individual. **Resources** The service is highly resource intensive. **Roles and responsibilities**	**Overall score** +

1. A commitment to social inclusion for all as highlighted by Valuing People Now (2009) including those with the most complex needs is paramount. 2. A person-centred, respectful and empirical approach towards behaviour that challenges. 3. From a clinical perspective, an adherence to the principles of PROACT SCIPr-UK where emphasis is placed upon proactive working when meeting individuals' needs. **Country** UK. **Methodology** Qualitative evaluation. **Content/ components of service** **Regular review** Circle of Support meetings which are attended by key stakeholders including the individual and family members wherever and whenever appropriate to do so. This meeting reviews risk assessments, celebrates achievements and aims to involve the individual and his or her social network meaningfully as much as practical and possible.	diagnosis of autistic spectrum disorder, require at least one to one support, might be experiencing breakdown of placement or existing care package. **Relationship** Often have complex familial intra-relationships. **Characteristics of behaviour** Present with challenging behaviour with a high risk to self and/or others.	There is (an) ongoing need for clinicians and other team members to engage in discourse about the nature of their roles, the differences and similarities in their respective approaches to the work and the ways in which they can increase the level of collaboration. **Facilitators identified** **Collaborative team working** The model is also reliant on strong inter-agency working, with an individual sometimes supported by up to 3 other agencies as well as the FRS. **Staff skills** The FRS has demonstrated the need to enable support workers to become more highly skilled by clinicians working alongside, modelling, reflecting and empowering them to develop sophisticated strategies and approaches. **Summary of findings** The FRS has evolved in response to the demands of service users, their families and support staff, the result of which is a person-centred approach to meeting needs that has social inclusion and citizenship at its heart. The model emphasises the role of the 'capable'	

Clinical/ educational/behavioural psychologists FRS model therefore committed direct support hours on a weekly basis from assistant psychologists and behaviour specialists, so that clinicians are working directly in collaboration with support workers. **Training** FRS has developed a core training package that all staff are required to complete. This comprises areas such as PROACT SCIPr-UK with specific attention to the writing and evaluation of positive behaviour support plans, proactive low-arousal approaches and de-escalation) Autistic spectrum disorder, communication (and specifically a qualification in Makaton), sensory integration, risk assessment, capacity, deprivation of liberty, safeguarding and skill teaching. **Day services** **Person centred support** The majority of the service users offered the model have historically been unable to manage a full day at a more traditional day service and have demonstrated greater concentration,		environment, placing energy into developing staff competencies and ensuring the provision of support that is proactive, carefully planned and regularly monitored. The spirit of interdependence and collaboration that runs through the service has enabled clinicians and direct support staff to join together equitably with partner organisations to develop increasingly creative ways of working to meet complex needs in ordinary community settings. **Study limitations** No study limitations described by the author. Evaluation data not available from this paper. **Mechanism for change** **Partnership and collaboration** The Circle of Support meeting takes place at least monthly; this meeting reviews risk assessments, celebrates achievements and aims to involve the individual and his or her social network meaningfully as much as practical and possible. Integration of health and social care models. **Services working with other services** Integration of health and social care models. The FRS model committed	

attention and overall enjoyment when sessions are shorter, more focused and are built solely around the individual’s preferred activities and ability to tolerate and process sensory stimuli. **Positive behavioural support** Positive behaviour support plans which eventually describe how the individual shows others that they are relaxed and enjoying themselves, the indicators that they are becoming unsettled and the ways in which they communicate frustration and distress.		direct support hours on a weekly basis from assistant psychologists and behaviour specialists, so that clinicians are working directly in collaboration with support workers. The junior clinical staff working within the FRS were required to shift away from their previous consultative role to a way of working that included both a direct support role and a contribution to clinical and service development. They are asked to provide a maximum of 15 hours direct support to service users during their working week, usually but not exclusively as part of 2:1 or 1:1 support offered to a particular individual. **Services working with the person – co-production** There is no longer a review of ‘vacancies’ in current services but an assessment of the person’s preferences and needs and what this implies for the creation of an individualised support package. Sessions are shorter, more focused and are built solely around the individual’s preferred activities and ability to tolerate and process sensory stimuli. Consequently, a 3- to 4-hour session is usually the maximum on offer, with an individual’s programme structured to initially include 3 or 4 such	

		sessions each week. Service users new to the FRS are initially offered assessment sessions in so called ‘safe spaces’, rooms in buildings throughout the locality that have been identified as appropriate for getting to know people without needing to be overly concerned about their impact on or vulnerability to others.	

15. Chadwick O, Beecham J, Piroth N et al. (2002). Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it? Child and Adolescent Mental Health 7(2): 66–72

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim 1. To find out what was different about families who wanted respite care from those who did not. 2. From those that wanted respite care, what was different about those families who received respite care from those who did not? **Country** UK. **Methodology**	**Participants** Carers/family members. Parents/family carers were interviewed. Children with learning disabilities and behaviour that challenges. **Sample characteristics** **Age** 5–11 year olds. Children and young people. **Disability**	**Satisfaction with care** Dissatisfaction. Only 2 families expressed dissatisfaction about the form of respite care. **Service use** **Number treated** N=31 (30%) received respite care during the previous 6 months; n=21 (67.7%) was in local authority home; n=10 (32.2%) was with another family. However, in 2 out of the 3 boroughs most (91.3%) received the respite care in a local authority home, in the other borough shortly before the study	**Overall score** ++

Qualitative study. **Source of funding** Government department NHS R and D executive. Part of a larger study entitled 'The Prevention of Behaviour Disorders in Children with Severe Learning Disability'. Health authority Additional resource and support provided by the South London Maudsley NHS Trust.	Children with a standard score of < 50 on the Vineland Screener, considered to have a severe intellectual disability. Severe disabilities in mobility, self-help and communication skills common in the sample. **Gender** Sex ratio (1.6:1). Note: assume the researchers are talking about gender and male is listed first. **Health status** Non-ambulant n=23% epilepsy n=23% Down syndrome n=13% cerebral palsy n=17% autism n=16% rare syndromes n=13% post-natal causes n=6%. **Level of need** Only half of the sample could feed themselves, a quarter could dress themselves and 1 in 7 could wash themselves without help. Over a half of the sample needed daily toileting. One in 7 had no effective means of communication and communication was restricted to the use of a few sounds or	started the local authority home was closed down (for economic reasons) so the small number (n=8) of children needing respite care were placed with another family. The length of respite care episodes during the previous 6 months ranged from 3 to 36 days (mean =16.6 days) **Qualitative themes** **Access to support** Of the 72 families who had NOT received respite care during the past 6 months: n=25 (37.3%) said they did not need it n=23 (34.3%) wanted it but were told that no place was available n=13 (19.4%) were unaware of respite services n=6 (8.9%) had declined it because they didn't want to accept an overnight placement away from home. What distinguished families who wanted and received respite care from those who did not? Children who received respite care were as a group 1 year 4 months older (mean age =8 years 6 months) than those that did not (p=0.012) – 41.9% of them came from families with at least 4 children at home, compared to 4.3% (p=0.002) that did not want respite care - they were significantly more likely to suffer from epilepsy, 32.3% compared to 1% (p=0.012). **Information**	

	concrete gestures in a further 17%. **Relationship** 63% were looked after by a couple living together and 37% by lone parents. **Socioeconomic position** Neither parent was employed in 20% of 2-parent families. 92% of lone parents were not employed. **Sample size** N=103. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).	Of the 72 families who had NOT received respite care during the past 6 months: n=13 (19.4%) were unaware of respite services ’Lack of awareness of respite care provision was strongly associated with lack of contact with social workers. Only n=2 (15%) of the 13 families who were unaware of respite care had been in contact with social workers during the previous 6 months, in contrast to 59% of the remainder of the sample’ (p68). Families who were unaware of respite care were: more likely to be of African origin (46% of the group) – more likely that their child’s level of functioning was higher, mean sd=2 years 11 months; compared to 1 year 8 months. **Respite care** 66.7% of those who had received respite care would have liked to have received more; 40% wanted more short respite breaks 23.3% wanted longer periods of respite; 10% greater flexibility in the duration of episodes. Of the 72 families who had NOT received respite care during the past 6 months: n=25 (37.3%) said they felt they did not need it (p68). What distinguished families who wanted respite care from those who did not? They were less likely to speak a language other than English at home (7.4%) than families that did not need respite care (28%) – carers	

		had significantly higher scores on both the Parental Distress measure of the Parenting Stress index (p=0.006) and the Malaise Inventory (p=0.020) – group had significantly more severe behaviour problems related to: destructive behaviour (t=2.45, 77 df: p=.017), over activity (t=2.04, 77 df: p=.044), screaming (t=3.04, 77 df: p=.003), sleeping difficulties (t=1.99, 77 df: p=.050), and scattering/throwing objects (t=3.29, 77 df: p=.002). Families that wanted more respite care reported: more severe behaviour problems in the child – more severe stress in themselves – they were less likely to have large families. **Costs** No. **Summary of findings** None of the factors that distinguished families who wanted respite care appeared relevant to the issue of who received it. The factors that distinguished families who wanted respite care from those who did not include: carers had significantly higher levels of stress – group had significantly more severe disabilities and behaviour problems – they were less likely to speak a language other than English at home. From those that wanted respite care, the factors that distinguished those families who	

		received respite care from those who did not include children who received respite care were older – they were significantly more likely to suffer from epilepsy – came from families with at least 4 children at home.	

16. Challenging Behaviour Foundation (2015) Paving the way: how to develop effective local services for children with learning disabilities whose behaviours challenge. Chatham: Challenging Behaviour Foundation

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Aims to provide practical examples of different elements of positive behavioural support that deliver good outcomes for children and young people and their families. **Service aims** Implicit − 5 services are considered in the evaluation: 1. Wolverhampton Special Needs Early Years Service Provide an assessment, diagnosis and early intervention for individual children from 0 to 5 through a coordinated multi-agency approach. 2. Coventry and Warwickshire	**Participants** Carers/family members Some views of carers/family members are provided in the case studies. Administrators, commissioners, managers, 5 services that provide local behavioural support to their populations. **Age** 0–5 Wolverhampton Special Needs Early Years Service; 18 months–3 years; Coventry and	**Social care outcomes** **Quality of life** Ealing Intensive Therapeutic Short Break Service report that 'the ability of families to cope increases, improving quality life for the young person and family' (p21). **Social interaction or support** Stepping Stones in Brighton and Hove. Triple P Stepping Stones has been endorsed by the DfE and the Early Intervention Foundation for the strength of its evidence base and its success in improving parent and child outcomes. In Brighton, it is evaluated using a 'before and after' approach, with questionnaires	**Overall score** -

Community Learning Disability. To provide multi-disciplinary provision of services for children whose needs cannot be fully met by general health services. 3. Stepping Stones in Brighton and Hove. To provide evidence-based parenting programmes to give parents the skills and confidence to manage behaviour effectively. 4. Bristol Positive Behavioural Support Service The service aims to develop new skills to promote independence, social participation and quality of life and to avoid school breakdown and out of area placements. 5. Ealing Intensive Therapeutic Short Break Service The aim of the service is to enable the young person to remain within their family home and community settings longer term. **Country** UK. **Source of funding** Department of Health. **Methodology** Qualitative.	Warwickshire Community Learning Disability Team; 2–12 years; Stepping Stones in Brighton and Hove; Bristol Positive Behavioural Support Service doesn't specific age but states supports 'children and young people'; Ealing Intensive Therapeutic Short Break Service states the service is for 'young people'. **Level of need** Two of the 5 services describe level of need as: for young people with learning disabilities who display behaviour described as challenging at imminent risk of residential placement or at high risk of a breakdown of their school placement. **Sample size** This document provides 5 evaluations of different services with person centred outcomes. Bristol Positive Behavioural Support Service supported 12 children over 5 years Coventry and Warwickshire Community Learning Disability supports up to 50 children at any one time.	to measure changes in the behaviours of the child, parenting capacity and well-being. These show improvements on nearly all the measures. **Clinical outcomes** **Function** As a result of Bristol PBSS support, all 12 children supported (over 5 years) learned new skills and made developmental progress, usually in relation to communication. The Bristol PBSS demonstrates (consistent with research literature) that positive behaviour support plans based on functional assessments can deliver positive outcomes for children and young people. Ealing Intensive Therapeutic Short Break Service monitors individual interventions and overall interventions from the service demonstrate a statistically significant improvement. **Behaviour that challenges** Stepping Stones parenting programme in Brighton and Hove. The authors say that in Brighton, it is evaluated using a 'before and after' approach, with questionnaires to measure changes. These showed improvements in the behaviours of the child.	

Services of interest **Behavioural support** Three of the services in this review provide behavioural support services: 1. Wolverhampton Special Needs Early Years Service 2. Coventry and Warwickshire Community Learning Disability 3. Bristol – Positive Behavioural Support Service. **Community support** The 5 services covered in the evaluation all provide community support: 1. Wolverhampton Special Needs Early Years Service 2. Coventry and Warwickshire Community Learning Disability 3. Stepping Stones in Brighton and Hove 4. Bristol Positive Behavioural Support Service 5. Ealing Intensive Therapeutic Short Break Service. **Positive behavioural support** Three of the services in this review could be described as providing positive behavioural support services: 1. Wolverhampton Special Needs Early Years		**Person-centred outcomes** **Choice and control** At Coventry and Warwickshire Community Learning Disability service measures show positive results and very few children from Coventry and Warwickshire are placed out of area, unless there are safeguarding issues or external factors. For those children who are in residential school placements outside of Coventry and Warwickshire, the team review their progress regularly and offer advice and support to the school about their care and development. **Qualitative themes** **Access to support** Exclusion from school for behaviour that challenges can also lead to an exclusion from respite care services too. In this case study Josie was denied access to her respite centre due to her school exclusion report suggests: Intensive, child-focused one-to-one support for families to assess their child’s needs and provide access to the right interventions. **Personalisation of care** Wolverhampton Special Needs Early Years Service: ‘It is the best example in the country of key working for disabled	

Service 2. Coventry and Warwickshire Community Learning Disability 3. Bristol Positive Behavioural Support Service. **Content/components of service** **Behavioural support plan** A functional analysis of A’s behaviour was carried out by Bristol PBSS and a Positive Behavioural Support programme was used to help A label his emotions so he could express his feelings through Makaton signs rather than aggression. A was supported to develop his emotional literacy and to reintegrate back into school. A’s family learnt new skills so they could help A with his emotional literacy and communication skills. A was much calmer and happier by the time he was discharged from the service and staff described him as a ‘joy’ to work with. **Crisis prevention and management** Ealing Intensive Therapeutic Short Break Service Provides a crisis intervention service for young		children under 5’ (Council for Disabled Children) (p13). ‘If our son had been taught how to communicate “stop” or “finished” when he was young, he would not have needed to throw his plate across the room at the end of every meal’ (father) (p15); ‘Because of the help I received from the clinical psychologists, my son is still at home and not in residential care’ (parent) (p21); ‘As a result of the work our child is now sleeping at night, she is calmer, happier, and levels of self-injurious behaviour have reduced a lot. The whole family feel happier and less stressed now – it has had a positive effect on all of us’ (parent) (p20). **Respite care** Exclusion from school for behaviour that challenges can also lead to an exclusion from respite care services too. In this case study X was denied access to her respite centre due to her school exclusion. After 8 months at home this then resulted in admission to a 52 residential school over 200 miles away from the family as there was no services locally who could provide respite care for children with behaviour that challenges. X’s mother found that all support stopped (school and respite). **Community service use**	

people at immediate risk of residential placement. Interventions include: extended/additional short breaks; Intensive clinical psychology interventions; ongoing family support and psychological therapy for the young person and family members; development of a behavioural management plan based on PBS approaches; training of school, home, carers, short break setting and other professionals in the young person's network. Training aims to support the development of problem solving strategies; liaison and consultation with short breaks staff, school and other professionals; and ongoing monitoring of the intervention plan and modification as necessary. **Family focus support team** All 5 services described in the review provide family focused support. At the Wolverhampton Special Needs Early Years Service, the family focus is particularly relevant. 'Services refer children to a multi-agency panel that meets every 3 weeks		The Bristol PBSS enabled 10 of the 12 children to stay permanently in their local school. The other 2 children stayed for longer than had been anticipated. Almost all children who have received the crisis intervention provided by Ealing Intensive Therapeutic Short Break Service have remained in the community. **Barriers identified** **Capacity** Finding the right short breaks service – this is key to success; staff must have the right training and the service must be flexible (Ealing) (p21). **Knowledge and skills** At Coventry and Warwickshire Community Learning Disability they found, engaging with social care and working with services which are not as child-focussed is a barrier. The service works hard to help other professionals understand how to meet individual needs. Bristol report that there is 'very little expertise in most schools about challenging behaviour and mental health' (p19). Ealing say 'working with social care staff who have expertise in challenging behaviour is a challenge' (p21). **Organisational structures/cultures**	

and considers referrals for all children under 5 identified as having complex needs. The panel considers the child and family as a whole – for example, sibling needs, parental capacity, health needs. The panel agrees a “team around the child” package to provide the right support for the child and their family and the family is then able to choose a key worker from amongst this team, to co-ordinate support for their child’ (p12). **Person-centred support** The 5 services covered in the evaluation all provide person centred support services: 1. Wolverhampton Special Needs Early Years Service 2. Coventry and Warwickshire Community Learning Disability 3. Stepping Stones in Brighton and Hove 4. Bristol Positive Behavioural Support Service 5. Ealing Intensive Therapeutic Short Break Service. **Positive behavioural support training** Stepping Stones in Brighton and Hove. Provides evidence-based		In Bristol, support from senior managers in schools when performance and inspection frameworks prioritise other issues was seen as a barrier. However, when Heads and school leaders want a solution and are committed to change they can make it happen. **Misconceptions** Coventry and Warwickshire Community Learning Disability found that working with families in complex situations who do not want to engage with the service or learn new parenting skills can be a barrier. Overcoming negative opinions – ‘we’ve tried everything’ – helping people see that there is another option to a 52-week school (Ealing) (p21). **NHS local authority interface** At Wolverhampton Special Needs Early Years Service health block contracts make integrated working and personalised support more difficult. **Resources** At Stepping Stones in Brighton and Hove, insecure funding from year to year, making it hard to plan ahead and to meet demand, offering support long before families reach crisis point. At Wolverhampton Special Needs Early Years Service retaining a high quality	

parenting programmes (training) to give parents the skills and confidence to manage behaviour effectively.		service (including short breaks and other essential elements) within tight funding constraints. **Facilitators identified** **Collaborative team working** In Brighton and Hove, partnership working with an active parent-led community organisation and strong parent involvement in service design and delivery results in a more effective service. **Family involvement in care planning** Wolverhampton Special Needs Early Years Service suggests involving families in the strategic planning of services right from the start. **Family support** According to Coventry and Warwickshire Community Learning Disability, a key element of an effective child-focussed service is good support for the emotional well-being of parents (e.g. parenting groups and mindfulness interventions). This has a huge impact on the capacity of the family to cope and a direct impact on the outcomes experienced by the child. **Organisational commitment** Bristol found that, success takes time – working with one child to develop skills	

		saw seemingly little progress within 6 months but significant success after 18 months. Commissioning and funding arrangements must recognise the time required to support children to develop new skills Evaluate and develop the service each year, demonstrate the reality of ‘invest to save’ (Ealing) (p21). **Service design** Families sign a form giving permission to share information so they don’t have to repeat their story to multiple professionals. (Wolverhampton Special Needs Early Years Service). In Bristol, good assessment tools and data collection systems are key to a successful service and the evaluation of outcomes. In Brighton and Hove, partnership working with an active parent-led community organisation and strong parent involvement in service design and delivery results in a more effective service. **Multi-agency interdisciplinary involvement** Brighton and Hove, multi-agency working is key – there is a history of this in Brighton and Hove. **Staff skills** Build key working into the job descriptions and training of all professionals	

		(Wolverhampton Special Needs Early Years Service) Staff need to be skilled in PBS approaches and able to work within a PBS framework (Bristol) (p19). **Early intervention** Provide person-centred behaviour support early, before children start school. (Wolverhampton Special Needs Early Years Service). **Summary of findings** The paper describes a 5 step path to better outcomes illustrated by 5 case studies: 1. Establish a person centred approach, right from the start, supported by a key-worker and a team around the child Wolverhampton Special Needs Early Years Service finds that assessment, diagnosis and early intervention for individual children from 0 to 5 through a coordinated multi-agency approach can deliver positive outcomes. Each child is supported by a ‘team around the child’ package and is able to choose a key worker. 2. Identify problems early and respond rapidly using an integrated, multi-disciplinary approach to ensure all needs are met In Coventry, intensive, child-focused one-to-one support for families to	

		assess their child’s needs and provide access to the right interventions is provided by the Community Learning Disability service. The service show positive results and very few children are placed out of area, unless there are safeguarding issues or external factors. For those children who are in residential school placements outside of Coventry and Warwickshire, the team review their progress regularly and offer advice and support to the school about their care and development. 3. Provide evidence-based parenting programmes to help parents to support their child in the best possible way Parenting skills are a top priority in Brighton and Hove. The Stepping Stones parenting programme has used a ‘before and after’ approach to evaluation which shows improvements on the measures of changes in behaviours of the child, parenting capacity and well-being. 4. Establish a local positive behavioural support service, working across homes and school The Bristol Positive Behavioural Support Service finds that providing a service tailored for each child working across homes and school and have positive outcomes. As a result of PBSS support, all 12 children supported	

		(over 5 years) learned new skills and made developmental progress, usually in relation to communication and the PBSS enabled 10 of the 12 children to stay permanently in their local school. 5. Develop a local approach to crisis prevention so children can stay nearby if there is a crisis The Ealing Intensive Therapeutic Short Break Service aim is to enable the young person to remain within their family home and community settings longer term. For people using the service, almost all children who have received the crisis intervention have remained in the community and the ability of families to cope increased, improving quality life for the young person and family. **Study limitations** These 5 case studies or examples of good practice are not proper service evaluations and there is only 1 page of information to go on for each one. However, they are outputs from the Early Intervention Project, funded by the Department of Health and put together by the Challenging Behaviour Foundation and Council for Disabled Children.	

17. Chaplin E, Kelesidi K, and Emery H et al. (2010) People with learning disabilities placed out of area: the South London experience. Journal of Learning Disabilities and Offending Behaviour 1: 5–14

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The study aims to determine the demographic, clinical and offending characteristics of people with learning disabilities placed out of area in South London. The second phase of the study compared the needs and quality of life of the out of area group and another receiving treatment locally. **Service aims** Implicit. Provide specialist mental health services on the care programme approach in residential healthcare placements or in residential care for people with learning disabilities and mental health problems. **Country** UK.	**Participants** Adults with learning disabilities and behaviour that challenges Challenging behaviour was present in 41% of the group. **Sample characteristics** Adults. **Gender** Stage 1: n=32 (73%) men; n=12 (27%) women. **Health status** Stage 1: high comorbidity with dual and triple diagnoses. n=36 (82%) prescribed psychotropic medication n=30 (68%) behavioural therapies n=29 (66%) psychiatric diagnosis n=18 (41%) challenging behaviour n=20 (46%) psychosis n=15 (34%) autistic spectrum conditions (ASC) n=8 (18%) personality disorder n=8 (18%) substance abuse n=5 (11%) mood disorder n=2 (5%)	**Social care outcomes** **Quality of life** In terms of quality of life, there was no significant difference in the total score or the score on any of the 4 dimensions as used in QoL questionnaire of 'personal satisfaction', 'competence', 'independence and empowerment' and 'social belonging' scores between the groups. However, the total score for dimension of 'independence and empowerment' shows a trend (p=0.064) suggesting that with a larger sample the out of area service users may be being less independent and empowered than service users in local services. **Clinical outcomes** **Behaviour that challenges** People placed out of area experienced more 'behaviour problems to others' 74% of the group placed out of area compared with 48% for those in local services. Out of area participants were also significantly more likely to have problems with daily	**Overall score** -

Methodology Case–control study. **Source of funding** Voluntary/charity. The Guy’s and St Thomas’ charity.	both ASC and attention deficit disorder. **Ethnicity** Stage 1: n=27 (61%) from a black and ethnic minority background; n=15 (34%) from a white background; and n=2 (5%) from other backgrounds. **Level of need** A clinical diagnosis of learning disability was found in 40 participants with the following level of functioning: mild (n=31, 71%), moderate (n=6, 14%), or severe learning disability (n=3, 7%). The remainder of the participants were in the borderline range (n=4, 9%). **Residence** Prior to placement out of area: n=20 (46%) secure placements n=9 (21%) inpatients 34% community. Characteristics of behaviour n=7 (16%) cognitive behaviour work aimed at offending, i.e. anger management n=6 (14%) sex offender programme n=1 (2%) fire setting programmes Of	activities inside their living environment (x2=6.577, df=1; p=0.010). This authors say that this finding reflects the type of setting where the majority of out of area participants resided (i.e. hospital). There were no significant differences between the 2 groups on: self-harm behaviour and other behavioural problems that did not involve aggression to others. - problems with relationships, communication, engagement in activities outside home, involvement in occupational and leisure activities and level of self-care skills **Service use** **Number treated** **Level of need** People who were in out of area placements had a significantly higher total number of needs (24.39) than the locally-treated group (18.85), p<0.05. There were no significant differences between the 2 groups in regards to their met needs, current unmet needs, or the proportion of their needs being met. **Out of area** Key reasons why people (n=44) referred out of area: n=20 (46%) forensic (committed an offence) n=15 (34%) challenging behaviour and anti-social	

	those with an offending history: 61% for violence n=18 (41%) assault 23% sexual offences and 45% of index offences n=5 (11%) arson n=3 (7%) damage to property. **Legal status** N=12 (27%) held under a Section 3 treatment order, MHA 2007 n=14 (32%) held under court order n=16 (36%) not detained under the MHA 2007. n=20 (46%) referred out of area for offences n=24 (54%) had no index offence. **Sample size** Comparison numbers n=27. Intervention number n=28. **Sample size** Stage 1: n=44 Stage 2: n=55 (n=28 from stage 1; n=27 controls). **Treatment of groups** Prospective allocation into more than 1 group. **How do the groups differ?**	behaviour n=9 (21%) severe mental illness 'The study found that younger males and those with offending behaviour were more likely to be place out of area'.(p10) For those moved out of area, in terms of levels of security, n=14 (32%) participants were placed in medium security, n=9 (21%) in low security and n=19 (43%) in specialist residential care. The length of time spent out of borough (mean = 8.41 years, sd = 7.45 years) was skewed by 1 outlier of 41 years. People had an average of 3.02 moves between out of area placements. The mean distance of the placement from London was 78.57 miles, though wide variation again was evident (sd = 76.82). **Staff contact/assistance** There were no significant differences for monthly visits from professionals such as social workers and care managers between the 2 groups. However, it is worth noting that half (50%) of those living locally never had a visit from a social worker or case manager compared to a quarter (25%) of those placed out of area. **Person -centred outcomes** **Relationships** **Family contact**	

	Explicitly stated. Treatment group were placed out of area and the controls from local services.	Significant differences were revealed for average visits per month from family and friends in those living locally. Other types of contact through telephone, letters etc. from family and friends was more common for those placed out of area. Frequency of contact, in-area, out of area group visit from family/friends – more than once a month, 75%, 20% Visit from family/friends - less than once a month, 12.5%, 73.3% Visit from family/friends – never, 12.5%, 6.7% Other family contact – more than once a month, 37.5%, 66.7% Other family contact – less than once a month, 0, 20% Other family contact – Never, 62.5%, 13.3%. **Costs?** No. **Implementation issues** Resources from local services are significantly consumed as a result of out of area placements due to monitoring commitments, e.g. Involvement and visits from case managers and this must be considered in the costing of such placements. The development of local care pathways should reflect the needs of the 3 groups identified within the study i.e. Forensic, challenging behaviours and severe mental illness.	

		Study limitations The study is small scale and confined to inner London. There were only n=28 out of area participants in the main study. Only 64% of all out of area participants in the locality could be recruited to take part in the study. The authors suggest some findings that came as a surprise because they weren't mentioned in other parts of the study, e.g. p10 says 'This study found that younger males and those with offending behaviour were more likely to be placed out of area.'	

18. Christopher R, Horsley S. (2015). An evaluation of a behavioural support team for adults with a learning disability and behaviours that challenge from a multi- agency perspective. British Journal of Learning Disabilities. Advance online publication: doi:10.1111/bld.12137

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim This evaluation aimed to investigate whether the Dudley Behavioural Support Team (BST) meets the guidance set out	**Participants:** Professionals/practitioners n=5 Administrators, commissioners, managers n=14.	**Staff satisfaction** The responses to the question 'Overall how did you find working with the Behavioural Support Team?' were overall positive in nature with some suggestions for improvement. They indicated that a focus on 'joint working' had been the most important feature of the work with this theme being coded in 15 responses. Participants talked about the team being supportive and taking	**Overall score** +

in Ensuring Quality Services (McGill 2013) from the perspective of other services. This service evaluation aims to develop a more in-depth understanding of how the BST are working with service providers and social care to implement a PBS pathway to identify the team’s strengths and areas for improvements. **Service aims** Dudley Behaviour Support Team (BST) aims to help make areas of life better for people with behaviours that challenge. It also aims to help their carers support them better. The BST was set up based on Positive Behavioural Support (PBS) principles.	**Sample characteristics:** Adults. **Relationship** **Total** 14 participants were recruited service providers, including 7 service managers, 3 team leaders and 4 support workers. 5 staff from social services; 2 social workers, 2 community nurses and 1 assistant care coordinator. **Sample size** N=19. The participants in this evaluation were 19 staff members from independent service providers and social services.	into account the client’s and the staff team’s perspectives, understanding the pressure of working day-to-day with challenging behaviour. This included listening rather than being prescriptive in the way the service was delivered and making reasonable adjustments for the client. Respondents also highlighted the amount of knowledge they had gained through working with the BST. This was in 7 of the questionnaires. ‘It was really good, I learnt a lot. It was a classic example of joint working’ (private service provider manager) (p6). **Qualitative themes** **Access to support** Three of the 19 participants suggested possible improvements for the team, which included taking referrals over the phone, being available unsociable hours and more follow- ups after discharge. However, these were framed as additional pointers to an already high-quality service. ‘Sometimes need to see somebody out of hours. If you don’t see the client outside of hours, then you don’t see the behaviours. That would put the icing on the cake’ (private service provider team leader) (p8). **Seeking help** The data also indicated that some of the participants valued the team being readily available to answer any questions or to be able to help plans to make sense. The theme of being contactable/approachable was highlighted in 3 of the responses. You can dip in and out of the service. The client is discharged but you can still phone to ask questions. ‘They always get back to us’ (private service provider manager) (p7). **Staff skills**	

<table>
<tr>
<td>Country
UK.
Source of funding
Not reported.
Methodology
Survey.
Services of interest: Behavioural support; positive behavioural support.
Content/ components of service
Assessment reports and intervention plans.</td>
<td></td>
<td>A secondary theme identified was the theme of ‘personal qualities’. This was endorsed in 10 of the responses. Participants talked about qualities such as being pleasant, person-centred, empathic, approachable, flexible and professional being valued those working with the team. ‘Always collaborative, approachable, professional. Not robotic, they actually care about the clients and have hands on experience’ (private service provider manager) (p7).
Working together
Participants indicated that a focus on ‘joint working’ had been the most important feature of working with the Behavioural Support Team. ‘Participants talked about the team being supportive and taking into account the client’s and the staff team’s perspectives, understanding the pressure of working day-to-day with challenging behaviour. This included listening rather than being prescriptive in the way the service was delivered and making reasonable adjustments for the client’ (p7).
Service quality
The quantitative responses to 5 out of the 7 questions were 100% yes. For the remaining 2 questions, 1 on support to implement any changes and the other about advice given to monitor and evaluate any changes made in individual support plans, the respective responses were 84% and 68% respectively.
Table 1 Frequencies and means for the quantitative responses (replicated from p7)
<table><tr><th></th><th>Percentage Yes/No (N)</th><th>Mean Rating</th></tr></table></td>
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		(out of 10)
Did The Behavioural Support Team complete a thorough assessment of the behaviour?	Yes 100% (19)	9.33
Did the Behavioural Support Team share the findings of the assessment with you/the rest of the staff team?	Yes 100% (19)	9.11
Did you talk about or get a summary of the most probable reasons for the individual’s challenging behaviour?	Yes 100% (19)	8.92
Did the Behavioural Support Team help you/ the staff team of the referred person to develop strategies for dealing with the challenging behaviour?	Yes 100% (19)	9.05
Were recommendations given to you by the Behavioural Support Team to support your documentation e.g. care plans?	Yes 100% (19)	9.00
Did the Behavioural Support Team give any advice on how to put into practice any changes in your documentation e.g. care plans?	Yes 84% (16) No 11% (2) Not Directly 5% (1)	9.06
Has the Behavioural Support Team given any advice on how to monitor or evaluate any changes?	Yes 68% (13) No 21% (4) Not Directly 11% (2)	9.31

Overall how did you find working with the Behavioural Support Team?		9.37

Staff assistance

100% of respondents answered ‘yes’ to the question ‘Were recommendations given to you by the Behavioural Support Team to support your documentation, for example care plans? The data collected indicate that the participants felt that the recommendations were given in a way that is additional to any of their existing support plans or guides any documentation to be written. In response to the question ‘Did the Behavioural Support Team‘ help you/the staff team of the referred person to development strategies for dealing with the challenging behaviour?‘ response 100% yes. In response to the question ‘Has the Behavioural Support Team given any advice on how to monitor or evaluate any changes?‘ The most frequently endorsed theme for this question was ‘being given tools’ which was coded 11 times. From respondents who felt they had not been given any advice on how to monitor or evaluate any changes, there was a theme of ‘needing additional support’.

Participants talked about ‘the advice being given in a way that allowed the BST and staff team to come together as 1 and that gives insight in the assessment process.’ (p7) ‘There were also 2 subthemes under working jointly as to how the BST achieved this, ‘working in a way that is not prescriptive and being contactable/approachable’. (p7) Responses indicated that BST had an approach that was not telling staff what to do but which was more receptive in nature.

Summary of findings

		This study looked at whether the behaviour support team is meeting guidelines set out by the government to ensure services are doing their job well. This study found that the behaviour support team is meeting the government guidelines to a high standard. These standards are achieved through a focus on joint working and inclusion of services throughout the assessment and intervention process and a fluid, flexible approach to the needs of the client and service. The personal qualities of the team, such as being approachable, professional and respectful were also highlighted as important. One area, identified for improvement is that of monitoring and evaluating outcomes. The team is moving towards a ‘Behaviour Pathway’ more focused on measuring outcomes of distinct pieces of work for the same client. For example, outcomes will be documented throughout the process of assessment, formulation and intervention at each point of the client’s journey through the pathway, rather than just showing a change at the point of closure to the service. **Implementation issues** While monitoring outcomes is an essential part of ensuring services effectiveness, activity monitoring on the basis of face-to-face contact with clients may be problematic for services such as the BST. Therefore, any activity monitoring systems for teams such as the BST need to take into account the complex nature of the work being done and allow the flexibility that has been identified as important by the services in this evaluation. **Study limitations** The convenience sampling method used may have created a bias in the results here, as services may have been more willing to take part if they have a positive relationship with the BST. The evaluation also doesn’t take into account the views of service	

		users and their families; however, this was beyond the scope of the present evaluation. The evaluation could also be strengthened by including an audit or paperwork to evidence standards are being met.	

19. Davis A, Doyle M, Quayle E et al. (2015) Am I there yet? The views of people with learning disability on forensic community rehabilitation. Journal of Intellectual Disabilities and Offending Behaviour 6(3/4): 148–64

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To find out what people with a learning disability subject to a forensic community rehabilitation order think about the services they receive. **Service aims** To provide high levels of supervision for people with a learning disability and a forensic history living in the community and subject to rehabilitation order. **Country** UK.	**Participants** Adults with learning disabilities and behaviour that challenges. **Sample characteristics** Adults. **Age** Range in years: 23–49. **Disability** All participants has a significant learning disability. **Gender** Participants were all male as no females were using the services. **Residence**	**Qualitative themes** **Choice and control** **Freedom within limits** Most people felt there was an opportunity within their community order to try new things: e.g. joining classes and groups, and enjoying holidays. 'Well, it's easier from my, it's easier for me, eh? It just […] makes it a lot easier for me as well to, to go out and do things that I've never dreamt of doing' (participant 7) (p154). Participants also expressed a sense of autonomy and choice in their daily lives, which they viewed very positively. One participant talked about a weekly planner and deciding themselves what went into it. However, frustration was also expressed by some that the freedom was not all it could be and there were still limits 'Eh, I felt like […] I says to myself, this	**Overall score** ++

Methodology Qualitative. **What is the sampling frame (if any) from which participants are chosen?** Two health board areas in Scotland – NHS Tayside and NHS Fife. **Time to follow-up** No follow-up. **Source of funding** Not reported. **Mechanism for change** Care pathway Need to be shared with people that use services and services need to be transparent in explaining to people that use services that they will be helped to have as meaningful a life as possible within the restrictions of their community order. Services working with the person and their family Part of the disempowerment participants expressed in this study was due to not understanding the roles of	All participants had their own tenancy. Characteristics of behaviour Most (n=8) had an index offence of sexual offending or sexually inappropriate behaviour. **Legal status** N=6 compulsory treatment. order n=3 guardianship order. N=1 compulsion order time on order =1–15 years. **Sample size** N=10. **Services of interest** Specialist Forensic community Intellectual disability services	is rotten – I can't do what I used to do when I was in the [hospital]' (participant 3) (p156) Some participants 'reminisced about their time in hospital, with close living quarters and shared social events' creating a sense of community, which appeared lacking in the actual community setting. **Loss of control** Participants talked about not 'having control over their situation'. They didn't know what the 'rules are' and felt that staff had too much control. Most participants thought the main role of staff was giving support with household tasks: '[…] I'm cleaning the hoose. Why don't they just come in and help? No' (pilot participant) (p155). There was also a consistent feeling throughout participant response that they had not ever had the chance to consider and reflect on some aspects of their care. Participants also described a lack of control in relation to their care plan, feeling that their progress was dependent solely on the subjective judgement of others. **Attempting to get control back** Participants attempted to regain control though advocacy groups or via their lawyers; by more passive-aggressive behaviours such as 'sneaking' extras, refusing to engage, or employing a 'keep your head down' approach; or by giving up and ceasing to try: '[…] I'm keep on nowadays progressing with my independent	

the support team around them and what to do in order to have their legal order removed, which suggests that more discussion needs to take place with people that use services so they get a better understanding of the system. And it would be helpful for people that use services and staff teams to have a better understanding of their dual roles of support and public safety. Staff care practices encouraging teams to reach a shared understanding of the individual, in terms of psychological factors which may drive his/her behaviour and resulting needs. **Source of funding** Not reported.		living. I'm not giving any of these professional people any excuses or any cases to argue' (participant 9) (p157). **Inclusion/isolation** Loneliness: participants described very limited social networks and difficult family relationships and maintaining the relationships they did have, due to staff presence: 'Aye – ha'ing staff. I got to lie. But the second time you go and meet them with someb'dy else, "who's that?" "Oh aye, that's my brother". You cannae, you cannae win that way eh?' (participant) (p157). Also, for many participants, staff became like friends due to shared activities, contact over time, and lack of others in their lives. It was difficult for them to consider moving on and not having staff with them all the time. 'I don't know if it's be […] I'll be really honest, I think I'd be lost' (participant) (p157). However, not everyone reported loneliness; and some reported feeling that family relationships were actually eased by the presence of a third party. **Safety** This quote captures the frustration most participants seemed to feel regarding the compulsory care they received. 'It's just […] sometimes I feel like eh […] I could do without them, and other days I'm no wantin' them, and other days I do want them. And some days I feel	

		like I’ve just done enough time, being in prison and all this crap ya ken? I’ve just done enough time, being in here and […] I just feel like I’ve done enough’ (pilot participant) (p159). Stigma of a service user: participants appeared to experience more shame associated with needing help to care for themselves and having someone with them at all times in public, than with being seen as a risk to the public: ‘And I don’t want to learn to read and write, If I do, I’m learning on the computer myself, I’m no wantin’ someone to come along and do it for me’ (participant) (p158). **Costs?** No. **Study limitations** The authors say that this is the first piece of research that looks at compulsory forensic care for people with LD from the perspective of people that use services. Participants did have difficulties with expression, comprehension, and speech which reflects the general difficulties with communication for this group. Participants LD may also affect their understanding of the support services they are being offered although this should not detract from the feelings described in the study. This was a very small study and most of the participants had an index offence of sexual offending or sexually inappropriate behaviour so you need to consider	

		if their views would be representative of people subject to compulsory care or high level of support that display other forms of challenging behaviours.	

20. Devapriam J, Alexander R, Gumber R et al. (2014) Impact of care pathway-based approach on outcomes in a specialist intellectual disability inpatient unit. Journal of Intellectual Disabilities 18(3): 211–20

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Service developed in Leicester, Leicestershire and Rutland, implementing a core care pathway. The successes, challenges and experiences of professionals in the implementation of core and clinical care pathways in this service are described. **Mechanism for change** **Care pathway** Care pathways outline the essential steps in the care and treatment delivered for a patient, including anticipated	**Participants** Adults with learning disabilities and behaviour that challenges. **Sample characteristics** Adults (aged 18 years). **Sample size** N=24 **Comparison numbers** Pre-pathway implementation 6. **Intervention number** Post-pathway implementation 18. **Treatment of groups**	**Clinical outcomes** **Physical health** Mean (sd) average HoNOS-LD scores. On admission – pre-pathway 19.4 – post-pathway 21.5 n.s. On discharge – pre-pathway 5.1 – post-pathway 3.2 n.s. **Service use** **Length of hospital stay** Mean (sd) average length of stay: admission till medically fit for discharge – pre-pathway 77 (28.4), post pathway 20.4 (20.5), $p<0.000$ – admission till actual discharge: pre-pathway 148.2 (179.2), post pathway 7.8 (24.7). $p<0.008$. Discharge delay (mean	**Overall score** +

care over a given time period and documentation of milestones and clinical interventions throughout the patient's clinical experience. **Services working with other services** The approach adopted a multi-agency and lean method (systematic method for waste minimization), specifying a referral checklist, admission procedures, formulation and multidisciplinary meetings, assessment and intervention time frames, discharge planning and outcome measurements. A band 6 nurse was employed as a pathway coordinator with the sole responsibility of ensuring progress of patient journey through the pathway by working jointly with the relevant agencies and professionals. Working jointly with community teams in a tiered model of care approach ensured good continuity of care and timely discharges for patients who were admitted. There was also a clear framework of timescales	No prospective allocation – use of pre-existing differences to create comparison groups before or after the implementation of the care pathway approach. **How do the groups differ?** Explicitly stated. A specialist inpatient unit for adults (aged 18 years) with intellectual disabilities. The unit consists of 8 acute assessment and treatment beds (category 2 beds).	days) pre-pathway 131.3 (180.4), post-pathway 8.4 (15.7), p<0.000. **Summary of findings** In this study, it was found that following the introduction of a care pathway-based approach, there was a threefold increase in the number of admissions to the inpatient unit. This increase is because the unit was able to accommodate all patients with intellectual disability who needed inpatient care. Due to care pathway principles of lean working, timely assessments and interventions and proactive working with community teams, the average length of hospital stay for patients was reduced considerably. The findings of this study are positive, as it provides evidence that a care pathway-based approach to inpatient service provision contributes to good outcomes for patients in terms of timely assessments, treatments, continuity of care and reduced lengths of stay. **Study limitations** Single group before and after. Short period of time, multiple other factors like staff skills, morale, attitude, leadership, environment and resources that could have had an impact on the outcomes we have described.	

and responsibilities, relevant across health and social care Monthly meetings were held with stakeholders from clinical commissioning groups, NHS England, respective local authorities and inpatient and community staff from provider services to review the care and progress of patients in the unit. **Service aims** The use of care pathways has shown promising results in terms of risk assessment, monitoring, interdisciplinary communication and patient satisfaction with services **Country** UK. **Methodology** Single group, before and after. **Source of funding** No funding. No specific grant.			

21. Douma JCH, Dekker MC, Koot HM (2006) Supporting parents of youths with intellectual disabilities and psychopathology. Journal of Intellectual Disability Research 50: 570–81

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The aim of the study was to find out about the specific support needs of parents who perceive emotional and/or behavioural problems in their child with ID and to find out which needs for support are met; the variables related to both needing and receiving support; and the reasons why parents don't seek help (p571). **Country** Netherlands. **Methodology** Cross-sectional study. **Source of funding** Not reported.	**Participants** Carers/family members. Parents who perceived their emotional or behavioural functioning as (somewhat) problematic were included in this study. Children with learning disabilities and behaviour that challenges. **Sample characteristics** **Age** Range 10–24; mean 16.5, sd=2.9. Children and young people. **Disability** Mild ID (IQ range 60-80) and moderate ID (IQ range 30-60). 37% had moderate ID. **Gender** Male 60.9%. **Health status**	**Service use** Community service use. **Qualitative themes** **Access to support** Most parents (88.2%) needed some type of support because of their child's emotional or behavioural problems. Moreover, 67.4% needed at least 3 different types of support (p575). The supports most often needed were 'a friendly ear' (78.1%), 'information' (68.0%) and 'child mental health care' (56.7%), whereas the other supports were needed less than 48.4% of the time. Compared with parents who perceived only emotional or only behavioural problems, parents who perceived both types of problem needed support the most. Parents of children with moderate ID or physical problems especially needed 'relief care', that is, respite care, activities for the child and practical/material help. **Met and unmet need** Need for 'a friendly ear', 'respite care' and 'information' were most often met (75.3%,	**Overall score** +

	Child 71.3%, past psychopathology 22.4%, physical problem (higher level). Parents 26.2% parental psychopathology. **Ethnicity** This is a Dutch study, and 87.2% of participants had at least 1 Dutch parent. The researchers report that when they compared the characteristics of the sample against the wider data-set and after adjusting for the correlation between these variables, they found that ‘only significantly fewer non-Dutch parents had participated [in the study] ($p< 0.05$)’ (p572). **Level of need** 56.7% of parents perceived both emotional and behavioural problems, 21.3% only behavioural and 22.0% only emotional problems. **Relationship** 21.2% were single parents. 24.3% problematic parenting. 25.3% problematic parent-	61.1% and 51.3%), whereas the other support needs were met in less than 43% of the time. ‘Parental counselling’ and ‘activities’ were most often unmet (65.5%, 61.5% of the time). Variables that significantly related to parents having their need for support met differed for the different types of support and included: having a high need for support increased the odds of receiving ‘a friendly ear’, ‘respite care’ and ‘child mental health care’. Parents who worried most about their child more often received ‘information’. Parents of younger children and with a moderate ID more often received ‘activities’. Parents who had less problems with parenting more often received ‘practical/material help’. Parents with a higher social economic status (SES) more often received ‘parental counselling’. **Family life** Problematic parenting, hostile family functioning and higher parental educational level and SES increased the odds of families needing support. **Information** This was a need identified by 68% of parents and met 51.3% of the time. **Navigating care services**	

	adolescent relationship, 90.7%. more than 1 child in the family, 18.7%, hostile family functioning, 23.9%, negative involvement. Compared with the wider study population, families in the sample experienced a problematic relationship between child and parent(s) more often. **Socioeconomic position** Parents 49% medium/high socio-economic status, 48.8% medium/high education level. Characteristics of behaviour: compared with the wider study population, the sample had significantly more emotional and behavioural problems, as indicated by the Child Behaviour Checklist (p572). **Sample size** N=289. **Treatment of groups** N/A (not more than 1 group).	The authors suggest that 'parents' unawareness of the existence of "practical or material help" might explain why only a quarter indicated a need for this support. It might also be that this type of support was not their highest priority' (p578). **Respite care** This was a need identified by 38.9% of parents and met 61.1% of the time. The authors suggest this is relatively low but can be explained by the fact that this need is more often present in parents of youths with more severe ID and younger age (p578). **Seeking help** Reasons for not seeking support. The parents' main reasons for not seeking support were: wanting to solve the problems themselves, considering the problems not so serious, not knowing where to find support and considering the problems as temporary (p578). **Stress and strain** The needs most often reported ('a friendly ear' and 'information') related to providing the parents with informal or emotional support or advice and were not aimed at directly dealing with their child's problems. The variables that increased the odds of	

		needing any type of support largely represented increased parental stress and include: the type of problems parents perceived – the child’s past psychopathology – parental psychopathology – parental worries about their child. **Costs?** No. **Summary of findings** The findings suggest that service providers need to address both the child’s problems and the parents’ and families ability to deal with these problems because the stressful circumstances the family are under increase the odds that they will need help. **Implementation issues** The study results suggest that service providers need to become aware of parents’ high level and diverse needs for support. As support needs were frequently unmet, service providers should aim to provide information, activities, child mental health care and parental counselling. **Study limitations** While the findings suggest that parents experiencing ‘problematic parenting’ are more likely to need ‘practical/material help’ the authors suggest that this result should	

		be interpreted with caution because the wide confidence interval indicates that this result lacks precision and is not very reliable. One of the main barriers that parents said stopped them from seeking help was 'not knowing where to find help' (p579). While this might suggest the service providers' role in unmet need, e.g., through local unavailability, or lack of information, no firm conclusions can be drawn about the exact role of service providers because this study only considered the perspective of parents.	

22. Evans T, Gore N (2016) Staff behaviours valued by service users: views of people whose behaviour challenges. International Journal of Positive Behavioural Support 6(2): 4–11

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To find out directly from people with a learning disability and behaviour that challenges what staff behaviours they like and don't like. **Service aims**	**Participants** Adults with learning disabilities and behaviour that challenges. **Sample characteristics** Adults **Age** Median age =40. **Disability**	**Qualitative themes** **Choice and control** **Theme 3**. '**Not controlling of my life'** Ten participants talked about not being controlled by support staff. Some people were very annoyed when this happened, and some people seemed to feel there was nothing they could do about it. People who talked about this theme also	**Overall score** +

Provide one to one support for people with mild to moderate learning disability and behaviour that challenges services. **Country** UK. **Source of funding** Not reported. **Methodology** Qualitative. **What is the sampling frame (if any) from which participants are chosen?** Not stated. **Details of data collection instruments or tool(s)** Researcher designed questionnaire. Interviews were semi-structured and aimed to identify valued staff behaviour and qualities that participants thought make a good support worker. **Mechanism for change**	All participants had a mild to moderate learning disability and were described as presenting with behaviour that challenges. **Gender** N=10 male; n=7 female. **Other** They had all experienced a range of services in a range of settings and had lots of experience of having staff support them. **Sample size** N=17. **Services of interest** **Community support** Participants were receiving between 23 and 103 hours per week of one-to-one support from an organisation in the south of England.	said there was a difference between giving advice and trying to take over and be controlling. 'They were good at giving advice, what to do what not to do, advice not telling' (participant 6) (p8). Three subthemes were also identified from this theme: (f) Being told what to do – participants who said they did not like support staff controlling their life sometimes said that they did not like being rushed, or being told what they could and could not do, being bossy or nagging; (g) Being 'told off' – when people talked about being told off, this was often felt to be unfair; (h) Service arrangements and rules – this theme emerged as about how staff approached service arrangements and rules. Some people said that the way staffing was arranged had nothing to do with their needs. Some people said that having too much staff support was intrusive and controlling: 'cos I'm independent, I wanna go in the real world, see my friends family, stuff like that really, but y'know, I don't want it all the time but I like to be around people but I don't need support all the time. It don't get me anywhere' (participant 7) (p8). **Personalisation of care**	

Staff care practices. Participants thought that support workers should know them well and appreciated it when support staff made time for them, to talk or made time to be available to give support. Participants also valued support workers being nice or kind and who also helped them do things when they could not do things themselves. They didn’t like being controlled by support staff. **Source of funding** Not reported. **Time to follow-up** No follow-up.		**Theme 4. ‘Know me well’** Seven participants talked about how support workers should know them well. People have different preferences and routines, and if support staff didn’t know or forgot, this could cause upset and anxiety and behaviour that challenges. Another example was when the schedule for the next week didn’t say which support worker could be expected. ‘I always want to know who’s working with me. I wish they would sort it out’ (participant 17) (p9). **Theme 5. ‘Make time’** Participants said that they appreciated it when support staff made time for them, to talk or made time to be available to give support. ‘They spend time with me, they talk to me, make time, talk about things’ (participant 4) (p9). But when staff didn’t make time, or seemed to busy, it made people feel less valued or important. **Seeking help** **Theme 2. ‘Help me’** Of the 17 participants, 14 talked about help, being helped to do things, being helped when they could not do things themselves, being looked out for or being	

		looked after. There were 3 subthemes that were related to the theme. (a) Practical help – some people said it was the practical help they valued, and others said they did not get enough practical help from support staff; (b) Emotional support and feeling safe – some people said that they valued it when support staff helped them with their emotional life, like if they had family problems; sometimes this was making people safe and reassured; (c) Help when angry or upset – some participants said what sort of support they needed if they were angry or upset. That support staff should be able to know what to do to calm them down. **Staff skills** **Theme 1 'A nice person; a kind person'** All 17 participants said they valued support workers being nice or kind. Some people said that they also liked it when their support workers had a sense of humour or ability to make participants laugh, treating them 'in a good way', being 'caring', 'generous', 'honest', 'talkative'. Subthemes: (a) How staff speak – when staff spoke in a respectfully and in a calm way, this was	

		valued by participants. Interviewer: ‘What do they do that upsets you?’ D: ‘It’s the way they speaks to people I don’t like.’ Interviewer: ‘How?’ D: ‘This is it: [adopts loud voice] “D” like that. Aggressive. I don’t like loud aggressive. I like calmly’ (participant 13) (p7); (b) Friendliness – participants valued friendliness in staff members, being unfriendly was when they were’ taking the mickey’ or saying unkind things. **Costs?** No. **Summary of findings** The researchers looked for common patterns and themes in what people said about the things that they liked and didn’t like about staff characteristics. They found 5 themes and 8 subthemes. **Study limitations** The participants were all able to communicate verbally with the interviewer and generally had mild to moderate learning disability and so represent the views of a proportion of people with learning disabilities. We do not know if people who communicate differently or have more severe learning disabilities have different needs or value	

		different things from their support staff. The people who took part were all from the same region of the country and receive services from the same providers so may not be representative to other areas and other providers. There may be agreement on themes that result from common experiences rather than the relative importance of the themes that were raised. However, the interviews were well conducted and allowed time for people to speak. The researchers made sure that more than 1 persons' interpretation of the views was in the analysis.	

23. Felce D, Perry J, Romeo R et al. (2008) Outcomes and costs of community living: semi-independent living and fully staffed group homes. American Journal on Mental Retardation 113(2): 87–101

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To compare costs and quality of life outcomes for adults with intellectual disabilities with relatively	**Participants** Adults with learning disabilities and behaviour that challenges. **Sample characteristics** Adults.	**Social care outcomes** **Quality of life** Fully staffed group home (FSGH), semi-independent living (SIL).	**Overall score** +

low support needs in fully staffed care homes compared to semi-independent living settings matched on adaptive behaviour, challenging behaviour and mental health status. **Country** UK. **Services of interest** Fully staffed group home, Semi-independent living. **Methodology** Comparison evaluation.	**Age** Mean ages of fully staffed and semi-independent living participants were 50 years and 44 years. **Gender**. There were 22 men and 13 women in fully staffed settings, 17 men and 18 women in semi-independent living settings. **Ethnicity** All but 1 of the fully staffed participants and all but 2 of the semi-independent living participants were Caucasian. **Residence** The average durations that fully staffed and semi-independent living participants had resided at their current setting were 74 months and 59 months, respectively. **Sample size** Comparison numbers: 35 in fully staffed settings.	Money management scale: % 1 or more of exploited financially, run out of money, utility bills unpaid FSGH 8.6 SIL 51.4 Home likeness (%) have garden FSGH 91.4 SIL 45.7 Body mass index(%) underweight FSGH 3 SIL 6.7 Overweight but not obese FSGH 30.3 SIL 33.3 Obese FSGH 48.5 SIL 40 Exercise mean bouts of moderate / vigorous activity (sd) FSGH 6.3 (7.5.) SIL 4.8 (8.8) Proportion inactive (%) FSGH 78.1 SIL 84.8	

	Intervention number: 35 in semi-independent living settings.	Health checks (% receiving) general in last year FSGH 70.6 SIL 67.9 Blood pressure in last year FSGH 88.2 SIL 75 Dentist in last year FSGH 87.9 SIL 83.3 Vision in last year FSGH 88.6 SIL 55.9 Hearing in last year FSGH 31.4 SIL 20.6 Healthcare scale FSGH 31.3 SIL 27.3 Risks (%) perceived to be at risk FSGH 54.3 SIL 65.7 Major accident in the past year	

		FSGH 0 SIL 2.9 Victim of abuse past 5 years FSGH 5.7 SIL 17.1 Victim of crime FSGH 14.3 SIL 22.9 Safety inventory mean (sd) FSGH 15.1, (0.9) SIL 14.3, (2.4) Index of community integration FSGH 2.3, (1.0) SIL 2.4, (1.6) Variety of community activities FSGH 6.2, (1.2) SIL 6.0, (1.8) No. of social activities in last month FSGH 9.3, (6.7) SIL 8.5, (10.5) No of community activities in last month FSGH 46.8, (20.8) SIL 45.4, (24.4) Variety of activities	

		FSGH 9.8, (2.0). SIL 9.2, (2.9) No of activities in the last month FSGH 53.5, (20.3) SIL 48.4, (24.1) Activities done independently FSGH 1.4, (1.9) SIL 6.5, (4.7) Social networks total size (no. of people) FSHG 13.5, (12.1) SIL 12.1, (6.2) With family members (%) FSGH 82.9 SIL 90.9 With people other than family or peers FSGH 82.9 90.9 Loneliness scale (sd) FSGH 3.3, (3.6) SIL 4.8, (4.7) Participation in domestic life (% of max) FSGH 68.2, (16.7) SIL 80.7, (15.5) Choice scale	

		FSGH 89.9, (7.1) SIL 98.2, (4.8) Choice questionnaire % FSGH 61.6, (4.1) SIL 71.3, (3.1) Recreational activities FSGH 8.0, (11.8) SIL 9.3, (11.2) Community activities subscale FSGH 8.3, (5.2) SIL 7.5, (5.9) **Service use** **Service quality outcomes** Fully staffed group homes (FSGH) Semi-independent living (SIL) Mean no. of persons living together (sd) FSGH 2.5 (0.7), SIL 1.4 (0.7) Mean staff hours per person per week (sd) FSGH 76.8 (49.4) SIL 13.3 (13.2) Working practices (%) Individual planning FSGH 94 SIL 97	

		Behavioural assessment / teaching FSGH 83 SIL 60 Planning activities FSGH 89 SIL 40 Planning staff support FSGH 91 SIL 84 **Costs** Economic evaluation - full or partial Cost information **Narrative findings** Significant differences between the 2 homes: Residents in semi-independent living were: • more likely to have money problems • less likely to have a garden • less likely to have had their eyesight tested in the last 2 years • have poorer health related to lifestyle • undertook a lower variety of community activities	

		• they were more likely to have taken part in community activities independently • more likely to have social networks other than family members staff members and other people with learning disabilities • participated in more domestic and household activities • exercised greater choice.	

24. **Gangadharan S, Bretherton K, and Johnson B (2001) Pattern of referral to a child learning disability service. British Journal of Developmental Disabilities 47 part 2: 99–104**

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Describe how a specialised learning disability team integrated into the Child and Adolescent Mental Health service works. To describe the demographic characteristics, nature of the disabilities and the referral reasons of the children referred to the team over an 8-month period. **Service aims**	**Participants** Not clear. Children with moderate, severe or profound learning disabilities and mental health problems. There is no mention of level of ‘challenging behaviour’ in the population, however based on the reason for referral to the service most of the children were referred for behaviour	**Service use** **Number treated** Total 66% of the children referred to child learning disability service had multiple disabilities (autism, speech and language difficulties or epilepsy). **Staff contact/assistance** Referrals came from: 24% general practitioners, 32% paediatricians, 12–19% social workers, 10–16% educational services/other professionals.	**Overall score** -

Implicit To provide care and treatment for children with a moderate, severe or profound learning disability. **Country** UK. **Methodology** Cross-sectional study. Secondary data study. **Source of funding** Not reported.	problems including 59% aggressive behaviour. **Sample characteristics** **Age** The mean age of the sample was 9.36 years (range =3 to 18; sd=4.48) and there were 8 young people aged 16 or above. Children and young people. **Disability** N=24 (49%) children had moderate learning disability. N=23 (47%) children had severe or profound disability. **Gender** N=40 male n=23 female. **Health status** N=22 (45%) epilepsy; of these n=15 (62.5%) had severe or profound disability and n=7 (30%) had moderate disability n=17 (35%) autistic disorder; of these n=9 had severe LD; n=6 moderate LD; n=2 mild LD. **Characteristics of behaviour**	**Qualitative themes** **Defining behaviour that challenges** Total 45% of the sample had epilepsy which makes assessment of behaviour problems difficult because of the complex interactions between uncontrolled epilepsy, anti-epileptic medications and behaviour. Access to the joint neurology clinic in this study is therefore very important. **Transition** Total 10% of the children were aged 16 or above. The authors say that in generic child mental health services children that have left full-time education and are over 16 are transferred to the adult health team, however some children with learning disability continue at school until the age of 19. This suggests that there is a need for an effective transition service to ensure smooth transfer of these people to the adult learning disability service. **Costs?** No. **Summary of findings** This study gives the broad picture of the patient population attending a child learning disability service for children	

	N=29 (59%) aggressive behaviour was the main reason for referral. ‘The other problems that resulted in referral were eating difficulties, toileting difficulties, issues related to compliance at school and home, self-injurious behaviour, repetitive obsessive behaviour and sleep problems’ (p102). Of the n=17 with autistic disorder, n=8 aggressive behaviour; other problems included (no specific breakdown provided): sleeping difficulties, repetitive behaviour, eating problems or toileting difficulties. **Sample size** N=63 referred to the service during the study n=49 received treatment and data analysis was completed for them. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).	with moderate, severe or profound learning disability. **Study limitations** Only covers 1 service.	

25. Golding L, Emerson E, and Thornton A (2005) An evaluation of specialized community-based residential supports for people with challenging behaviour. Journal of Intellectual Disabilities 9: 145–54

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim 'The aims of the present study were to add to this literature on deinstitutionalization by evaluating the effects of relocation from institutional to specialized community-based provision for people with severe challenging behaviour' (p146). **Country** UK. **Services of interest** Fully staffed group home, residential placements in the community. NHS trust-run houses. **Methodology**	**Participants** Adults with learning disabilities and behaviour that challenges; 12 men with mild to moderate learning difficulties (6 intervention, 6 control). **Sample characteristics** Adults. **Age** Intervention group: mean 49.5 years (range: 35–60), control group: mean 32.2 years (range: 22–57). **Disability** All classed as having 'mild to moderate learning difficulties' (p.145). **Gender** All male. **Ethnicity** Not detailed. **Residence**	**Social care outcomes** **Quality of life** Evaluation measured quality of life according to Life Experiences Checklist. **Clinical outcomes** **Function** Evaluation measured 'ability' according to 'Adaptive Behaviour Scale-Residential and Community Second Edition. Part 1: Designed to evaluate coping skills considered important to personal independence and responsibility in daily living' (pp148–9); Part 2: 'Behaviour domains and measures which relate to manifestations of personality and behaviour disorders'. **Costs?**	**Overall score** +

Comparison evaluation.	The average durations that the hospital and community group participants had spent in institutions were 23.3 years and 11 years, respectively. **Sample size** Comparison numbers: 6 individuals. Intervention number: 6 individuals.	No costs data. **Summary of findings** **Effect sizes** Intervention group: 3 months following move. Results are divided into the following categories: personal competence, problem behaviour, quality of life and engagement. - Personal competence: domestic activity scores increased significantly (z=2.02, p<0.05). This increase was still present at follow-up (9 months following move) (z=2.21, p<0.05). - Problem behaviour: observed problem behaviours (not ABS) decreased post move (z=-2.20, p<0.05) decrease maintained at follow-up (9 months following move) (z=-2.20, p<0.05). - Quality of life: significant increases in all subscales. Home: increased by 51% pre-move and post move and was maintained at follow-up (post move z=-2.23, p<0.05) (follow-up	

		z=-2.21, p<0.05); Freedom: 46% increase (post move z=-2.21, p<0.05) maintained at follow-up (z=-2.03, p<0.05); Leisure 51% increase (pre-move to follow-up) (z=-2.22, p<0.05); Opportunities 48% increase (post move z=-2.21, p <0.05), maintained at follow-up (z=-2.21, p<0.05); Relationship 53% increase (post move z=-2.33, p<0.05) maintained at follow-up (z=-2.33, p<0.05). TOTAL LEC: 49% increase between pre move and post move. (z=-2.20, p<0.05) and maintained at follow-up (z=-2.21, p<0.05). Engagement – observed data. This data was aggregated into: no activity, leisure activities and other tasks. overall ‘activity’ in all categories was found to increase by 68% post move (z=-1.99, p<0.05) and at follow-up (z=-2.20, p<0.05).	

26. Griffith GM, Hastings RP (2014) ‘He’s hard work, but he’s worth it’. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research. Journal of Applied Research in Intellectual Disabilities 27(5): 401–19

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating.**

Study aim	**Participants**	**Study limitations**	**Overall score**
The systematic review aims to synthesise qualitative studies that report the experiences of caregivers of individuals (both adults and children) with intellectual disability and behaviour that challenges specifically on their experiences of receiving support services or interventions. **Country** Not clear. **Methodology** Systematic review. **Services of interest** Residential school. Residential placement. Short breaks/respite services. Community support. Day care services. **Source of funding** Not reported.	Professionals/practitioners. Carers/family members. **Sample characteristics** Adults. **Age** Caregivers age (when reported) ranged from 27–78. **Children and young people** **Disability** The majority of the included studies did not include information on the severity of intellectual disability. Of those reported (n=94) 67% were reported as having severe intellectual disability. Seven studies provided a description (n=173) of these 88 had an autistic spectrum disorder, 9 a rare genetic syndrome, 4 had Down syndrome, the remaining 72 had other types of physical disabilities or mental health difficulties, including	The only studies where parents consistently reported satisfaction with a service they and their family member received were those that were conducted by the service provider, which raises the question of potential conflict of interest when a service reports their own outcomes. This review is limited by the small number of papers meeting criteria. **Barriers identified** **Knowledge and skills** Training professionals and staff members to deal effectively with complex challenging behaviour is a difficult task. **Organisational structures/cultures** The structure of service systems was not conducive to collaborative working, and were instead cumbersome, time-consuming and tiring (p413).	++

	psychiatric disorders, epilepsy and 'other medical problems'. **Gender**: Total 87 carers were female, 13 male and 117 not specified. The majority of people with learning disability and behaviour that challenges (where reported) were male (male n=153, female n=69). **Ethnicity** Ethnicity was reported for 33% of the studies (n=129); 74% were of European origin, 8.5% of African origin, 6% Latino and 7% 'other'. **Relationship**: 140 participants were mothers, 26 fathers, 8 'other' (siblings, grandparents etc.) **Residence** Nine studies reported the permanent residence of the person with learning disability and behaviour that challenges (n=248), the majority resided in the family home (n=171), 42 lived in residential schools, 16 in residential	One carer said of their social worker: 'I think she does her best to within what limits she can go' (Qureshi 1992: 118). Carers could see that professionals were bound by the same bureaucracy as they were, and overall found the structure of service systems was not conducive to collaborative working, and were instead cumbersome, time-consuming and tiring. **Facilitators identified** **Family support** Carers felt that had they access to proactive and consistent support for their family member's challenging behaviour, rather than a reactive crisis management support, then severe episodes of challenging behaviour would be less frequent, and crisis interventions be utilized less frequently (p413). Support service rated highly were those that led to improvements in their family members' behaviour, which had a	

	care/ support facility, 19 lived in ‘other’ accommodation, including foster care and living with a roommate or partner. **Sample size** Total 391 caregivers participated. Systematic reviews: participants in number of studies –15 studies. **How do the groups differ?** N/A (not more than 1 group). **What methods were used to collect the data?** Focus group interview. One-to-one interview (face to face or by phone). Meta-ethnography synthesis. Self-completion questionnaire.	stabilising and cohesive effect on the entire family. **Proactive support** Services most appreciated by carers were those that were proactive and able to work with parents when problems arose. **Staff skills** Carers felt that all support services (from schools, to respite care, to day centres) needed to have an understanding of their family members’ challenging behaviour to support them adequately. Thus, all services needed to have an element of being a ‘challenging behaviour’ service. Professionals who took a personal interest in their family member were greatly appreciated by caregivers, and fostering this attitude could be emphasised in clinical training. **Facilitators** Griffiths (2014) – caregivers were deeply appreciative of ‘good‘	

		professionals, characterised by being proactive, genuinely interested in the wellbeing of their family member and communicated openly and honestly. High levels of satisfaction were reported for (staff and professionals with) high levels of expertise, collaborative working between carers and professionals, then family members behaviour was improving, having confidence in services being able to cope with challenging behaviour. **Access to support** Griffith (2014). Carers felt that if access to support was proactive and consistent rather than reactive then episodes of behaviour that challenges would be less frequent and severe. Page 12: Families were asked to wait in noisy waiting rooms, causing additional agitation to their family member, and staff lacked experience and skill: 'They	

		do not have psychiatrists trained to deal with this population' (Weiss et al. 2009: 357). **The future** Page 15: 'His future is such a big, dark thing so many things could go horribly wrong' (McGill et al. 2006b; 'I worry that he [would not be] well cared for, that's what bothers me, who would care for him?' (Hubert 2010: 222) 'We are looking, but like we said there is nowhere for our Mary to go. We can't really, they haven't told us, like when she's 40 or 30, where she's supposed to go' (Qureshi 1992: 117). 'I'd rather give him an overdose, then see him go in there [residential service] he'd be better off dead. What sort of life would he have? They're [other service users] suffering in there because they can't say any different you've got to think about the content of life, haven't you?' (Hubert 2010: 222). 'I'd like to have the guts to do her in, rather	

		than let her go there … she’s not going to have any life in there so she might as well be done in’ (Qureshi 1992: 117). ‘Ideally I would like him to be half an hour from home in a very small home looked after by familiar people where he is loved’ (McGill et al. 2006: 611). **Information** Page 14: 1 mother said: ‘I’m just thoroughly and continually amazed and appalled at the lack of information that the professionals have on autism’ (Ruef et al. 1999: 49). **Impact on carers** Page 11: ‘I’m not allowed to be a person, I’m just Penny’s mum that cares for her 24 hours a day’ (Qureshi 1992: 113). Carers also spoke of having little spare time: ‘Everything suffers because you haven’t got time for yourselves, any quality time because	

		everything centres on time for the child' (Brown, et al. 2011: 913). **Inclusion/isolation** Page 12: 'She [mother] was in prison virtually because of his behaviour, she couldn't even go out in the garden without him misbehaving. We didn't get any visitors, as they were too scared of him to come round. It was a lonely life' (Robertson et al. 1996: 86). 'It's growing up that has separated me with the outside world with Arturo, because you are limited to where you can go with him, because of his behaviour problems' (Fox et al. 2002: 447). 'I am so stressed, I'm just living without a life' (Allen et al. 2006: 359). **Love and respect** One mother said, 'my heart is always where he is ... I feel closer to him than to anybody' (Hubert 2010: 219 in Griffith 2014: 411). Nearly all studies explicitly	

		described love and desire for the best outcomes for their family member 'very little of the time did they ever speak to her (the family member) they would just talk to me about what she needed, but she is fairly high functioning ... I felt it was a respect thing. They would ignore her and talk to me. Love for family members helps carry parents through many of the difficulties of raising and supporting a family member with learning disabilities and behaviour that challenges 'he's a good wee soul. He's hard work, but he's worth it, you know, I wouldn't part with him' (Hubert 2010: 219 in Griffith 2014: 411). One mother said: 'He's a good wee soul. He's hard work, but he's worth it, you know. I wouldn't part with him' (Hubert 2010: 219). **Navigating care services** Page 13: 'It just seems over-whelming, and after years and years of fighting the bureaucracy,	

		and looking for services, and trying to get someone to listen, that we run out of energy after a while’ (Ruef et al. 1999: 50). ‘Find[ing] out what provision was available on our own, no-one offered direction or advice’ (McGill et al. 2006b: 606). ‘I feel that unless make a nuisance pester people to death, nothing is done’ (McGill et al. 2006a: 162). Support services were regarded as complex and cumbersome systems, and parents were often overwhelmed, with 1 parent describing arranging services for her son as ‘a full-time job in itself (Ruef et al. 1999: 50). **Personalisation of care** Griffith (2014: 411): there was frustration when support services did not provide the appropriate care or understand the needs of their family member (McGill 2006a, 2009; Quereshi 1992; Robertson et al. 1996; Wodehouse and McGill 2009).	

		One mother said ‘it’s like having mental tick boxes in their heads [the service providers] of autistic traits that don’t actually have any bearing, or fit in at all with what your son’s like’ (Wodehouse and McGill 2009: 649 in Griffith 2014: 411). Griffith (2014): carers felt that all support services needed to have an element of ‘challenging behaviour’ service. Carers felt that there were too often poorly trained staff trying to cope with complex challenging behaviours and there was a positive impact of receiving reliable and proactive support Page 413: ‘Nobody listens, I found out that professionals actually hold another meeting after I have attended an arranged meeting’ (McGill et al. 2006b: 606). **Respite care** Page 404: ‘Respite care couldn’t cope with her not sleeping so constant phone calls to come and pick her up as she would self-injure’ (McGill et al. 2006b: 604).	

		‘Once we were at the cinema and we were rung just before the film ended and we had to … go and pick him up’ (Wodehouse and McGill 2009: 650). ‘The pot-luck aspect of respite care … most effective tool for coping in my view is a national disgrace’ (McGill et al. 2006a: 162). ‘A joke, the only time you could get it was at times you didn’t really need it like a Wednesday evening. We needed it at weekends really’ (Robertson et al. 1996: 85). **Stress and strain** Page 412: Low-intensity but high frequency difficult behaviours could also be very challenging for parents: ‘When I am around him it is constant noise. He talks or squawks. By afternoon I am frazzled’ (Turnbull and Reuf 1996: 283). ‘It’s the most distressing thing possible to watch your child self-harming. As a mother, it kills you’ (Allen et al. 2006: 359). ‘I	

		was bruised all over, but the emotional pain was far more to cope with' (Allen et al. 2006:359). 'The ethical quandary faced by carers when using restrictive interventions themselves was also reported to be a significant emotional strain: 'It's a very fine line between whether it's right to restrain or wrong, and I'm not qualified to say' (Elford et al. 2010: 78). 'School were 'phoning saying "Can you come and pick him up? We can't cope." I just think Yeah it's me on my own here, you've got a whole team of people' (Wodehouse & McGill 2009; p. 650) **Staff skills** The Griffith review (2014) found lack of skilled support could mean that children and young people are excluded from school or other support services, leaving carers to cope at home for more hours with no additional support. (Hubert 2010; McGill et al. 2006b; Ruef et	

		al. 1999; Wodehouse and McGill 2009). **Transition** Page 415: Some carers struggled to get support services to prepare for the transition to adulthood support services: ‘We have tried to get them on board since he’s been 16 and a half asking why we had no input from the young adult team he is 19 soon and we have heard nothing’ (McGill et al. 2006b: 610). **Trust** Page 404: ‘I don’t mind if they let us know the truth [of why their son comes back with injuries]. Don’t try and cover up, let us know the truth. This is what you get right the way through. There is always somebody trying to cover up something somewhere, and it annoys me because I’d rather know the truth’ (Qureshi 1992: 116).	

27. Griffith GM, Hutchinson L, Hastings RP (2013) 'I'm not a patient, I'm a person': The experiences of individuals with intellectual disabilities and challenging behavior – a thematic synthesis of qualitative studies. Clinical Psychology: Science and Practice 20: 469–88

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To include the views and experiences of people with learning disabilities and behaviour that challenges who use services, as research has often been quantitative in nature. People's views and experiences are often overlooked by policy and research. **Country**: UK (n=12). USA (n=2). Canada (n=1). **Methodology** Systematic review. **Services of interest** Residential placement. **Time to follow-up**	**Participants** Children with learning disabilities and behaviour that challenges. Adults with learning disabilities and behaviour that challenges. **Sample characteristics** **Adults** **Age** Between 18–76 years. **Disability** Total 20 men with profound to severe ID and challenging behaviour. Gender: 105 male, 49 female, 9 not specified. **Sample size** Total 180 participants.	**Summary of findings** The evidence from the synthesis of themes indicate that people with learning disabilities and behaviour that challenges would most value proactive, preventive interventions to manage their behaviour than restrictive, reactive strategies. Relationships with staff can be important to provide encouragement and support. Participants wanted to be valued and respected as individuals. **Qualitative themes** **Choice and control** There was an imbalance of power between staff and service users. Participants often described authoritarian attitudes of staff 'I don't like people coming' in my	**Overall score** ++

No follow-up.	**What is the sampling frame (if any) from which participants are chosen?** N/A **How do the groups differ?** N/A (not more than 1 group).	room and tellin’ me what to do, sayin “Well you should do this and you should do that” [mimics authoritarian voice] (Reuf et al. 1999: 49). ‘They are drawing up my guidelines, they’ll tell me though, not ask me’ (Harker-Longton and Fish 2010: 147). Participants spoke of the frustration, injustice, helplessness and anger in living in a (forensic) environment in which they had little control (p477). Strict limitations on freedom ‘I can’t go out of the apartment, we get into trouble‘ (Reuf and Turnbull 2002: 131). There was also a high value placed on autonomy **Defining behaviour that challenges** Residential placements intended to support people in improving challenging behaviour were sometimes seen by participants as being the cause of challenging behaviour. **Environment**	

		Participants described their secure/forensic) environments as an unpleasant, sometimes violent atmosphere, a rather cold atmosphere. Inclusion/ Isolation: being ignored by staff left participants excluded and rejected as ‘interactive social beings‘ (Hubert and Hollins 2006: 71). **Staff skills** An imbalance of power was expressed. Attempts to communicate feelings and needs got little recognition or response from staff. A common reason given for engaging in challenging behaviours was frustration of not being listened to or feeling misunderstood (Fish and Culshaw 2005: 99) (on residential placements). Some support staff make no attempt to hide their negative moods and feelings, being described as rude, bad-tempered, authoritarian and ‘not bothered‘ (Clarkson et al. 2009). In a few	

		studies, participants talked about the positive impact of good relationships with staff who had good interpersonal skills and were respectful. **Trust** It took a long time to build trust in people, this was hard to establish, especially given the high staff turnover. ‘It feels strange them leaving and then other new staff come in and you have to get used to them’ (Clarkson et al. 2009: 286).	

28. Hall I, Yacoub E, Boast N et al. (2014) Secure inpatient services: a needs assessment. Journal of Intellectual Disabilities and Offending Behaviour 5: 38–53

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The project objectives were to: agree a definition set for what constitutes forensic and secure learning disabilities services; identify those originating from	**Participants** Professionals/practitioners. The 7 core reference group members were clinicians with experience of both secure care and community services,	**Service use** **Incidence** Patient has been involved in an incident in the last 6 months. Patient category (n=136) Yes, Yes % of patients in these settings.	**Overall score** +

London currently using secure inpatient services, and make a basic assessment of their needs; make predictions about the future need for secure services for people with learning disability; further understand the commissioning and provider landscape; and develop a commissioning strategy. **Mechanism for change** Identification of needs. **Service aims** Implicit. Secure inpatient care for people with learning disabilities and offending behaviour or severe challenging behaviour. **Country** UK. **Methodology** Survey.	including clinical directors and consultant psychiatrists for people with learning disability from a range of services in London. **Sample characteristics** **Adults** All people in secure care for people with learning disability. **Gender** Identified: 170 male, 49 female, 30 gender unknown, 101 patients identified but not included in analysis (51 males; 20 females; 30 gender was not provided); 148 complete data sets collected (119 males;29 females); 136 data sets underwent full analysis (109 males; 27 females). **Health status** Class of drug used (maximum). Number (%) Class A(a) 19 14 Class B(b) 28 20.6 Class C 0 0 No history of drug misuse 85 62.5 Alcohol misuse 40 29.4 No information available 4 2.9 Notes: (a) most commonly heroin, crack cocaine and	High secure (8) 7, 87.5. Medium secure – forensic (40) 30, 75.0. Medium secure – forensic and CB (5) 4, 80.0. Low secure – forensic (38) 26, 68.4. Low secure – CB (20) 18, 90.0. Low secure – forensic and CB (7) 6, 85.7. Not requiring HSU, MSU or LSU (18) 15, 83.3. Totals (136) 106, 77.9. **Length of hospital stay** Length of stay for current spell of care Patient type (n=136) Maximum length of stay (years), average length of stay (years) High secure (n=8) 24.9 12.1 Medium secure – forensic (n.=40) 30.1 4.8. Medium secure – forensic and CB (n=5). 16.0 6.7. Low secure – forensic (n=38) 35.4 7.9 Low secure – CB (n=20) 12.8 5.3. Low secure – forensic and CB (n=7) 9.5 4.7 Not requiring HSU, MSU or LSU (n=18) 12.3 4.2 NHS overall 29.3 5.0 Independent service provider overall 35.4. 6.1 Male overall 35.4 5.9 Female overall 30.1 6.9	

	cocaine; (b) most commonly cannabis. **Ethnicity** Number % White British 66 48.5 White Irish and other 11 8.0 Black Caribbean 20 14.7 Black African 10 7.4 Black other 7 5.1 Black dual heritage 11 8.1 Asian Indian, Pakistani and Bangladeshi 5 3.7 Other and missing 6 4.4 Total 136 100 compared to 2001 census Ethnicity 2001 census for London (%) Our study (%) White 71 56.5 Black 11 27.2 Asian 12 3.7 Source: Bartlett et al. (2007). **Level of need** Diagnoses Number % Mental illness 70 51.5 Personality disorder 45 33.1 Pervasive developmental disorder/autistic spectrum disorder 37 27.2 Other(a) 43 31.6 Notes: includes ADHD, epilepsy, Tourette's syndrome and genetic disorders, e.g., Klinefelter's syndrome. Degree of intellectual functioning (including IQ bands) Number %	**Summary of findings** The reference group found there was a greater need for low security than medium security. Most of the patients requiring medium secure care (45) required forensic type care, which is consistent with the offender patient status of these inpatients. The situation was further complicated by joint commissioning arrangements for services for people with learning disabilities between health commissioners and local authorities. The local authority was usually the lead agency, so that the person responsible for commissioning secure beds for people with learning disability may have limited expertise in the area of health provision generally and forensic secure services in particular. However, local authorities have more expertise in commissioning step down facilities and community services. The review of the provider landscape shows that there is a severe insufficiency of low secure beds in the NHS, with many people placed a considerable distance away from home. Different types of care should be integrated so that patients can progress to less restrictive settings ('step down') as soon as is appropriate for their needs. **Barriers identified**	

	70-75a 10 7.4 50-69 mild 94 69.1 35-49 moderate 16 11.8 20-34 severe 6 4.4 Missing 10 7.4 Note: (a) Patients with significant impairment of social functioning and likely impairment of intellectual functioning allowing for the standard error of measurement of the IQ test. **Residence** Patients were a mean distance of 61.5 miles from home (NHS 12.1 miles; independent hospital 71.3 miles; F=29.14 (1, 134), p<0.001). Within NHS facilities no patient was more than 27.2 miles away from their home unless in the national high secure service. Within the independent sector 59 inpatients (82%) were over 50 miles away from home. Overall, 101 patients (70%) were in contact with a family member who was based in London. Total length of stay in hospital for current spell of care, patients were first admitted to hospital under section for an average of 6.4 years. Length of stay in	**Study limitations** The authors were unable to persuade some professionals and organisations to allow data collection, sometimes because of limited data held by commissioners, concerns about consent and both client and commercial confidentiality. It was impossible to get any response from other stakeholders. The analysis is skewed towards people with learning disability in medium secure units as opposed to those in low security. The majority of cases identified but not included in the analysis for lack of data were cared for by independent service providers. Reporting bias. Some information was collected via interviews with members of the treating multidisciplinary team, e.g., that relating to current progress. This type of information is subject to a reporting bias and may lack objectivity, particularly if a staff member wanted to provide a particular impression of their hospital and the quality of care provided. Description of services. There was some degree of inconsistency in the descriptions of services and patient groups provided by service providers. Valid comparisons between hospitals may be made more difficult by different hospitals using terms such as ‘long term’, and ‘rehabilitation’ differently. Even differences in the physical security	

	current admission Patient type (n=136) Maximum length of stay (years) Average length of stay (years) High secure (n=8) 8.9 2.6 Medium secure – forensic (n=40) 15 2.6 Medium secure – forensic and CB (n=5) 3.4 1.4 Low secure – forensic (n=38) 18.3 3.5 Low secure – CB (n=20) 6 3.1 Low secure – forensic and CB (n=7) 5.9 2.7 Not requiring HSU, MSU or LSU (n=18) 9.8 2.7 NHS overall 17.4 2.5 Independent service provider overall 18.3 3.2 Male overall 18.3 3.0 Female overall 9.8 2.5. **Characteristics of behaviour** Only a small number were thought to require the physical security of a medium secure unit. In respect of high secure care the reference group findings can be summarised as an estimated need for 1 less high secure placement. Only 31.6% of patients had been convicted of an index offence. Behaviour leading to admission Type of behaviour leading to admission Male (n=109)n %	provided existed between different 'low secure' hospitals. The data collected also conflates a range of wards and settings, particularly in more generic hospitals which provide a range of services to people with learning disabilities. Lack of prison data. We had originally hoped to include data from a regional prison needs assessment for people with a learning disability, but unfortunately this separately managed project did not go ahead. Inclusion of this group would have been helpful as there is likely to be a proportion who would benefit from temporary or long-term transfer for inpatient rehabilitation. (the people identified are those who are already in the secure care system, and may not represent those who have not been convicted, or charged with an index offence).	

	Female (n=27)n % Total patients (n=136)n % Arson/arson with intent 7 6.4, 4 14.8, 11 8.0 Sexual offences 28 25.7, 0 0, 28 12.8 Violence and threats 38 34.9, 6 22.2, 44 28.5 Acquisitive offences 7 6.4, 2 7.4, 9 6.9 Challenging behaviour 22 20.2 , 13 48.1, 35 34.2 Other risk to self/others 9 8.2 , 2 7.4, 11 7.8 **Service use** Regarding the type of care need, the predominant need was for forensic type services (66.1% for the men, with an additional 12.8% of mixed forensic and challenging behaviour inpatients); 64 patients cared for by NHS 72 patients cared for by an independent service provider. 10.3% patients in a locked ward/security not defined; 1.5% patients on a PICU ward; 34.6% patients in low secure conditions 44.9% in medium secure conditions 8.8% in high secure conditions Security level required by gender Male n=109 Male (%) Female n=27 Female		

	(%) High secure M8 7.2 F0 0 Medium secure M37 33.9 F8 29.6 Low secure M51 46.8 F14 51.8 Locked ward M9 8.3 F1 3.7 Open ward M3 2.8 F1 3.7 Community M1 0.9 F3 11.1. Length of stay for current spell of care Patient type (n=136) Maximum length of stay (years), Average length of stay (years). High secure (n=8) 24.9 12.1 Medium secure – forensic (n=40) 30.1 4.8 Medium secure – forensic and CB (n=5) 16.0 6.7 Low secure – forensic (n=38) 35.4 7.9 Low secure – CB (n=20) 12.8 5.3 Low secure – forensic and CB (n=7) 9.5 4.7 Not requiring HSU, MSU or LSU (n=18) 12.3 4.2 NHS overall 29.3 5.0 Independent service provider overall 35.4 6.1 Male overall 35.4 5.9 Female overall 30.1 6.9. **Sample size** Authors identified 249 patients from 6 NHS and 21 independent sector providers. Data was collected on 148 patients. 136 were judged by		

	the reference group to have a learning disability. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).		

29. Harris J (2010) The use, role and application of advanced technology in the lives of disabled people in the UK. Disability and Society 25: 427–39

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The objectives of the research were to explore the challenges, barriers and facilitators to acceptance and acceptability of advanced technological devices designed to assist and support independent living (p429). **Service aims** Advanced technology to	**Participants** Professionals/practitioners: users, designers, engineers and service providers at the Innovation Day. Carers/family members: personal assistants and families in the User Clubs. Adults with disabilities. **Sample characteristics** **Level of need** Quota sampling strategy ensured that people with physical, sensory or multiple impairments, learning	**Summary of findings** **Barriers identified** **An ordinary life** Depending upon/taking advantage of family help to learn. **Knowledge and skills** Participants stated their need for technology that already existed, showing that they lacked up to date knowledge about it. **Barriers to learning**	**Overall score** -

increase independence in and beyond home. **Country:** UK. **Methodology** Qualitative study. **Mechanism for change** Use of technology. **Source of funding** Economic and Social Research Council, award no. RES-062-23-0177. **TYPES OF SUPPORT** Assistive technology **Time to follow-up** No Follow-up	difficulties, mental health issues and/or chronic illness could participate. **Sample size** Total 45 individuals plus user clubs (n = 7) and focus groups (n=4) , in which 31 disabled people, personal assistants and family members collectively formed opinions concerning advanced technology usage. **How do the groups differ?** Not applicable (not more than 1 group). **What methods were used to collect the data?** Focus group interview, one-to-one interview (face to face or by phone).	Time (2), patience (2,) costs, connecting older and new devices, learning to use the functions on new items, lack of on-going support, non-compatibility of software. **Knowledge/capacities Assumptions by designers** **lack of flexibility/ adaptability** An 'unusable instruction' given to 1 user for a telephone that was hands-free was to plug it into a mains sockets to recharge at night, but the user could not do this independently. Difficult to understand instructions/manuals (5), usable instructions or there were Specific problems with: reading instructions (2) concentration, prefer human instruction (2). **Technology not currently available** Examples given were: facial expression controlled electric wheelchair, a small, light conference folder (portable loop system), an 'emotions clock' for autistic children who do not speak and a light and portable 4-wheeled walker, cheap and useable videophone so that deaf people can sign to each other, a device that translates the spoken word into text instantly on a phone	

		and for cinemas to caption (subtitle) all films. A machine that converts speech to text without going through the medium of a palantypist or human operator. A solar powered battery for a ‘talker’ (communication device), as the batteries are constantly wearing down, several devices for gardening, a multiple-use device that could enable a wheelchair user to turn small knobs, e.g. heating controls or light switches, via a long pole mounting. Voice activated fully automatic car was also desired, but the current models all require some degree of hand control. **Technology not working as it should** Most participants who used voice recognition software were excited at the possibilities for communication purposes using computers, however, several reported that the software made copious errors and the process could be laborious, particularly in training the device. Only engineers or speech therapists knew how to enter new words, thus limiting the independence and creativity of the user. **Training and support**	

		There was a lack of training and support in how to use the technology. Training was rushed, or poor from: provider (2) family, technician, no training/support (7), or the costs were too expensive. **Facilitators identified** **Family Support** Family help with learning valued (5). **Training and support** Good training from: provider (3), employer, social worker, electrician, technician (3), online peers, friends (4), helpline (3), helpers at respite care centre, charity, speech therapist (3)	

30. Hassiotis A, Guinn A, Tanzarella M et al. (2015) Community-based services for people with intellectual disability and mental health problems: literature review and survey results. London: The Royal College of Psychiatrists

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This review summarises the current evidence on existing community service models for adults with	**Participants** Professionals/practitioners - Members of the Faculty of Psychiatry of Intellectual	**Clinical outcomes** **Function** Outcome measures are not used routinely, but the Health of the Nation	**Overall score** -

intellectual disability and mental health, behaviour or forensic problems and reports the findings of a survey of community-based psychiatrists. For our review we are only including the findings of the survey of practitioner views, as the relevant studies in the literature review have already been screened as part of our review. **Service aims** The treatment and care of people with intellectual disability and a mental health condition in the community. **County** UK. **Source of funding** Not reported. **Methodology** Survey (we only included the survey part of the review). **Services of interest** - Community support. - Content/ components of service. - Assessment reports and	Disability at the Royal College of Psychiatrists. **Sample characteristics** **Relationship** Consultant psychiatrists with the psychiatry of intellectual disability as their main specialism. **Residence** There was a good geographical dispersion of respondents from across England, with the top 4 areas by number of respondents being the South East (14%), West Midlands (14%), Yorkshire (12%) and North Central/North East London (12%). **Sample size**: n=65	Outcome Scales for People with Learning Disabilities (HoNOS-LD) tool was by far (78%) the most commonly completed. This is followed by the Aberrant Behaviour Checklist (27%). **Behaviour that challenges** Total 27% of respondents used the Aberrant Behaviour Checklist (Aman et al. 1985) as an outcome measure. **Qualitative themes** **Access to support** Increased access to mainstream mental health services and growing awareness of intellectual disability within these services. A variety of opinions were offered in this survey regarding the service developments respondents felt would be important for their local area: increasing numbers of intensive support teams and greater integration – developing more robust community services and assertive outreach services to meet the needs arising from decommissioning of inpatient services. **Navigating care services** A small majority of respondents were aware of local care pathways related to mental health services for adults with intellectual disability (58%). In total, 26	

intervention plans. - Crisis prevention and management.		respondents specified which local care pathways they were aware of: 8 respondents mentioned pathways related to joint working of mental health and intellectual disability teams; 7 respondents mentioned dementia/memory assessment pathways; 5 mentioned challenging behaviour pathways; and 1 respondent was aware of an autism pathway. **Working together** The majority of services (71%) were not integrated with social care, except for London, where teams integrated with social care (69%) outnumbered those who are not (31%). Integration differed markedly by area. In the North, only 8% of teams were integrated with social care. Likewise, only 20% of teams in the South and Midlands areas were integrated. The majority of services offered liaison with mainstream mental health services (61%). This was true of all regions except the Midlands, where the majority of services did not offer mental health liaison. **Community service use** The most common model for community intellectual disability teams was the generic community intellectual disability	

		team (84%). Next were specialist challenging behaviour services (21.5%), stand-alone mental health intellectual disability teams (16%) and neurodevelopmental disorders services (16%). the majority of teams (70%) categorise themselves under 1 particular model. 17 teams had multiple functions. **Barriers identified** **NHS commissioning practices** Community intellectual disability service need to be more outcomes-focused and commissioning should encourage this approach. **Summary of findings** The survey findings provide a current picture of how community based services are provided for people with intellectual disabilities. The survey finding show that there is geographical variation in the integration of health and social services: London is more integrated and other parts of the country are less integrated. Challenging behaviour teams are the most common specialist type of community service. The most commonly reported care pathways are those for the care of people with dementia and people with challenging behaviour. Outcome measures are not used routinely, but the	

		Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) tool was by far the most commonly completed. In terms of future service provision, consultant psychiatrists thought these 3 areas would be important to their local area: increase in the number of intensive support team and greater integration; increase access to mainstream mental health services and developing more robust community services and assertive outreach services to meet the needs arising from decommissioning of inpatient services. The survey findings suggest that community intellectual disability services are key in supporting people with intellectual disability in their homes and local communities. However, they need to be more outcomes-focused and commissioning should encourage this approach. Commissioners and providers need to work in partnership to create local community-based services that are personalised, effective and safe. More research is needed into the effective components of community intellectual disability service models and care pathways for adults with mental health, behavioural and forensic problems in reducing the use of inpatient services.	

		Implementation issues More research is needed into the effective components of community intellectual disability service models and care pathways for adults with mental health, behavioural and forensic problems in reducing the use of inpatient services. **Study limitations** This survey is limited because of a low response rate (20%) making the findings difficult to generalise. It also covers mental health service for people with intellectual disabilities and doesn't focus specifically on people that exhibit challenging behaviour, making it difficult to identify the elements of current services that are relevant to the that specific population. Also the survey did not take into account services where more than 1 consultant worked in a community team.	

31. Hatton C, Emerson E, Kirby S et al. (2010) Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and family impact. Journal of Applied Research in Intellectual Disabilities 23: 63–74

Research aims	Study characteristics	Outcomes and findings	Overall validity rating

Study aim To understand family carers' perceptions of the causes or meaning of behaviours that the carer considers to be challenging, and the impact of these behaviours on the family. To document family carers' experiences of existing service supports, and what supports would best meet the family's needs. To explore the extent to which family experiences may differ within and across ethnic groups. **Service aims** Not stated. **Source of funding** Health authority, Preston NHS Primary Care Trust (now part of NHS Central Lancashire). **Methodology** Qualitative study. **Country** UK. **Services of interest**	**Participants** Carers/family members. **Sample characteristics** Adults. **Age** The age of family carers ranged from 33 to 70 in the minority ethnic (MIE) group and from 36 to 53 in the majority ethnic group (MAE). **Ethnicity** Total 7 carers were from minority ethnic groups; 6 preferred to be interviewed in Gujarati and 1 preferred Urdu/Punjabi. **Residence** All lived in the same city in Northern England. **Socioeconomic position** On the basis of decile scores, where 1=most deprived and 10=least deprived MAE group, 1 family was in decile 1 and 6 families were in decile 2. MIE group, 2 families were in decile 1; 2 families were in decile 2; 2	**Caregiver satisfaction** Page 6: Family carers reported widely varying views of local services, although difficulties with service supports were more commonly reported than positive experiences of services. Page 7: Family carers from minority ethnic communities were more likely to report negative experiences of service support, which was compounded by all minority ethnic families reporting that services did not communicate with family carers in their preferred language. **Qualitative themes** **Access to support** Many families reported a constant sense of struggle to get and keep service supports at all. If support services had been used, they were often reported as being of limited use in terms of their timing, duration, flexibility and relevance, and constant changes in service staff, service delivery and regulations were a source of great frustration and uncertainty to family carers. 'MIsd4: We have had absolutely no support or services whatsoever for the last 8 years. It was just until recently that after a second social worker got involved we have started to find out what services are available, so we have just started tapping into services	**Overall score** ++

- Person-centred active support (PCAS) - Content/ components of service. - Family counselling and support.	families were in decile 4 and 1 family was in decile 9. **Characteristics of behaviour** MAE group – 5 families the adult with intellectual disabilities was identified by the service as displaying challenging behaviour. MIE group – 5 families the adult with intellectual disabilities was identified by the service as displaying challenging behaviour. **Sample size:** n=14 family carers, n=7 from minority ethnic groups, n=7 from majority ethnic groups.	now. We just didn't know anything' (p23). Family carers reported widely varying views of local services, although difficulties with service supports were more commonly reported than positive experiences of services. Many families reported a constant sense of struggle to get and keep service supports at all. If support services had been used, they were often reported as being of limited use in terms of their timing, duration, flexibility and relevance, and constant changes in service staff, service delivery and regulations were a source of great frustration and uncertainty to family carers. Family carers also report being isolated from local services that are helpful; family carers may be unaware of local services, or local services inaccessible due to limited hours of operation and them not being available in the preferred language of the family carer. Often, these family carers report that services are not available to support them in their role as carers, and that support to improve the difficulties of the person with intellectual disabilities is absent or ineffective. **Defining behaviour that challenges** Behaviours likely to be identified as challenging behaviour by support services	

		were only 1 aspect of problematic behaviour for family carers, who viewed a much wider range of behaviours as difficult within the ongoing social context of family life and often framed these behaviours in attitudinal, personality or motivational terms, such as impatience, a need for routine, or a desire to cause conflict. **Family life** There is a much broader range of problematic behaviour, than those identified as ‘challenging behaviour’ by support services, such as those framed in attitudinal, personality or motivational terms, such as impatience, a need for routine, or a desire to cause conflict. Families also commented about a ‘constant need for supervision’. ‘The rest of the family try to mix in, but B doesn’t want to mix in with them. She doesn’t talk to anyone or won’t look at anyone face to face. If the family are all sat together in a group, she will stand up and walk away and if you call her she won’t respond. She likes to do her own thing and not get involved with everyone else. If someone says anything to her or tries to help her, she snaps back and gets angry’ (participant) (p67). All the family carers in the study reported aspects of the adult with intellectual disabilities that presented a challenge to	

		family life. Some family carers also mentioned the potential negative impact of the adult(s) with intellectual disabilities on other family members, although these negative impacts could occur within a generally positive picture of family relationships. **The future** Family carers with negative experiences reported a lack of confidence in the future and a feeling that the situation was only going to get worse over time (p69). **Health and wellbeing** Although family carers felt they should be able to accept this situation as it is, carers report poor physical health and a sense of distress, worry and desperation. **Impact on carers** Relationship between person with intellectual disabilities and family carer. Many carers felt that the adult with intellectual disabilities was completely dependent on them. This often left carers feeling that they always had to put the needs of the adult with intellectual disabilities before their own needs, and that carers were trapped with no life of their own. (Participant): ‘I used to work before, but then my daughter’s problems got worse so I had to leave. So for about 10–12 years I	

		have been at home ... Since I have left my job I have been in the house and so a person becomes fed up with being indoors all the time, don’t they? If we are outside working, we get to sit and chat with friends and I don’t get the opportunity to do that any more’ (p69). Page 69: Many carers felt that the adult with intellectual disabilities was completely dependent on them. This often left carers feeling that they always had to put the needs of the adult with intellectual disabilities before their own needs, and that carers were trapped with no life of their own. Family carers reported a number of negative consequences of these dependent relationships, including poor physical health, psychological problems, feelings of powerlessness, and a negative impact on employment prospects and family finances. **Inclusion/isolation** Family carers varied in their relationships to local communities, with some of the minority ethnic group families in particular reporting negative perceptions of the extent to which they were accepted by the local community. Yet, some families did get some highly valued emotional and practical support from neighbours, friends and family. **Navigating care services**	

		Many families reported a constant sense of struggle to get and keep service supports at all. If support services had been used, they were often reported as being of limited use in terms of their timing, duration, flexibility and relevance, and constant changes in service staff, service delivery and regulations were a source of great frustration and uncertainty to family carers. **Respite care**	

		‘Respite services do help, they calm them [3 children with disabilities] down and help them change their mood. But N is always happy there so I can’t complain. She seems very happy there, they take her out to movies or something and help her mood so I do think they are very helpful ... Respite is always so helpful, every time’ (participant 5) (p69). **Seeking help** ‘If you talk to people in your own community, they laugh at you and make jokes about your situation so you cannot talk to anyone even in your own Gujarati community and discuss the problems you have with your children. Sometimes it feels very difficult to be part of such an Asian community too whereas no matter how much one talks someone in the English community they do not mind at all.’ (p23). **Stress and strain** Family carers who were receiving support from family, friends and services reported a more positive outlook. **Staff skills** ‘The problems would tend to occur when you’ve passed him [son with disabilities] on to somebody else to care, that’s what we worry about. We had 2 occasions, 1 where a career came in here from domiciliary in-	

		house support, obviously the person hadn’t been properly trained and she locked K in the observatory, when we came back she said I’ve put him in there with his radio and you’re horrified at the things people do’ (p69). ‘At the minute the learning disability team, our nurse has been off sick so that’s all falling down and we haven’t had any support like that since B has been 5. So we didn’t have anything all that time and then we finally get something. She been 3 or 4 times, not done that much with us and now she’s off sick. So we are left with nothing new’ (MAsd5)(p69). **Trust** Negative experiences of service support resulted in some family carers reporting a lack of a trusting relationship with services and service professionals, a mistrust that sometimes extended to the research interviewers and the aim of the research project (p69). ‘See in the last 12 years, so many social workers and support workers came to help us. To solve the problem of our son, yet it has not been solved. How can we believe in you? You are only going to do the research; you are only interviewing us and then send our problems on to someone else’ (MINsd2) (p69).	

		Summary of findings The analysis of family carers' interviews generated a single set of themes and a single model that seemed to readily account for the experiences of families from both minority and majority ethnic communities. 4 major themes emerged: 1. Challenge to family life – much broader range of problematic behaviour, than those identified as 'challenging behaviour' by support services, such as those framed in attitudinal, personality or motivational terms, such as impatience, a need for routine, or a desire to cause conflict. Constant need for supervision. 2: Relationships to local community – family carers varied in their relationships to local communities, with some of the minority ethnic group families in particular reporting negative perceptions of the extent to which they were accepted by the local community. Yet, some families did get some highly valued emotional and practical support from neighbours, friends and family. 3. Relationships to services – family carers reported widely varying views of local services, although difficulties with service supports were more commonly reported than positive experiences of services. Many families reported a constant sense of	

		struggle to get and keep service supports at all. If support services had been used, they were often reported as being of limited use in terms of their timing, duration, flexibility and relevance, and constant changes in service staff, service delivery and regulations were a source of great frustration and uncertainty to family carers. 4: Relationship between person with intellectual disabilities and family carer – many carers felt that the adult with intellectual disabilities was completely dependent on them. This often left carers feeling that they always had to put the needs of the adult with intellectual disabilities before their own needs, and that carers were trapped with no life of their own. While the themes were consistent for both minority and majority ethnic communities, there was a difference when it came to ‘negative’ and ‘positive experiences. The minority ethnic group families (5/7) gave accounts of their experience that reflected very closely the negative picture of family experience, and the other 2 minority ethnic group families gave accounts of their experience that were either mixed or positive (these 2 families were living in comparatively affluent neighbourhoods). **Study limitations**	

		This relatively small sample of family carers (n=7) from minority ethnic communities resulted in a matched sample of majority ethnic group family carers that was less diverse in terms of socioeconomic position and service defined challenging behaviour than the researchers initially hoped to obtain. Although the analysis suggested some variations in family experience according to both ethnicity and socioeconomic position, more diversity within the study sample would have provided more confidence that these variations were robust. In common with all qualitative research, a second limitation of the study concerns generalisability. This study was focused within a specific urban location in Northern England and the themes generated, although highly consistent both within the sample and with previous research, may not readily generalise to other locations and times.	

32. Inchley-Mort S, Hassiotis A (2014) Complex Behaviour Service: Content analysis of stakeholder opinions. Advances in Mental Health and Intellectual Disabilities 8: 228–36

Research aims	Study characteristics	Outcomes and findings	Overall validity rating

Study aim	**Participants**	**Social care outcomes**	**Overall score**
To find out what service users and carers think of a complex behaviour service, based on positive behaviour support principles. **Service aims** Deliver interventions based on positive behaviour support (PBS) and reactive techniques that do not include physical restraint. The service is also fully integrated within the community intellectual disability service with staff working across team boundaries. **Country** UK. **Services of interest** Positive behavioural support. Included as part of an enhanced service. Peripatetic specialist challenging behaviour (intensive) support: the service consisted of a team made up of 2 part-time clinical psychologists, a behavioural support worker and an assistant	Carers/family members: included paid and family carers. Administrators, commissioners, managers, support staff – managers of supported living accommodation and professionals – care managers. Adults with learning disabilities and behaviour that challenges: service users were all adults receiving support from the CBS. **Sample characteristics Adults** All participants were aged 18 years and over. **Age** Mean age of the carers/informants was 41.7 years (sd=11.33, range=27–62). Service users: mean age of 23.8 years (sd=5.57, range=19–31). **Disability** N=5 mild intellectual disability; n=1 moderate intellectual disability. **Gender**	**Quality of life** The majority of participants reported improvement in quality of life even in the absence of an obvious decrease in behaviour difficulties (p234). **Clinical outcomes** **Behaviour that challenges** The majority of participants reported improvement in behaviours even in the absence of an obvious decrease in behaviour difficulties (p234). 'Change in level and frequency of challenging behaviour was reported in many cases by carers, and changes in service user response to situational triggers were occasionally linked to the decrease in behaviours perceived as challenging. In some cases, following decrease in challenging behaviours the service user was described as having changed as well: "There is less damage in the house. The service user now thinks ok I am going to get violent ok I am going to walk away" (mother, 46) (p233). "If you look at the incident reports from previous placement cared to how the service user is now it is like 2 completely different people it really is amazing" (Social worker, 49)' (p233). For service users change was seen in the	++

psychologist, all trained in positive behaviour support. Offered, e.g., functional analysis of behaviours, proactive strategies for managing it and aimed to improve quality of life (Carr et al. 1999; LaVigna and Willis 2012) and non-restraint-based reactive strategies. Other techniques used included social stories, anger management, support to bring people back into their home borough and restraint removal. Further details of the service structure are described in Inchley-Mort et al. (2014). **Content/ components of service** Behavioural support plan, case management, peripatetic behavioural advisors. **Source of funding** North Central London Research Consortium (NoCLoR, grant reference 2C10). **Methodology** Qualitative study. **Time to follow-up**	Service users: n=5 male; n=1 female. Carers/informants: n=8 male; n=17 female. **Health status** N=1 service user had been diagnosed with autism prior to the study. **Level of need** All service users exhibited challenging behaviour: n=5 mild intellectual disability; n=1 moderate intellectual disability. **Relationship** N=8 parents, n=9 support/key workers, n=3 managers supported living, n=5 professional care managers. **Residence** N=2 service users lived at home, n=4 service users lived in supported accommodation. **Sample size** N=6 service users, n=25 carers (including paid and family carers, support staff and professionals). **Treatment of groups**	frequency of the incidents they were referred for and also in their responses to their environment: ‘cos I am calmer, yeah, cos I am not in problems no more. I am not in fights. um, if I had problems and stuff, if I got into issues with my mum or family and we talk about it and then that is when it will calm me down’ (service user, 46). ’My manger has got a lot better” (service user, 59)’ (p233). **Satisfaction** **Satisfaction with care** ‘Overall both the informants and service users stated they were satisfied with the service despite a minority of negative comments about the CBS’ (p234). ‘It appears that the targeted focus on challenging behaviour as provided by positive behaviour support is acceptable to both service users and paid and family carers of people with intellectual disability and challenging behaviour. The majority of the informants appreciated the flexibility and availability of a service such as this’ (p235). **Qualitative themes** **Access to support** When the service was experienced as unavailable this was linked to disappointment and falling short of	

No follow-up.	Interviews were held with both service users and carers. The topic areas covered was the same for each group.	expectation, 2 carers reported feeling this: '... to get CBS (complex behaviour service) is difficult. We called many times I think but I don't think that CBS got back to us (Support worker 28)'. 'I think I was expecting more input' (social worker, 40). In addition, 2 service users found that it was difficult attending all appointments with CBS potentially suggesting that, unlike carers' reports, the contact frequency was too high for them: '... I don't know how long I saw her for but it was for a little while' (service user, 24).' 'I was meant to see him yesterday but I keep forgetting to see him [...] (Service user, 46). (p231). 'This was a recurrent theme brought up by the carers that was frequently linked to the level with which they felt supported by the service. Carers described frequent contact across various mediums (face to face, e-mail, phone calls) and security in knowing that the service was continuously available to them in between appointments if concerns arose. The team comprising the enhanced service was flexible and responsive to carers in crisis: "If we needed anything we could just ask for it and for help" (mother, 23)' (p230). 'Several interviewees stated that they would like longer involvement with the enhanced service. However, ongoing and	

		responsive engagement was construed in both positive and negative ways' (p233). **Impact on carers** 'In one case, behaviour frequency did not decrease, however, change in understanding the service user's need for the action led to greater acceptability and lower levels of subjective carer distress in response to the behaviour: if this is something that he needs to do then it is something that we will support him with [...]. This is because we have seen that it causes great discomfort if he is not able to carry out this behaviour' (support worker, 60) (p233). 'Change was also noted in the carers feeling less anxious and more able to cope: […] "the fact that someone is coming, I do not panic" (Mother, 25)' (p233). 'CBS not only helped him but I feel like they have done therapy with me too as I am now able to cope with things. […] People now seem to be happy to work with the service user. I think that they know how to relate to him without being scared (mother, 58)' (p233). **Love and respect** Carers mentioned talking with the enhanced service staff about their current context and own responses to certain behaviours, and also the power of communicating respectfully with the service	

		user: ‘I think that we spent a lot of time talking about my feelings (Mother, 42)’ (p232). ‘I think that the service user had someone in his life that really showed respect and demonstrated that respect every time […] I think that made the service user feel like a grown up and realise the way he wants to be treated by people (care manager, 42)’ (p232). **Costs?** No. However, the researchers say ‘this study took place over 2 years and involved considerable financial cost and professional time and therefore as Bonell et al. (2011) discussed it is unlikely this level of service user and stakeholder consultation will be feasible for all new services implementing new interventions and services’ (p235). **Barriers identified** **Level of need** Two carers felt dissatisfied in their expectations of the service which they had linked with severity of the challenging behaviour displayed: […] ‘I was probably expecting a lot more. I do understand the fact that the service user’s behaviours are not bad […] and therefore he wasn’t given priority (care manager, 40)’ (p234). **Organisational structures/cultures** Carers alluded to difficulties linked to the	

		enhanced service itself, e.g. completion of tasks given by the enhanced service to care staff such as monitoring forms; language barriers between CBS and a family member, change in supported living management; staff not following the guidelines put in place: ‘So we were filling in these forms everyday over maybe a month or so (manager, 24)’ (p234). ‘If the ward staff followed the guidelines […] I think that the service user’s challenging behaviours would reduce (support worker, 45)’ (p234). One carer found the guidelines put in place by CBS challenging due to their length and suggested a quick reference version to address this (p234). **Facilitators identified** **Family involvement in care planning** ‘Talking about behaviour and being listened to’ was 1 of the main themes that came out of the interviews. Talking and listening in a way that made the interviewee feel heard was linked to supportive or positive, experiences of the service and was reported as a form of intervention/support for the service user and the carer. Carers mentioned talking with the enhanced service staff about their current context and own responses to certain behaviours, and also the power of communicating respectfully with the service user: ‘I think	

		that we spent a lot of time talking about my feelings (Mother, 42)' (p232). 'Multiple carers reported feeling that their ideas and ways of working were requested, heard and utilised by the service; in these cases carers positively connoted the service: "When CBS and I spoke near the beginning I said that I felt that the service user was particularly responsive to pictures and images […] CBS listened to this and this was shown in the work that CBS did" (mother, 58)' (p232). In 1 case, where the carer did not feel listened to it was clear that this underpinned her overall experience of the service: 'I was against it immediately but I wasn't listened to (mother, 48)'(p232) **Ways of working** Being understood 'was a central concept in relation to the service user and his/her behaviour, and also of the carer. Where understanding was achieved, interviewees described a positive experience of the service: "It is always good to know that your concerns are understood" (support worker, 43)' (p232). The majority of paid carers also felt that the work carried out by the CBS allowed for challenging behaviours to be understood, interpreted and explained in a way that was meaningful to them. An example is the statement by support staff that behaviours could be understood as	

		communicating something: ‘Before this I didn’t know that behaviour could be communicating something or have a meaning (care manager, 40)’ (p232). **Summary of findings** Overall both the carers/informants and service users said they were satisfied with the service despite a minority of negative comments about the CBS. Positive experiences of the service were linked to: - talking and listening in a way that made the person feel heard - carers feeling that their ideas and ways of working were requested, heard and utilised by the service - the CBS allowing for challenging behaviours to be understood, interpreted and explained in a way that was meaningful to paid carers - the level and response of contact with the CBS - in-depth analysis of behaviours and discussion with wider networks. Negative experiences of the service were linked to: - involvement or engagement with the CBS ending too soon	

		- carer’s expectations of the service, which they had linked with severity of the challenging behaviour displayed. The positive and negative experiences of care, reflect what service users and carers say about what they like and don’t like about positive behaviour support services, and could be considered by service providers when creating acceptable and useful services for people with learning disabilities and behaviours that challenge in the future. **Implementation issues** While the need for service user and carer involvement in service development and evaluation has been widely recognised (Bonell et al. 2011) and reflected in government policy (e.g. Department of Health 2004; Scottish Executive 2006), it may not be feasible to include this level of service user and stakeholder consultation when implementing new services or interventions. However, some of the findings from this study will be generalisable to other services that are considering how to work with service users with intellectual disabilities and challenging behaviours. **Study limitations**	

		While this study identifies some of the things that help the service work better from the perspective of the service users and carers, such as the flexibility and availability of the service, it doesn't identify exact things like, out of hours availability and level of behaviour severity that can be safely treated in the community that would provide a framework for the service to operate within. It is also worth noting that while the sample size covered the majority of all those who worked with the CBS, it was a convenience sample and therefore, may not be fully representative of the diversity of all possible stakeholders. The authors also acknowledge limitations relating to participants not feeling like they could be critical of the service. This is because in 2 of the interviews with service users, with the agreement of the service users, their support worker stayed in the room throughout and therefore, the service users might have been reluctant to speak freely. And another service user spoke freely prior to the formally recorded interview but he spoke less and answered 'I don't know' to questions that he had previously answered differently once the recording of the interview had begun (p234). However, the researchers were careful and tried to reduce any potential bias by the interviewer by including a final	

		question inviting participants to discuss anything they thought had been missed and using 2 additional researchers independent of the project to validate the coding scheme.	

33. James N (2013) The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: what do carers say? Journal of Intellectual Disabilities 17(1): 6–23

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim To provide an overview of the reported experienced of family carers about their own support. The review considers the needs of carers and the extent to which their needs are met. **Country:** Not clear. **Source of funding** No funding. **Methodology**	**Participants** Carers/family members. **Sample characteristics** Children and young people. **Sample size** Total 2706 + (numbers of participants not always reported). **Systematic reviews** Participants in number of studies: 17 studies.	**Summary of findings** The author concludes that carers need more support to help them manage. Carers have to ‘fight‘ for support. Have to reach crisis before services are delivered. Carers experienced services that were uncoordinated and bureaucratic. Carers welcomed good communication with professionals that make them feel their situation is appreciated and empathized with. Carers need information that is clear and understandable. They want to develop skills to help them manage difficult situations and behaviour themselves. The support that carers want are those that seek to empower them to maintain their	**Overall score** ++

Systematic review – qualitative.		relationship with their relative, to help them manage and continue their caring role. **Barriers** ‘Inadequate planning, provision of information and support can result in a state of crisis where more complex and resource intensive interventions are required.’ (Wodehouse and McGill 2009 in James 2013:17) Carers report they needed to reach a state of crisis before help was given. (Wodehouse and McGill 2009 in James 2013:17) Carers reported a lack of ‘partnership working‘ in respect of planning and support. (Wodehouse and McGill 2009 in James 2013:18) Support from respite services was unavailable, or unsuitable for their relative’s needs. Lack of access and provision at a time when they had their greatest need. (Wodehouse and McGill 2009 in James 2013:19) An increase in their relatives needs is met with a withdrawal of support and restricted access due to their relatives behaviour. (Faust and Scior, 2008; McGill et al., 2006a, 2006b in James 2013:19) Barriers to seeking help could include not knowing where to find help, fear of not being	

		taken seriously, fear of being a burden and services being too far away. (Faust and Scior, 2008; Weiss and Lunsky, 2010 in James 2013: 20) **Facilitators** Carers who used short breaks and intensive support services reported that relationships based on trust, effective communication and ongoing support were most important (McConkey, 2011: 8) (p18). Having someone to listen increased carers' satisfaction with services. **Access to support** Carers reported that services tended to be reactive, rather than proactive. They have to 'fight' and 'battle' not just for their relative but for their own needs, highlights sense of being alone. **Defining behaviour that challenges** Labels used to define behaviour that challenges have changed over time, and have included problem, disturbed, maladaptive or difficult behaviour. Blunden and Allen used the term challenging behaviour in 1987 to highlight a person's individual behaviour should be seen as a challenge to services, rather than a problem located in the person. **Information**	

		An evaluation of the programme Signposts for Building Better Behaviour, carers reported experiencing less anxiety, stress and depression and well as increased confidence in managing their child. Careers reported that their needs for information was not fully met due to the lack of skilled and knowledgeable professionals. Advice can be unsympathetic to their individual context but factual information was well explained. Carers could report that their concerns were not taken seriously until they had to ‘shout‘ Did not always feel fully informed. Information not explained fully could lead to further confusion and uncertainty. **Impact on carers** Diagnosis of additional needs as a re-experience of feeling of grief and loss from the first diagnosis of learning disability. (Faust and Scior, 2008 in James 2013: 16) Carers reported experiencing increased levels of physical and emotional strain from dealing with unfamiliar and unpredictable problems, as well as anxiety, fear for their own safety, feelings of anger and poor sleep, limited opportunity for engagement in external activities and reduced quality of life. (Foundation for People with Learning Disabilities (FPLD), 2005; Fox et al., 2002; Kenny and McGilloway, 2007; Lecavalier et	

		al., 2006; Maes et al., 2003 in James 2013: 16). Carers feel that they are being judged and criticized for their relative's behaviour and experience a sense of stigma and shame in how other people are viewing them and their relative. (Faust and Scior, 2008; Kenny and McGilloway, 2007 in James 2013: 16) **Navigating care services** Carers preferred a named key person, such as a social worker of case manager who acts as their single point of access. (Faust and Scior, 2008; Hemmings et al., 2009; Williams and Heslop, 2005 in James 2013: 19) Carers want information that helps them understand the problems and changing needs of their relative. (Douma et al., 2006; FPLD, 2005; Faust and Scior, 2008; Kenny and McGilloway, 2007 in James 2013: 18) Carers want information on available services and explained clearly. Faust and Scior, 2008 in James 2013:18) **Personalisation of care** Support from respite services was unavailable, or unsuitable for their relative's needs. (Wodehouse and McGill, 2009 in James 2013: 19) Careers stated there was a need to have support that is flexible and delivered in a	

		way to meet the needs of the whole family. (Hemmings et al., 2009 in James 2013: 19) **Seeking help** In finding it difficult to care for their relative's needs, combined with lack of appropriate support, carers may seek an out of home placement. When seeking specialist help, carers hope for training advice and help in understanding specific psychiatric and behavioural problems and taught how to manage difficult situations. (Maes et al., 2003 in James 2013:16) Carers reported unmet needs around the provision of practical/ material help, mental health care for their relative and counselling for themselves. (Douma et al. 2006 in James 2013: 17) Carers reported concerns for the future service provision, consistency of staff and transition to adult services. (McConkey, 2011 in James 2013: 18) Carers often did not seek help because they saw the problem as being only temporary, wanting to cope without support and not knowing where to find support, previous negative experiences and lack of trust. (Douma et al. 2006 in James 2013: 19)	

34. Knapp M, Comas-Herrera A, Astin J et al. (2005) Intellectual disability, challenging behaviour and cost in care accommodation: What are the links? Health and Social Care in the Community 13: 297–306.

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To look at the patterns of service use and costs for people with intellectual disabilities and challenging behaviour in care accommodation in some areas of England and to explore the links of those patterns (p298). **Service aims** Not stated. **Country** UK. **Methodology** Cross-sectional study. **Source of funding** Government department. The data used in this paper were originally collected for another research project, funded by the NHS Information Authority.	**Participants** Administrators, commissioners, managers. Data was collected from service providers. Adults with learning disabilities and behaviour that challenges. **Sample characteristics** **Age** Full sample mean 44.4, range 18–93 costed sample mean 44.4, range 20–92. Disability Intellectual disability in the costed sample mean 21.9, range 0–42. Characteristics of behaviour Challenging behaviour in the costed sample 7.5 mean 0–30 range. **Sample size** N=930. **Treatment of groups**	**Service use** **Community service use** Service use (date reproduced from Table 3, p301). Cols: general hospital services. Utilisation rate (%), average weekly costs for users £ (1996/97). General hospital outpatient 10.4 93.60. General hospital accident and emergency 7.3 25.96. Day activity services Intellectual disability hospital-based day activity 17.2 168.73. Work-orientated centre 11.1 0. Day centre or social club (non-NHS) 39.3 74.01. Education centre 16.9 7.80. Drop-in centres 15.4 9.14. Other day care 29.8 29.15. Primary care and community support General practitioner 55.7 23.19. Dietician 25.2 0.25. Speech therapist 20.5 4.86. Occupational therapist 22.4 41.20. Psychologist 12.2 2.82. Psychiatrist 20.1 0.28.	**Overall score** +

	N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).	Hospital-based day activity made the largest contribution to total cost, reflecting both an intensive use as well as a higher unit cost than the other types of day services. Day centres and social clubs were the more widely used day services. Service use patterns The degree of intellectual disability influenced the use of all services. Individuals with more severe intellectual disabilities were more likely to use services such as speech therapy, physiotherapy or hospital based day activities. Non-hospital-based day activities tended to be used by people with more moderate intellectual disabilities. While the extent of challenging behaviour only influenced used of: day centres/social clubs – psychologists – psychiatrists – dieticians. Higher challenging behaviour scores increased the probability of seeing a psychologist or a psychiatrist. Other characteristics, such as age, affected the probability of receiving services. Older people were less likely to be offered services such as places at work-oriented centres, or seeing a psychologist or a speech therapist, but more likely to see a GP (p301). **Size of residential home** People in smaller homes were less likely to go to work centres, education centres or drop-in centres, but on the other hand were	

		more likely to go to day centres. (p302). Private or voluntary – people living in private/voluntary homes were less likely than people in NHS facilities to use hospital-based day activities, but more likely to go to education centres or drop-in centres, or receive other types of day care. They were also more likely to see a GP, but less likely to see an occupational therapist or dietician (p302). **Number treated** NHS trusts tended to specialise in providing services for people with more profound levels of severity. The mean score on intellectual disability of people living in an NHS home was 25.6 compared with 13.5 for private or voluntary sector. The mean score on challenging behaviour of people living in an NHS home was 8.9 compared with 5.8 for private or voluntary sector. In the costed sample, accommodation was provided by: 7 NHS trusts (66% of people in the sample) – 6 private for profit providers (25% of the sample) – 1 voluntary or non-profit provider 99% of sample). **Cost information** The average weekly cost for sample members (£, 1996/97 prices) was £692, which includes averages of: £588 accommodation (and associated staffing),	

		£75 day care, £22 professional or community services, £7 acute healthcare. Average costs were higher in NHS settings where residents scored more highly on both the intellectual disability and challenging behaviour indicators, which may partly explain the higher costs. ‘Costs were higher for those people with more severe intellectual disabilities and those who displayed greater levels of challenging behaviour’ (p303). In terms of scale of facility, NHS facilities benefited from economies of scale with cost being just under £2 lower per resident week for each additional resident in the facility. Whereas in the voluntary/private facilities there was ‘diseconomies of scale’, with each additional resident in the home generating an additional cost of £2.48 per resident week across all residents (p303). **Summary of findings** ‘Overall, we found evidence that whether or not an individual uses a service was linked to a certain extent to their needs-related characteristics; we also found that the size and sector of accommodation were influential’ (p302). **Implementation issues** In the context of a national policy commitment to person-centred planning,	

		the study suggest that commissioners need to explore the sources of cost variation between individuals, sectors and types of accommodation in order to meet the policy objectives on quality, choice, independence and inclusion. **Study limitations** The sample in the study over represented the NHS sector and under-represented the other sectors which makes it difficult to generalise from the results of the study. We should be cautious in drawing conclusions from the cost data particularly when it comes to intersectional differences because the data in the study is from a relatively small number of independent providers. Other limitations in the study include: the sample of people with intellectual disabilities was drawn non-randomly, mainly from NHS facilities, making it difficult to generalise the findings nationally. Aggregated cost for residential accommodation settings were used and we don't know the extent of which any service costs might have been included in the accommodation cost and means the analysis relates only to services not already provided within the accommodation budget. The statistical analyses were able to 'explain' only a third of the observed variance in costs. The authors suggest that	

		it is part methodological and part situational and might be due to poor responses by services to individual differences in intellectual disability and behaviour and services responding poorly due to a number of situational factors. The authors say that ‘many other cost studies in the intellectual disability field have attained very similar proportions of variance explained’ (p304).	

35. Kroese B, Rose JL (2011) Mental health services for adults with learning disabilities. London: The Judith Trust

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim 1. Identify what service users and paid workers consider desirable personal qualities for people working in this field to possess. 2. Explore experiences of staff and service users to identify strengths and weaknesses of current service provision for adults with learning disabilities and mental health problems. 3. Collate suggestions for service	**Participants** Professionals/practitioners n=38. Included qualified professionals as well as unqualified staff. Adults with learning disabilities and behaviour that challenges n=16. **Age** The age of the service users is not described. The residential staff members interviewed (n=12). Their ages ranged from 20 to 52 years (mean =38) The	**Qualitative themes** **Access to support** Page 30: generic mental health services appear to be, in some instances at least, inaccessible to service users with learning disabilities. Examples of inaccessible services include memory clinics (30) and the ‘Improving Access to Psychological Therapies’ initiative (IAPT; 31). **Navigating care services**	**Overall score** +

improvements and training/supervision programmes. **Service aims** Not stated, not relevant. This study is about exploring the experiences of staff and service users about current service provision for adults with learning disabilities and mental health problems. **Country** UK. **Source of funding** Voluntary/charity. This research was funded by The Judith Trust. The Judith Trust is a family foundation which seeks to work for better lives for people – women and men, boys and girls – who have both learning disabilities and mental ill-health. **Methodology**: Survey. **Services of interest** Inpatient services. **Content/components of service**	peripatetic professionals interviewed (n=10). Their ages ranged from 24–64 (mean =43). **Gender** Service users (n=16): 8 female 8 male staff. Focus group (n=16): 10 female 6 male staff. Interviews residential staff (n=12): 10 female 2 male staff; interviews peripatetic professionals (n=10): 7 female 3 male. **Level of need** All the service users have personal experience of having a learning disability and additional mental health problems. The attributed of behaviour that challenges is not mentioned. **Relationship** The staff focus groups included staff with a variety of roles in supporting adults with learning disabilities including support staff (n=7), a team assistant, nurses (n=2), an assistant social worker, a counsellor, psychologists (n=3) and an advocate. The residential staff members	Page 26: the referral systems, as already mentioned above, often resulted in negative outcomes for service users and their careers and supporters, leaving them in some instances without a service or with a disjointed package of support. **Staff skills** **Desirable staff qualities** According to respondents, the qualities which are most desirable for staff working with service users with learning disabilities and mental health problems include: having a genuine interest in working with people and building up trusting relationships within professional boundaries; having good communication skills and the ability to be open and honest yet gentle and sensitive; providing support in a way that is perceived as ‘competence promoting’ rather than ‘competence inhibiting’; and being able to understand and acknowledge that past experiences may have been central in causing current mental health problems and may influence their reactions to current events and interventions (p13). All staff interviewed stated that they considered training in mental health issues essential for themselves and for colleagues at all levels of the organisations: ‘... because of the high	

Regular review. Training.	interviewed (n=12). They included 2 team leaders, 1 senior support worker and 7 support workers. Qualifications included NVQ 1, 2 and 3, BTEC, and 1 RNMH (highest qualifications ranging from 2 to 4 award levels; 24); 4 staff members had received in-house training in at least 1 topic relevant to the mental health needs of people with learning disabilities (mental health, bipolar disorder, autism, challenging behaviour). The peripatetic professionals interviewed (n=10). They included 5 community nurses, 4 social workers and 1 assistant psychologist. Qualifications included a master's degree in social work, a diploma in social work, first degrees in sociology and psychology, RNLD and RNMH (highest qualifications ranging from level 5 to 7 award level; 24) and 4 staff members stated they had received in-house training in topics relevant to the mental health needs of their service users (mental health and learning disabilities,	level of mental health problems amongst our [service users] … it should be part of the mandatory training and it's a shock to hear, even amongst my esteemed colleagues, how little they think they've had in terms of mental health training …' (community staff) (p25). **Working together** Both residential and community staff stressed the need for a flexible, responsive service and for good liaison between the various services in order to meet the needs of service users in a crisis: '… we have a community nurse who's brilliant you know. He comes and gives us advice on how to do this and explains to us why this might be happening and we thrash out about what we can best do and that. Support from doctors and psychiatrists can be really helpful, to like give us some tips and hints and tools to work with to help that person and they're pretty quick to get here. They're only a phone call away, you can call up for expert advice coz we're not experts really here' (resident staff) (p15). The importance of people working together using good communication systems and avoiding 'passing the buck' scenarios, where service users who are on the borderline	

	drugs and alcohol, dual diagnosis). **Residence:** The research was carried out with Dudley Primary Care Trust and South Staffordshire and Shropshire Healthcare NHS Foundation Trust. The residential staff members interviewed (n=12) were sampled from urban (n=6) and rural settings (n=6) and from a range of statutory, private and voluntary services. The peripatetic professionals interviewed (n=10) were drawn from a number of teams covering urban (n= 4) and rural (n=6) areas. **Sample size** N=54. Service users focus group (n=16). Staff focus group (n=16). Staff interviews (n=22).	of a number of service are turned away, ending up as labelled 'ineligible' despite very real and complex needs. For example, a residential worker spoke about the importance of using good care plans so that: '… everyone sings from the same song sheet so to speak' (residential staff) (p15). Team work and multidisciplinary collaboration was considered an essential ingredient of an effective service because otherwise the service users might experience inconsistencies in the approaches taken by the various workers and possibly conflict and an over-load of information given to them, e.g. 'Yeah, good teamwork because people with learning disabilities and mental health issues, they often have a number of workers you know, they might be going to college and then seeing me [social worker], they might be seeing psychology, they might be having a support worker come out so there are lots of different people. It can make misunderstandings between the client and other people and myself. And I think that can create umm both frustration and uncertainty within the client so that can be a bit negative' (community staff) (p26).	

		Page 26: Moreover, liaison with Community Mental Health Teams did not always result in good care co-ordination and mental health colleagues appeared to be unwilling to remain involved long enough to ensure effective interventions **Barriers identified** **Knowledge and skills** When a service user with learning disabilities is admitted to a generic psychiatric ward, the expertise of ward staff was said to be at times inadequate. it would improve the continuity and quality of services if: ‘Psychiatric nursing staff, psychiatrists and other mental health professionals who are involved in the care of patients with learning disabilities receive training and supervision in aspects of learning disabilities in order to enable them to recognise and meet the needs of these service users; or alternatively to have the input of a learning disability specialist worker available to them (a similar role to the Health Access Nurse in physical health services)’ (p21). Topics which were most mentioned as important aspects of their knowledge base, relevant to mental health include: diagnosis; psychotropic medication; basic counselling skills; psychology;	

		relaxation techniques. Like the service users, staff participants were keen that training happened in the workplace and as an ongoing process with ‘refresher’ courses available on a regular basis. **Facilitators identified** **Family involvement in care planning** Staff participants but not service users often mentioned the importance of having a ‘family centred’ approach (28 participants) when service users are in close contact or live with their family: staff report that some families want a lot of support and some do not. Working with the family should identify what level of support they need and want. Staff participants but not service users often mentioned the importance of having a ‘family centred’ approach (28 participants) when service users are in close contact or live with their family: ‘There are some families who want a lot of support, there are other families who don’t and so it’s just keeping an eye on that really and umm, trying to help them in whatever way you can really’ (community support) (p23). However, it was widely acknowledged that the needs of the family as a whole must be considered and catered for	

		whenever possible, as long as they did not clash with the identified clinical needs of the service user. Some workers spoke of negotiating with service users’ families over long periods of time in order to achieve outcomes acceptable to all parties: ‘… it took them years to accept that maybe she’d be better of living apart from them, it worked out, and it worked out really well’ (community staff) (p24). Adopting a ‘family centred approach’ (28 participants) by which the needs of the family as a whole are considered as important factors in determining positive outcomes for an individual service user and therefore must be considered or ‘signposted’ to other services such as local carers support organisations. **Service design** The authors suggest that ‘mental health is included in the standard health checks and relevant primary care staff is trained in the symptomatology of mental health problems in people with learning disabilities’ (p21). The authors also suggest other ways in which the interface between learning disabilities and mental health services can be improved: - Carry out joint assessments when a service user falls in the ‘borderline’ of	

		learning disabilities, mental health, substance abuse and or forensic eligibility criteria so that a joint care coordinating approach can be adopted by the relevant services. - Create ‘virtual teams’ around service users to allow professionals to cross service boundaries and work together by each providing their particular area of expertise, thus avoiding unnecessary and time-consuming ‘battles’ between the services which result in exclusion or delay (p22). **Regular review** Both service users and staff participants appreciated the importance of regular reviews and meetings, e.g. ‘We have our annual reviews anyway and depending on their [mental] health we’ll have more reviews, you know formal professionals’ meetings’ (community staff). Regular reviews and good liaison between professionals was seen as an important determinant of service quality by both users and staff. **Single coordinator** Service users valued a link person who could be easily contacted by phone, although many of their responses	

		indicated that they were resigned to a delayed service response: 'I'd go to my social worker or a carer or a friend … If I have their number I'd call them and if they're not around I would make an appointment' (service user) (p15). **Staff skills** Staff selection, supervision and training are important in recruiting and retaining a workforce which possesses the attributes, experience, knowledge and skills needed to work effectively with this group of service users. The authors suggest that ways this might be achieved include: • well-defined personal qualities in person specifications and appoint service users on interview panels in order to rate candidates according to those qualities • provide new staff with induction programmes which include shadowing of, and mentoring by more experienced colleagues • provide regular and ongoing individual supervision for all by an experienced clinician/clinical lead in order to review competency in interpersonal skills as working with adults with learning disabilities and mental health problems requires	

		knowledge and experience in not just 1 but 2 complex areas of clinical expertise • appropriate and ongoing training is essential if workers at all levels – the authors also suggest that training is also given to residential support staff in order for them to detect mental health problems at an early stage and to have the knowledge and confidence to refer these to, and discuss them with, colleagues in psychiatry and psychology (p21). **Summary of findings** There were 2 main themes that emerged from participants ideas on how to improve services: 1. Finding and keeping good staff. For example, give more training in mental health and learning disabilities to all types of staff that work with people with learning disabilities and mental health problems; and when new staff are recruited, service users should help with choosing workers who have good ‘people skills’ and who are really interested in the job. 2. Giving the right support at the right time. For example, don’t just say someone is unsuitable for a service and	

		exclude them, but work with other services to help the person. Also, families and support staff have needs to and they must be listened to, because if they are unhappy, the service user will also be made unhappy. **Study limitations** This study is about the population of people that have learning disabilities and mental health problems. Moreover, the authors suggest that challenging behaviour and mental illness are often indistinguishable and there isn’t any description of how many of the service users exhibit characteristics of behaviour that challenges, so we can’t be entirely sure if the population in this study is that same as the one we are interested in. This study also includes an audit of university teaching; a study of gender differences in cause and presentation of mental health problems; and a focus on what could be done to improve things for staff. However, for the purposes our study we only data extracted information about how services could be improved and the barriers and facilitators of current service provision.	

36. **La Valle I (2015) Services for children with learning disabilities whose behaviours challenge: A survey of families' and professionals' experiences. Chatham: Challenging Behaviour Foundation**

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To collect baseline evidence from families and professionals on awareness of, and access to, a range of support for children with learning disabilities whose behaviour challenges, and the kind of challenges families face. **Service aims** Not stated. **Country** UK. **Source of funding** Department of Health. **Methodology** Qualitative. **Services of interest** - Behavioural support. - Community support. - Content/ components of service. - Assessment reports and	**Participants** Professionals/practitioners. These are professionals from the CBF mailing list so they are not representative of the children's workforce as a whole: most work with children with learning disabilities, and compared with the children's workforce more generally they are likely to be more aware of the issues faced by this group of children and the type of support they need. Carers/family members. **Sample characteristics** Children and young people; parents/carers of children aged 0–18 years. **Sample size** Parents/carers n=61. Estimated response rate of 65%. Practitioners n=128 (no estimate of response).	**Caregiver satisfaction** Parent/carer satisfaction: - Key worker – 87% found them (very) adequate. - Personal budget – 83% found it (very) useful. - Parenting training – 85% found it (very) useful. - Short breaks – 62% found them (very) adequate. Parent/carer satisfaction with community services (effective or very effective): - Occupational therapy (82%). - Special educational provision (81%). - Physiotherapy (70%). - CAMHS (61%) . - Speech and language therapy (57%) . - Social services (45%).	**Overall score** -

intervention plans. - Family counselling and support. - Person centred support.		**Qualitative themes** **Barriers** **Issues with parenting training** An issue a number of parents/carers reported was the failure to provide this training at home in the 'normal environment' where the learning is then mostly applied. **Personal budgets** When parents did not find them useful, comments suggest that it may be because there were no adequate services locally they could buy. **Key worker** Although most parents who had a key worker thought this was adequate, some parents did comment on the lack of relevant experience of some key workers, and failure to promptly replace them when they moved on. **Short breaks** Comments added by some parents/carers (and also professionals) indicate that the low quality of some of the provision, and the fact that it is not locally-based, were 2 of the reasons for dissatisfaction with short breaks.	

		Lack of home based support Parents commented on the lack of home-based support to complement the support children receive (or do not receive) in other settings. They saw home-based support as being vital to understand and deal with challenging behaviour, and prevent children from being placed in residential care. **Selection of quotes** Page 10: 'We have fought personally through Tribunals for all of our son's therapies and resources - nothing was ever given based on need.' 'In another area locally a charity runs an adapted Triple P programme for parents of children with additional needs. This wasn't available to us. Health visitors and school nurses do not know how to help. We have also really struggled to access any physical intervention support to keep everyone safe.' 'Terrific ignorance in LA children's services about what challenging behaviour is, what a proper behavioural approach is. CAMHS has no-one trained to deliver PBS – they pretend they can cover the base using something very much less, i.e. meeting with workers once and after a talk or 2 on the phone. NOT observing or working with the child.	

		NOT directly training parents or staff. CAMHS don’t have the skills they also don’t have the staff. I have had to lead on everything and fight every step of the way’ (p10). Page 11: ‘We were very well supported, but when behaviour became very challenging, a lot of that support dropped away as it was not able to cope. My son is not the only child in this position, but policies seem not to recognise him or others in his situation. Some of this is as a result of multi- agency working, which is brilliant when it works but when it falls down no one can own the problem.’	

		‘We have had to manage all our son’s needs ourselves from the outset including paying for private therapists and for diagnoses ... His provision is not coordinated or joined up and we have to try and do that ourselves. That is one of the reasons his school placement fell apart this year and also because no one really understands our son and his needs and assumed he was like others. We have also struggled to get basic things like blood tests – we have one outstanding for a year. And it is hard to get carers so we cannot use most of our direct payments and the only residential 4 night break we have was cancelled this year because of new Ofsted rules.’ ‘I have reports saying he needs specialist behavioural intervention, i.e. PBS, but neither the LA (education/social care) nor the NHS will deliver it. I have been to court and Tribunal over this’(p11). **Facilitators** **Professionals’ views on what would made the greatest difference** - Information provided early to families and practitioners on the causes and risks of behaviour that challenges.	

		- Better coordinated inter-agency work (including joint commissioning) and agencies adopting a consistent approach - Dedicated specialist, multi-disciplinary teams with relevant training and expertise e.g. PBS, ABA. - Better understanding, across agencies, of causes of challenging behaviour, and a focus on early intervention and evidence based approaches e.g. ABA, PBS. - Family-centred care planning based on accurate assessments of need, clear goals and pathways, and guidance for parents. - Working closely with families including providing training and in-home support - Better awareness, training and support for specialist and non-specialist staff. - Better planning around transition to adult services. - Better awareness among commissioners and managers of the needs of this group.	

		- Improve access CAMHS and their capacity to adequately respond to the needs of this group. - Key worker. - Locally based intensive/crisis support available at short notice. - Good quality community based short breaks. - Advocacy provided to children and their parents/carers **Access to support** Total 47% of respondents said their children were referred to a specialist after more than 12 weeks, while a quicker referral seems far less common; 29% had a key worker and 87% found them (very) adequate; 42% had a personal budget and 83% found it (very) useful; 45% had received parenting training and 85% found it (very) useful; 56% had access to short breaks and 62% found them (very) adequate. **Specialist behaviour support** Total 39% of children were not receiving specialist behaviour support. Among those who were receiving this support, in just over half of cases (51%) it was delivered in an	

		educational institution, in 14% of cases at home, and in 12% of cases elsewhere. Types of support children receive Special educational provision (84%) speech and language therapy (73%) occupational therapy (56%) social services support (41%) CAMHS (24%) physiotherapy (22%). Respondents’ comments suggest that low usage may reflect unmet needs, as families were unable to access relevant services. For example, ‘Referral to community mental health services [was] declined due to lack of resources. Still waiting 6 months on for occupational health assessment. No one to do speech therapy available’ (p6). ‘His diagnosis of his primary needs was very, very late and we have been in crisis management from the beginning ’(p6). **Environment** People indicated they wanted more behavioural support and in the home. **Information** For parents and carers who had been referred to a specialist service 48% said the referral was useful in identifying the causes of challenging	

		behaviour and 53% did not think it was useful. Total 31% of parents were given information on the causes of their child's challenging behaviour and 30% about local services that could support their child. Total 41% were given information about positive behaviour support (PBS). While a minority of parents were provided with relevant information and advice, when this information was provided, most parents found it useful. Lack of information and understanding of what families go through was one of the most common issues respondents mentioned when asked what additional support they would have liked. 'To be listened to as a parent from the start would have been very helpful for my child.' **Navigating care services** Professionals were asked if, in their area, there were clear pathways across health, social care and education for children with learning disabilities whose behaviour challenges from different age groups. Only a minority of respondents said these were available to most or all children. Under 5 (21%) 5–11 yr olds (23%) 12–18 yr olds (24%).	

		Respite care Short breaks were reported to be ‘very adequate’ or ‘adequate’ by less than 66% of respondents who had access to them. Comments added by some parents/carers (and also professionals) indicate that the low quality of some of the provision, and the fact that it is not locally-based, were 2 of the reasons for dissatisfaction with short breaks. **Seeking help** These results show that in 70% of cases signs of challenging behaviour started in the early years. However, most families who are in contact with the CBF have older children, suggesting that it may take considerable time for families to access help. **Staff skills** Professionals were asked about the training received to work with children with learning disabilities whose behaviour challenges; 76% said this training was ‘very adequate’ or ‘adequate’. **Community service use** Unmet needs	

		When asked, what would help your child many of these services were mentioned, including: information about managing the child's behaviour and about local services; positive behaviour support; short breaks; training for parents (including managing challenging behaviour and developing care plans); a key worker, and access to CAMHS. Other types of support mentioned were: - Independent living skills. - Sensory profile from occupational therapist. - Sensory processing therapy - (Cheaper) after-school and holiday clubs/provision. - Applied behaviour analysis (ABA). - Personal assistant with experience of supporting children with learning disabilities whose behaviour challenges. - Help for siblings. Professionals views on effectiveness of different types of support (in some or most cases) - Regular physical health checks 90%. - Regular sensory assessments 94%	

		- Training for parents 99%. - Residential placements 57%, but 38% believe it is rarely or never effective. - Short breaks 98%. - PBS to provide tailored care 95%. **Barriers identified** **Capacity** Parents commented on the lack of home-based support to complement the support children receive (or do not receive) in other settings. They saw home-based support as being vital to understand and deal with challenging behaviour, and prevent children from being placed in residential care. When parents did not find personal budgets useful, comments suggest that it may be because there were no adequate services locally they could buy. **Knowledge and skills** Some parents did comment on the lack of relevant experience of some key workers, and failure to promptly replace them when they moved on. **Facilitators identified** **Brokerage and advocacy**	

		Professionals identified advocacy to children and their parents/carers as 1 of the things that would make the greatest difference. **Commissioning** Professionals identified ‘better awareness among commissioners and managers of the needs of this group’, as 1 of the things that would make the greatest difference. **Service design** Professionals identified ‘better planning around transition to adult services’ and ‘better co-ordinated inter-agency work (including joint commissioning) and agencies adopting a consistent approach‘, as things that would make the greatest difference. **Summary of findings** The survey of families from the Challenging Behaviour Foundation network shows that their experiences were more likely to be characterised by late referrals when problems first appeared, difficulties in accessing the kind of information, advice and services families need, and agencies that are not equipped to adequately support children with learning disabilities whose behaviour challenges. When families	

		did manage to access different types of support, views were mostly positive. Another area of concern for families was the lack of home-based support, which is vital to understanding and dealing with challenging behaviour. The survey of professional’s shows that they think the main different types of support, such as training for parents, short breaks and PBS are all highly effective. However, with the exception of residential care, with 35% believing that this is rarely or never effective. They also pointed to big support gaps locally as they believed that most children do not have clear pathways across different agencies to provide consistent support. **Implementation issues** Most children do not have clear pathways across different agencies to provide consistent support. **Study limitations** The samples for the surveys were drawn from the CBF mailing list, therefore those who took part are not a representative sample of families with children with learning disabilities whose behaviour challenges and professionals who work with this group,	

		but they are representative of the kind of families and professionals who engage with the CBF.	

37. Lindsay WR, Holland AJ, Carson D et al. (2013) Responsivity to criminogenic need in forensic intellectual disability services. Journal of Intellectual Disability Research 57: 172–81

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim To compare specialist forensic services to general community and secure services and to find out if these services provide appropriate treatment for people that use these services. **Service aims** Provide services for people with intellectual disability who offend. **Source of funding** Department of Health, National Forensic Health research and development	**Participants** Adults with learning disabilities and behaviour that challenges. Forensic needs. **Sample characteristics** **Adults** **Gender** N=168 males; n=29 females. **Characteristics of behaviour** Reasons for referral to a service: - 42% physical aggression - 26% verbal aggression - 14% contact sexual offences - 13% non-contact sexual offences - 20% property damage - 5% cruelty or neglect to children	**Costs?** No. **Summary of Findings** The most frequently referred forensic problems were violence and sexual offending. The authors compared the number treated for these 2 types of forensic problems provided by each different type of service. Community forensic services and inpatient services provided appropriate treatment for 89% of referrals for violence and sexual offences, compared to only 9% of referrals receiving appropriate treatment by general community teams and 27% for secure services. The study finds that specialist services are more likely to provide appropriate treatment services compared to generic community services and secure services for this group.	**Overall score** -

programme – research grant no MRD/12/45. **Methodology** Quantitative evaluation. **What is the sampling frame (if any) from which participants are chosen?** Forensic services across a catchment area of around 12 million people or 20% of the UK population. **Details of data collection instruments or tool(s)** Researcher designed questionnaire. Standard form used to collect data. Data were collected on a range of variables including index offence, history of problem behaviour and psychological treatment received by each participant. **Mechanism for change** Specialist support: specialist community forensic services and inpatient services are more likely to provide appropriate treatment	- 5% for alcohol/substance abuse - 5% theft - 3% arson - 75 (38%) had violence as an index offence and 62 (31%) with a sex offence as an index offence. **Sample size** N=197. **Services of interest** **Inpatient category 2** Category 2: acute admission beds within specialised learning disability. **Inpatient services** Inpatient services were staffed by ID nurses, a psychiatrist and a psychologist and had access to speech and language therapists, occupational therapists and dieticians so were also considered to be specialist services. **In patient category 1** High, medium and low secure forensic beds. **Generic community intellectual disability services** In this study, 'generic community services' refers to community learning	**Study limitations** The data used in the study is now 15 years old and services are likely to have been developed since this study. It is worth noting that the general community services in this study were chosen because they had some experience of dealing with forensic referrals so you might expect the difference in outcomes between general services and specialist services to be less, so the finding that the difference is quite strong indicates that it might even be stronger if general community services with no experience at all of people with forensic needs were taken into account.	

services compared to general community services and secure services for people with a learning disability and forensic needs. **Source of funding** Government department, Department of Health National Forensic Health research and development programme – research grant no MRD/12/45.	disability teams which had a history of accepting individuals who had committed offences or showed signs of offending behaviour.		

38. **Mansell J, Beadle-Brown J, Whelton B et al. (2008) Effect of service structure and organization on staff care practices in small community homes for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 21: 398–413**

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim The aim of this study was therefore to explore the effect of a wider range of organisational variables (that had already been investigated) on the extent of active support in community-based residential services.	**Participants** Professionals/practitioners; adults with learning disabilities and behaviour that challenges. **Sample characteristics** Adults.	**Social care outcomes** **Engagement in meaningful activities** The importance of adaptive behaviour and active support in predicting engagement in meaningful activity. Higher engagement was predicted by younger, more able white British residents, with less stereotypy but with	**Overall score** -

Country: UK **Methodology** Comparison evaluation. **Services of interest** - Person centred active support (PCAS). **Content/components of service** Training - managers in 36 settings were trained in person-centred active support by the first 2 authors; 1 day classroom based, 1 day practical workshop. Managers then train their own staff.	**Sample size** Comparison numbers 36 homes; intervention number; 36 homes nominated by the charity for the introduction of active support. **Sample size** Total 72 homes, 359 adults and 354 staff.	more inappropriate speech; by staff who had worked in hospital and who were more knowledgeable about challenging behaviour; and where staff provided active support. **Service quality** Staff in the comparison group tended to attribute challenging behaviour to negative learnt behaviour explanations more than the PCAS group (z=2.753, p<0.01), The PCAS group tended to attribute challenging behaviour to the need for stimulation more than the control group (z=2.416, p<0.05). **Organisation and staffing** The PCAS group had significantly more staff with a professional qualification (z=4.145, p<0.001). The comparison group had more people who had worked for less than 6 months or more than 5 years. There were no significant differences between the groups in the pattern of sickness absence (78% reported that they had taken less than 5 days sick leave in the past 12 months). A higher percentage of staff in the comparison group report ted taking between 6 and 10 days sick leave in the last year (mean 9.91% compared to 5.45%; z=3.119, p<0.01). Staff in the	

		comparison group were more satisfied with their job (z=3.663, p<0.001). The PCAS group had attitudes significantly more in line with a policy of community care and empowerment for people with intellectual disabilities (z=3.880, p<0.001) The PCAS group rated most tasks they were asked to consider as less difficult than the comparison group. No difference between the groups in satisfaction with the team’s manager. Higher engagement was predicted by lower staff ratio, staff who were satisfied with the flexibility of their hours of work, more conflict about how tasks should be done and stronger rating that co-workers acted on staff members’ advice. The inclusion of staff ratio possibly reflected resident dependence since these were significantly correlated (rho=0.55). **Summary of findings** The PCAS group showed significantly higher implementation of active support, higher levels of assistance, and other contact from staff and engagement in meaningful activity. In the PCAS group, 53% of residents were judged to be receiving good active support (ASM score>30), compared with 29% in the comparison group.	

		There were no differences in participation in daily living or choice making. There was a modest difference between PCAS and comparison groups in engagement in meaningful activity, observed assistance and active support and this study offers further evidence that active support leads to higher engagement. Perhaps more notable is that 46% of staff had worked in the current service for less than 6 months. Professional qualification, knowledge and experience appear to be important as do some staff attitudes, clear management guidance, more frequent supervision, and support and training for staff to help residents engage in meaningful activity.	

39. Mansell J, Ritchie F, Dyer R (2010) Health service inpatient units for people with intellectual disabilities and challenging behaviour or mental health problems. Journal of Applied Research in Intellectual Disabilities 23: 552–9

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim The Healthcare Commission (the regulatory body) instigated a national audit of specialist health services for people with	**Participants** Professionals/practitioners. Sample size N=434 survey returns	**Clinical outcomes** **Behaviour that challenges** The number of incidents reported in the last 6 months where a patient was hurt by a patient or by a member of staff averaged	**Overall score** -

intellectual disabilities (Healthcare Commission 2007b). The audit comprised a national survey of health service inpatient units for people with intellectual disabilities, carried out by the Healthcare Commission, followed by visits to selected services. This study aims to describe the characteristics of the services studied (in the audit) and to compare the different types of service (assessment and treatment units, low secure and medium secure units). It also compares NHS and (independent healthcare) IH units. **Country:** UK. **Methodology**: Survey **Mechanism for change** **Identification of needs** The lack of useful information about mental health services generally has been identified as an important obstacle to monitoring the patient's journey through the system, the quality of care provided and		0.52 per patient, with no difference between NHS and IH units. There was a difference between types of units (KW v2=8.758, df=2, p<0.05). Post-hoc Mann-Whitney tests showed that assessment and treatment units had more incidents than low secure units. The same pattern was found for incidents of injury to staff (KW v2=8.698, df=2, p<0.05). **Service use** **Case load** Assessment and treatment units also had different occupancy rates: NHS units (n=107) had a mean occupancy of 42% whereas IH units (n= 5)all had 100% occupancy (z=2.182, p<0.05).There was no difference in occupancy levels for low and medium secure units, with an overall average of 91%. **Length of hospital stay** The majority of NHS services were assessment and treatment units and these units were smaller than such units provided by the IH sector. Small size is consistent with official guidance that services should be local and should provide only 'short-term, highly focused assessment and treatment … offering very specifically defined, time-limited services'	

compliance with equality legislation. **Service aims** Explicit. Inpatient units have been provided, to provide assessment and treatment of challenging behaviour, including challenging behaviour thought to be due to mental illness. Medium secure units for people with intellectual disabilities have also been developed to provide an alternative to special hospital provision for people who cannot be managed on psychiatric hospital wards (Department of Health and Home Office 1992; Home Office and Department of Health and Social Security 1975). A new type of provision, 'low secure units' has also developed. There is no clear definition of what these units are supposed to do and no central register of them (Hansard 2008). Many are now also provided by the independent health care sector. **Source of funding**		(Department of Health 2007a, paragraph 59). **Organisation and staffing** Overall, there was no difference between NHS and IH units in terms of staff/patient ratio or the percentage of agency staff. However, IH assessment and treatment units had lower staff/patient ratios (2.1: 1 versus 3.8: 1) and made less use of agency staff (3% vs.42%) than NHS assessment and treatment units. Medium secure units provided by the NHS, in contrast, made less use of agency staff than IH units. On average, units had provided 7 days training per member of staff (range 0–64) in the previous 12 months. IH units had provided appraisal to 72% of staff, compared with 55% in NHS units (z=2.428, n=199, p<0.05). **Provider type** Number of places by sector and service type. Assessment and treatment units NHS 854, IH 108. Low secure units NHS 476, IH 184. Medium secure units NHS 162, IH 107. All NHS 1492 IH 300 total 1891.	

No funding. The second and third authors were employed by the Healthcare Commission.		Average number of places by type and sector NHS n=170, IH n=31, All n=201. Mean (Range) Assessment and treatment NHS 8 (2–20), IH 22 (12–29). Low secure services NHS 10 (1–26), IH 10 (5–17). Medium secure services NHS 10 (4–16), IH 15 (4–31) AllNHS 9 (1–26), IH 13 (4–31). All NHS 9 (1–31), IH 13 (4-31). **Service quality** In 35% of units, managers reported that every patient had an up to date copy of their own care plan that was easy for them to understand and that they could look at when they want to. In 47% of units no patient had such a care plan. The number of visitors (family, friends or professionals) received by patients was higher in NHS than IH units (z=3.296, n=201, p<0.001) and differed between types of unit (KW v2=12.455, df=2, p<0.01). Post hoc Mann Whitney tests suggested that both assessment and treatment units and low secure units had more visitors than medium secure units. **Staff contact/assistance**	

		A higher proportion of patients in IH units had seen a GP or practice nurse (z=2.580, n=191, $p<0.05$) or a dentist (z=2.131, n=198, $p<0.05$) in the last 6 months. **Summary of findings** Services were extremely unevenly distributed. Of the 150 councils with social services responsibilities, only 58 had services within their area. Among those areas with services, the average number of places was 6.04 per 100,000 total population, but this concealed very wide variation from 1.75 to 24.19 places per 100,000. It is noteworthy that some patients did not have an accessible care plan in nearly 66% of units, and in nearly half of units no-one had an accessible care plan. IH units were bigger, had higher occupancy and lower staff ratio. In all 3 types of unit, IH units had fewer visits from friends and relatives to patients, used more seclusion, physical restraint and had more locked areas. They had more complaints in more services from users and (for assessment and treatment units and low secure units only) from relatives. On the other hand they used fewer agency staff in assessment and treatment units (though more in medium secure units) and provided more appraisals, more	

		visits from commissioners, more consultations with GPs and dentists and more use of whistleblowing procedures by staff. If the function (of low secure services) is assessment and treatment then their integration with other local services in the areas from which their patients are admitted become important. Otherwise there is a risk that this type of service is recreating the intellectual disability institutions which government policy intends to close (Department of Health 2007b: 558). **Barriers identified** **Implementation issues** Of the 217 returns received, 201 were useable in the analysis (others had large amounts of missing data). **Study limitations** Differences in numbers of incidents, responses or complaints may reflect differences in patient characteristics: They may also reflect differences in processes, where staff in some units are more likely to recognize and record events, perhaps as a result of greater training.	

40. Martin S, Kelly G, Kernohan WG et al. (2008) Smart home technologies for health and social care support. Cochrane Database of Systematic Reviews 4: CD006412

Research aims	Study characteristics	Outcomes and findings	Overall validity rating.
Study aim To determine the effects of smart home technology interventions on an individual's health status. To establish the effects of smart home technology interventions on healthcare resources (including clinician time and hospital admission). To explore whether the sophistication of smart home technologies is related to their effects. **Service aims** Not stated. **Country** Not clear. **Methodology** Systematic review.	**Participants** Adults with disabilities: participants with a physical disability, dementia or a learning disability. **Sample characteristics** Adults. Residence: adults over the age of 18, living in their home in a community setting. **Sample size** Systematic reviews: participants in number of studies. No studies were found that met the inclusion criteria. **Treatment of groups** Prospective allocation into more than 1 group.	**Summary of Findings** Current available published studies lack the application of robust empirical methodologies to validate smart home technologies as an effective intervention to support health and social care.	**Overall score** +

Mechanism for change Use of technology. **Content/components of service** Assistive technology. Smart home technology.	**What is the sampling frame (if any) from which participants are chosen?** Explicitly stated (please specify) a) the Cochrane EPOC Group Register); (b) the Cochrane Central Register of Controlled Trials (CENTRAL) (c) bibliographic databases, including MEDLINE (1966 to March 2007), EMBASE (1980 to March 2007) and CINAHL (1982 to March 2007). The Database of Abstracts of Reviews of Effectiveness (DARE). Grey literature, author contacts, No language limits.		

41. McBrien J, Gregory J, Hodgetts A (2003) Offending and risky behaviour in community services for people with intellectual disabilities in one local authority. Journal of Forensic Psychiatry and Psychology 14: 280–97

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim To survey the total population of adults with intellectual disabilities known to health and social services living in, or originating from, 1 local	**Participants** Professionals/practitioners Informants total n=39, consisting of: n=21 social services care managers – 21 of the 24 social services care	**Clinical outcomes** **Behaviour that challenges** Behaviours displayed in the 84 settings. Assault-related n=54 (64%).	**Overall score** +

authority area to establish the extent of offending and risky behaviour. The results were intended to form a basis for service development. **Service aims** Not stated. **Methodology** Cross-sectional study. **Source of funding** Other. The study was funded by the Plymouth Health Action Zone.	managers (3 were on long-term sick or maternity leave) n=8 community nurses – 8 of the 9 community nurses in the NHS trust intellectual disability service (1 was on sick leave); n=9 clinical psychologist and psychiatrist in the health team (all); n=1 a health authority employee, holding details of local clients placed out of district, was also interviewed Interviews were conducted at all 69 residential homes for adults with intellectual disabilities operational at the time of the study; at each of the 13-day services for adults; and at the 2 respite units. In total, these services provided a service for n=1043 people. The authors say no individual or setting refused to participate, all of these are termed the 'care management' group in the study and n=30 (note the total adds up to n=39, appears to be typo in the paper) Adults with learning disabilities and behaviour that challenges. Service users.	Sex-related n=50 (60%). Property-related n=42 (50%). Care managers experienced high rates of these behaviours among clients on their current caseloads: n=23 (77%) reported assault-related behaviours n=26 (87%) sex-related n=24 (80%) property-related, and n=27 (90%) 'other'. Behaviour displayed by individuals Assault-related n=163 (47%). Sex-related n=141 (41%). Property-related n=125 (36%). Other (e.g. show offensive social behaviour in public; throw temper tantrums in public places n=185 (53%) **Service use** **Community service use** Of the 84 settings: n=22 (26%) said all clients were there by virtue of having challenging behaviour n=29 (35%) said some were n=33 (39%) said none were. n=4 (5%) of settings said 1 or more clients had been temporarily excluded for behaviour problems n=36 (43%) had excluded people permanently. Most settings catered for a mix of men and women (62%). About	

	Sample characteristics Adults. **Gender** Of the n=348 individuals identified as displaying offending and risky behaviour, n=243 (70%) were men and n=105 (30%) women. **Residence** Residential homes: n=43 (62%) comprised 1–5 beds, n=15 (22%) comprised 6–9 beds and n=11 (16%) comprised 10 beds or more. n=49 (71%) that were privately run, n= 20 (29%) that were run by the voluntary sector. **Characteristics of behaviour** The criteria for offending behaviour used in the study was: ‘those people whose behaviour either constituted offending or was thought likely to place them at risk of offending’. The following people’s behaviours were excluded: those who were reported to have the potential to offend or act in a risky fashion;	a third were for men only (35%) and 3 were for women only (4%). **Characteristics** Contact with the criminal justice system (CJS). The majority of individuals (n=220) (63%) had had no contact with the CJS although demonstrating risky behaviour. Taking any type of contact with the CJS as a suspect, n=128 people (37% of the sample) had had such contact at some point in their lives – a prevalence of 9.7% of those known to services. Overall n=40 settings (48%) had clients with a history of contact with the CJS. This comprised n=31 (45%) of the residential homes, n=8 (62%) of the day settings and n=1 of the 2 respite units. In addition 93% of the care managers reported clients on their current caseloads who had had such contact. **Legal status** n=2 (2%) of the settings had 1 or more clients currently sectioned under the Mental Health Act, while 18 (21%) had 1 or more clients previously sectioned. However, 11 (13%) of settings could not answer the question on past sections. Of the 30 people in the care manager group 12 (40%) had clients	

	those whose inappropriate behaviour was very minor (e.g. a non-sighted person touching people inappropriately) or lacking in details (e.g. upsetting other residents); and those whose only reported behaviours comprised vulnerability (e.g. self-harming or being likely to run across roads). **Service use** Day centres n=11 (85%) were run by social services and n=1 each by the private and voluntary sectors. n=2 respite units were run by social services. **Sample size** N=1326, adults with intellectual disabilities in the city of Plymouth and known to health or social services. **How do the groups differ?** N/A (not more than 1 group).	currently sectioned on their case-load and 15 (50%) had clients previously sectioned. **Out of area** N=31 (9%) were living out of area and only n=10 (3%) in secure accommodation. **Provider type** Private homes were more likely to have experience of caring for clients with a history of MHA sectioning (x2 5.231, p<0.05). Of the 16 residential settings with MHA experience, n=15 (94%) were private sector. They also had more experience of client arrests than did the voluntary sector (x2 6.201, p<0.05). Of 22 residential settings reporting experience of client arrests, 91% were private sector providers. **Summary of findings** Offending behaviour n=348 (26%) showed risky behaviours that had been or might be construed as offences n=128 (9.7%) had a history of contact with the CJS n=38 (2.9%) had a history of criminal convictions n=11 (0.83%) had a current conviction. n=36 (16.6%) had challenging behaviour that was ‘risky’, but was not considered to	

		constitute offending. The finding that 26% of the known intellectually disabled population were reported to have offending or risky behaviour suggests a need to explore the needs of these people in more depth and organize services accordingly. **Implementation issues** The study suggests that it a common experience for local providers to have had experienced caring for people with a history of CJS contact. This suggests that training staff in forensic intellectual disability is important. Some 88% of those with CJS contact were living locally and might expect local provision. It is worth noting that this study was intended to only establish basic information on the extent of offending and risky behaviour. It did not include demographic information and did not seek to find out the reasons for risky behaviour. **Study limitations** The prevalence of intellectual disability in the adult population was low in the study compared to other studies. This is because it counted people in contact with health and social care services and there may be additional people	

		living independently or semi-independently and not currently in touch with services. However, there can be confidence that the study included all those living in a residential home, attending a day centre or respite unit, or open to care management or to a community nurse, psychologist or psychiatrist in the intellectual disability service. The data collection was also reliant on the perceptions of staff and did not involve client contact and relied on the service providers' experience of offending and risky/ challenging behaviour. Some informants did not have full information – e.g., whether or not people had ever been sectioned under the MHA or the nature of previous offences. There is a possibility that some people with forensic backgrounds living in local settings may therefore have been missed, although anyone with currently risky behaviour is likely to have been reported on.	

42. McConkey R, Gent C, Scowcroft E (2013) Perceptions of effective support services to families with disabled children whose behaviour is severely challenging: a multi-informant study. Journal of applied research in intellectual disabilities 26: 271–83

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Action for Children provide intensive support services to families whose children (up to 19 years of age) have developmental disabilities and severely challenging behaviours in 3 UK cities – Glasgow, Edinburgh and Cardiff. The study aimed to identify how these 3 services were perceived to meet the needs of families whose children are severely challenging. **Country** UK. **Methodology** Qualitative study. **Question areas**	**Participants** Professionals/practitioners, Carers/family members **Sample characteristics** **Age** The children were mostly teenagers. **Gender** Overall, more boys (74%) than girls used the services. **Health status** Many of the family carers had poor health (53%). **Level of need** Described as severely challenging. With nearly half of the families, there was some risk of family break-up and 2 of 5 children were at risk of having to move out of the family home. Upwards of 66% had an associated diagnosis of autism. Around a quarter of the children were dependent on others for feeding, dressing and toileting. More than 70% of the children currently had	**Qualitative themes** **Access to support** **Inappropriate services** 'We recently had a 16 year old boy who was very independent and realistically shouldn't have probably been placed here but there isn't always services available' (K33, p274). Families are often referred to the intensive support services in particular when a crisis has arisen, such as an existing provider can no longer cope. 'It is not easy though to strike the balance between the provisions of an emergency placement and disappointing another family by cancelling a prior booking (NB emergency overnight places rely on cancelling another child's planned break) (p275). 'Other children go and stay with their grandparents and things you know but he didn't have that option. So it's somewhere	**Overall score** ++

Types of service provision. **Population** Children. **Services of interest** Community supports (n=23), short-term residential care (n=63).	1 or more behaviour problems, of which sleep problems, aggression to others, damage to property, self-injury and hyperactivity were the most frequent (reported for more than 60% of children). **Relationship** A high proportion were lone parents (40%). **Residence** Mainly in rented accommodation (60%). **Socioeconomic position** Predominantly have low incomes (65%), dependent on welfare support benefits (55%). **Sample size** Total 123 families had accessed the services in the period 2008–10.	else for him to get used to living independently as well' (F25, p276). There seemed to be ambivalence among social workers in responding to the needs of families, especially when there was no apparent crisis. 'N was on the waiting list for over a year because it never came to a crisis but you don't want to go in as crisis management because sometimes it's just too late' (K35, p276). **Ambivalence to accessing services** 'Mum's been involved with social events... it's helped her accept that she wasn't failing; she has accepted that she was doing her best and that she did need support' (K33, p280). 'There's a sense in which I feel a failure for having to use the service. They have opened N to experiences, going on bus trips and staff taking him to places he wouldn't ordinarily go to with us, as he would find them stressful' (F24, p275). **Equity of access** 'Do you want the honest opinion? I think it's the people who shout the loudest get what they want' (K15, p276). **Family life**	

		(Benefit to parents) ‘The benefits I gain are uninterrupted sleep, the capacity to do my work as [I am] self-employed Disabilities’ (F24, p279). [Benefit to siblings] ‘It lets me get out and about with (names his sister) without pressure and it also gives her respite’ (F36, p2790). **The future** **Transitioning from child to adult** Creating a clearer pathway for families through the transition to adulthood will require concerted efforts from all partners. ‘There’s all this change – not only of them being adults but their safety net almost is taken away … and then this [short breaks] is going to be taken away from him and other clubs ... it’s as if one door is shutting and then another one’ (F33, p280). ‘... through the transition work that’s happened, it’s definitely going to benefit him to attend an adult service respite’ (K23, p280). ‘… but I think as he gets bigger and harder to manage a residential placement could possibly be better for him. He’s the type of child who will benefit from structure and routine and a safe environment for him to live in’ (K12, p280).	

		Inclusion/isolation Parents reported that at times the school were better equipped to enable social inclusion than they themselves were able to do: ‘I can’t take him out alone and even at [Action for Children] it takes 2 people. They can take him places and try new things ...’ (F15, p278). ‘Mum actually took the boys to London on her own for an overnight trip which is something she never would have dreamed of doing about a year or 2 ago, but all of this support has given her the confidence’ (R13, p279). **Navigating care services** ‘The services strive to integrate their work with that of the other services who are supporting the child and family’ (R14, p278). ‘What is great is the connection between the community sessions and the overnight respite – that works well you know, the staff being shared and knowing the child in different settings. Working across the 2 services that seems to be a smart way of doing things really’ (R12, p278). **Respite care**	

		A number of the families interviewed had 2 or more children with disabilities. The provision of short breaks for 1 child was of some assistance but in itself did not give parents a complete break from caring as both children may not be in the place at the same time. **Staff skills** Parents reported both positive and negative aspects of staff skills. Positive aspects Being non-judgemental, committed, confident and consistent. ‘I see them really as friends rather than workers and carers’ (F37, p277), ‘About 90% of the staff team go above and beyond [their hours], you develop that relationship and you are confident that those people have the skills’ (R24, p277), ‘but they seem to have a much deeper understanding of it, the severity, the rigidity’ (F36, p278). Negative aspects ‘... everybody is different and all the staff from [names another service] haven’t had the same training that we’ve had. They don’t know how to manage his behaviour’ (K22, p275). **Trust**	

		‘They’re a very typical working class family and an honest family and a hard working family. I think there is that sort of stigma you know that they don’t want social work involvement’ (K37, p275). ‘[As I came away, I thought] I’ve just left my kids with complete strangers and I didn’t know any of the staff at all’ (F15, p276). **Working together** Strategies could help parents learn they could use at home were welcomed and effective. ‘Also I think the parents are more able, they have embraced a lot of the strategies that the worker was able to offer them as part of how they now manage N’ (R31, p279). **Summary findings** Parents have mixed emotions when it comes to accessing these kinds of services. Parents and carers were less optimistic when the conversation turned to the future. Authors conclude: ‘short break services can make a vital contribution to retaining children who are challenging within their families but under some important conditions which this study has identified: notably, the management of complexity, the formation of trusted	

		relationships, and creation of tangible benefits for the child and for the family'. Concerns that the current climate of austerity may not invest in such services when children become adults, however failure to invest may lead to higher costs in the long term (p282)	

43. McGill P, Cooper V, Honeyman G (2010) Developing better commissioning for individuals with behaviour that challenges services: a scoping exercise. Canterbury: Tizard Centre

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study was commissioned by the Department of Health as a 'scoping exercise to develop better commissioning for individuals with behaviour that challenges services'. The aim was to map out the issues 'from a distance' and determine where future work was likely to be most useful. It involved: In-depth consultations with the families of 6 individuals with behaviour that challenges services aimed	**Participants** Carers/family members: n=6 families. Administrators, commissioners, managers: n=8 Commissioners **Sample characteristics** Adults. **Residence** Families: from across England. Commissioners: All were from London of South East Regions. Some were from local authorities, some from health, some were joint. Local authority commissioners	**Qualitative themes** **Access to support** 'Families consistently identified a lack of support for themselves in their role as a carer. The impact of not receiving adequate support had varying consequences affecting families financially, emotionally and physically. 'I wouldn't be able to count on 2 hands with spare fingers how many jobs' (p11). 'I have lost because I have put my son first' (father) (p13). The experiences of families demonstrate double standards when it comes to appropriate training – those who are trained and paid to provide support can	**Overall score** +

to provide an up-to-date picture of the outcomes of services for individuals and their families; extended interviews with 8 local authority and health commissioners sought to both identify obstacles to progress and consider the kinds of supports that might help in the process of local service development. **Service aims** Not stated. Not applicable to this study as it is a study about the views and experiences of families and commissioners of learning disability services. **Country** UK **Services of interest** Community support. **Content/ components of service** **Crisis prevention and management** Families consistently identified a crisis management approach to accessing services. Families	came from a mixture of metropolitan and county authorities. **Sample size** Not mentioned. **Sampling** Families were selected from those who had received information and support from the CBF and who were willing to be interviewed about their family experience. While inevitably repetitive of previous work it was hoped this would provide a very up-to-date picture of the outcomes of services for individuals with behaviour that challenges and their families. Commissioners: not stated how they were recruited, just where they came from. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** Not stated.	exclude an individual and the responsibility for that individual rests solely with the family, who are untrained and unsupported (p13). **Choice and control** Families consistently identified a lack of capable local services. For some families this has led to an out of area placement for their son/daughter. This placement has occurred not as a positive choice but because it was the only option in the face of inadequate local services. ‘My daughter was permanently excluded from our local special needs school aged 13 years. She now lives in a residential school 200 miles away, it takes about 3 and a half hours each way. We have to travel to that once every 6 weeks, I think it’s terrible really, there should be something in the local borough, but that is the situation unfortunately’ (mother) (p10). **Impact on carers** The impact on family members is often significant and substantial: ‘I had a breakdown in February and this is when everything changed for my son … and this is the reason why at the moment he is in residential care. If we were getting the help that we needed earlier things might have been different but we find it so frustrating	

identified and requested support and services early, yet it was only when they had reached crisis point that adequate services were offered. 'I just wanted to say I've had a very difficult time over the years. For years I've been asking social services to help with support during the holidays and it was refused and I knew something was going to happen. At the beginning of this year my son got arrested for smacking a baby ... The police had no understanding, and it was only because he was arrested that social services were involved and I've been given support. It makes me so sad and cross that things have to get to that point before you are given the help you need. It shouldn't have to take a child being arrested to get someone to listen to you, it shouldn't' (mother) (p11). **Source of funding** Department of Health.		that every step of Adam's life we have had to fight' (father) (p11). 'The additional burden of trying to access appropriate support via the system, in addition to pressures of supporting an individual with behaviour that is challenging, can be unsustainable: 'I mean last summer I was at the point of suicide really because when you are trying to deal with social services and the frustration that's there is just unbelievable. So it's just to get that point across really' (mother) (p12). 'Poor experience of accessing support and services over extended time clearly has a negative impact on the expectations of families – they have no experience of services being able to meet the needs of their relative' (p13). **Navigating care services** 'Negotiating the systems that are in place which are meant to support families was identified as a problem by the majority of those interviewed. It is difficult for families to find good practical information that will help them to get the support and services that their family member requires. Over the last ten years the Challenging Behaviour Foundation has received a high number of requests for information on transition from	

Methodology Qualitative. **Time to follow-up** No follow-up.		family carers.’ ‘I don’t know where to start, who to contact. I think all this information should be put into a booklet for people with special needs kids to say, you know, when they are young you are entitled to this and that and when they are older and transition you know, you need to contact this person or your local social services to just give people an idea of what they need to do, because they don’t know, they really don’t know. And I don’t think this borough is much different to any other borough really’ (mother) (p12). **Respite care** ‘Families often identify what local support mechanisms they would find helpful, but these are not available or offered: “If we had respite there is no way we would have put Adam in residential. If we were guaranteed respite every weekend, if we had a bit more support within the home, if I could phone social services and say this is the areas we are having difficulties with … Just sup- port me to help me take my son out, until my husband came in and respite that would be my top. Our local authority … have got no respite facilities for autistic children or young adults, it’s always been ‘it’s in the pipeline’ but how long this pipeline is and where it ends nobody knows”’ (mother) (p10).	

		Transition Most commissioners were aware that children placed in residential schools constituted a significant source of future out of area adult placements. While initiatives were being taken to address this in some areas, most commissioners reported a lack of joint working with the commissioners of children’s services, e.g. ‘I can tell you who my children’s commissioner is but I don’t see him very often... when I do I don’t understand what he is talking about because we use completely different sets of language and data and jargon’ (p17). **Working together** Families consistently report that they are not regarded as essential partners in planning support and services. Most families have a wealth of knowledge and expertise about how to support their relative well, and what works and what doesn’t, and this is not recognised or utilised: ‘No-one’s ever asked me what I want. Never. Never, ever. And I have had to fight … I’ve never been asked. I’ve just been told. Scrapping for the most basic of help’ (mother) (p14). **Costs** None.	

		Barriers identified **Capacity** A minority of the commissioners thought that there was a lack of emergency support that might help to prevent out of area placements. The decision regarding out of area and/residential placement is made when the support services are no longer able to cope. A couple of commissioners noted particular concern about future provision for young people with autism. In part there was some evidence of more people coming through to adult services than anticipated. In part, it was often difficult to identify suitable local providers who could continue the autism-specific approaches (such as TEACCH) used in residential schools/colleges (p18). Placement in residential college was also driven by the lack of suitable local college provision and there was concern that, although it was early days, the transfer of LSC funding to the local authority was not making an obvious difference. Most commissioners reported difficulties in finding suitable local providers for people whose behaviour was challenging and might otherwise be placed out of area. **Knowledge and skills**	

		Families consistently identified a lack of local expertise in understanding challenging behaviour. Most families acknowledge that many of the professionals who support their children are not equipped with the skills and knowledge to manage behaviour perceived as challenging: ‘At my daughter’s local special needs school the strategy was to isolate her in her buggy every time she lashed out. So this poor teacher was constantly taking my daughter, putting her in her buggy outside the classroom door and then a few moments later bringing her back in again, where my daughter would do it again. So she was in and out of the classroom door. After a couple of years of this her behaviour was dire because she actually preferred to be isolated … eventually the local educational psychologist said the school’s not coping, they don’t want her anymore, she’s going to have to go to...a residential school’ (mother) (p10). **Misconceptions** It is worth noting that families, and individuals, will express a preference for out of area placements, perhaps especially if the local area offers less housing space and, arguably, a more dangerous environment for their son/daughter. While	

		many providers described themselves as ‘specialist’ this was often mistrusted: ‘on their lovely glossy website they have challenging behaviour specialist and autism and you name it, they’re specialists in it ... there must be a very, very, very small percentage of providers who are actually able to do what they say they can do’ (p20). The perceived limitations of providers were linked to commissioner difficulties in judging the quality of provision. It was widely accepted that standard judgements (such as CQC ratings) were not sufficient for such specialist services and that a much more detailed focus on, e.g., the quality of staff support was required. **NHS–local authority interface** Commissioners reported a number of problems associated with continuing care. First, many people so funded were placed out of area and there was little resource to support bringing them back to the local area. Second, care manager input from the local authority was difficult to obtain. Third, some commissioners reported concerns regarding the continuing care assessment arrangements with long waiting lists, and assessors requiring additional support to properly assess people with learning disabilities. One commissioner felt that	

		continuing care arrangements created a significant incentive (see also Allen 2008; Mansell et al. 2006) for the local authority to ‘allow behaviour to escalate because it will bring people within the round of continuing care and full payment by the health service’ (p21). ‘The majority of commissioners reported problems between the local authority and the PCT regarding commissioning both generally and for people displaying challenging behaviour in particular. Pooled budgets were in the minority and there was ‘no appetite for joint commissioning’ (p21). In some areas this had clearly led to a ‘bunker’ mentality (‘I concentrate on health’) with each agency seeing the other as having a ‘different view of the world’ (p21). **NHS commissioning practices** Commissioners were labouring under a severe lack of, or difficulty in accessing, good quality information. Joint strategic needs assessments often contained only extrapolations from national data so that it was very difficult, for example, to establish the number of people displaying challenging behaviour in the local area. As a result services have been ‘commissioned on the basis of demand rather than on need’ (p19). Also lack of specification of the commissioner role so that wide	

		variation in the nature and quality of commissioning practice. One of the main barriers that families identified was a lack of local commissioning in response to need. They are offered ‘what is currently available’ (usually an out of area residential care home), rather than what is possible: ‘what I actually wanted for my son was a local support service designed around his needs. What I was offered was an out of area residential care home, because that just involved a few phone calls and negotiating the price. A local individual service would have to be set up from scratch – somewhere to live and staff to support him - and no one seemed to be able to do it’ (mother) (p14). The concern with data, in particular, was widespread. One commissioner reported 2 cases in the last year where (s)he only found out about the person 3 months before adult provision was required. More generally, there remained problems about identifying the number and needs of individuals far enough in advance, in part because of the different databases involved (see also Emerson and Robertson 2008). Even where approximate numbers were known there was concern about the validity of the information available with	

		some feeling that it was not always possible to rely upon children's services needs assessments: 'I think it is very difficult is to get a handle on what their needs are because they are so subjective so ... you know this young man is on £4,500 per week placement and children's services are really promoting that this is somebody with incredibly high needs ... but we have learnt that you can't assume that he does have that level of needs. In fact we have got quite a few examples of individuals who were getting 2 to 1 input as children and we've assessed them and come out with our packages and they are managing absolutely fine with much, much less support' (p17). Commissioners themselves, usually had very limited direct knowledge of specific clients or services and relied on contract monitoring processes which did not always focus on outcomes and were, inevitably, much more difficult to operate with out of area placements (p20). **Resources** A minority of the commissioners thought that there was funding/finance issues such as the difficulty of securing money to 'double fund‟ the transition between an out of area and in area placement.	

		Roles and responsibilities A minority of the commissioners thought that there was difficulties around the provision of services for people with mild/borderline learning disability which was often a source of dispute. ‘Some commissioners noted the potential for preventative, early intervention at a younger age to reduce the likelihood of residential school placement but recognised that there were limited incentives for children’s services to carry out such work as the costs during childhood were often shared across agencies and savings might primarily affect adult services. This prompted discussion of the value of a “whole of life” perspective: “we start seeing people, stop seeing children or adults. You start to see somebody who has, if you like, ‘a career of need’”’ (p18). **Facilitators identified** **Commissioning** Most commissioners thought a national programme board to drive the development of local services would be a good idea but there was also a general view that any such initiative should be ‘mainstreamed’ as much as possible within existing performance management arrangements.	

		Another commissioner noted their use of the person-centred commissioning Now pathway (Fulton and Winfield 2008) to help develop local services for individuals. While not a strategic framework this helped to offset the frequently reported difficulties facing care managers who were described as ‘usually looking for placements in crisis which means that you don’t have time to plan properly. You just place in what’s available and hope. And what’s available? Residential care is available’ (p19). **Staff skills** Most commissioners were positive about the suggestion of more training and support for provider organisations, though with some concern about its targeting and how it would be financed. One commissioner suggested that it would be useful to have a nationally recognised module for care staff. **Summary of findings** This study sought the views of families of individuals with behaviour that challenges and commissioners of services to find out about the current provision of services and to identify obstacles to progress and consider the kinds of supports that might help in the process of local service development. Families reported a lack of	

		expertise and capability in understanding and responding to challenging behaviour in local services. This was seen as an important factor in the use of out-of-area placements. Access to services was reported to be extremely difficult by families other than at times of crisis. As a result opportunities for crisis prevention were missed. Families also reported a lack of support and training for themselves in their roles as carers, with often detrimental effects on their physical and mental health. A lack of information and training hampered the extent to which families could plan realistically, and hopefully, for the future. Families consistently reported not being included as essential partners in planning for their relatives. It was noted that all of the experiences reported by families have been commonly reported in the past and are well-documented in the professional and academic literature. Commissioners reported continuing difficulties around the development of local services for people labelled as challenging. Discussions with commissioners identified a range of barriers to local service development: - Lack of coordination between adult and child services.	

		- Lack of a systematic commissioning framework based on good quality information about the quantity and nature of local need. - Lack of confidence in the ability of locally available providers to deliver high quality supports to people labelled as challenging. - Wide variation in the application of NHS continuing care criteria and associated inter-agency perverse incentives. - (With exceptions) continuing difficulties between local authorities and the NHS in coordinated and integrated working. - Lack of specification of the commissioner role so that wide variation in the nature and quality of commissioning practice. - Family preferences (sometimes) for specialist, out-of-area placements perhaps in the context of earlier, local placement failures. - Lack of collaboration and understanding (in some areas) between commissioners and clinical support services. **Implementation issues** 'In the absence of any significant attempt to prevent/intervene early around challenging behaviour and mental health problems, demand (especially from residential school and college leavers) may	

		seem unremitting and remains somewhat unpredictable. Commissioners faced with difficulties in finding suitable local providers, and with variable clinical support available, use established, out of area providers even though this makes it more difficult to monitor and judge the quality of provision. Once so placed many service users and their families are reluctant to consider a more local placement and will resist, often with the assistance of existing providers, any attempt to move back to the local area. The problem is exacerbated in some areas by poor inter-agency relationships and the use of continuing care criteria to fund placements which create an incentive for local authorities to avoid supporting local competence in the absence of closer partnership working across the health and social care economy. Given the frequent lack of systematic commissioning frameworks and a clearly defined commissioner role such processes operate piecemeal and prevent the identification or strategic tackling of the issues' (p27). **Study limitations** The main limitation with the study is that it only a 'scoping' study, intended to map out the issues 'from a distance' and without, necessarily, being able to detect the	

		detailed nature and generality of each issue. Only a small number of commissioners were interviewed and they all came from London or the South East, plus there was no information provided about how they were recruited, so cannot tell if their might have been any bias in the selection process. In addition, only a small number of families (n=6) were interviewed, and there is very little information about the families to know if their views are likely to be representative of all service users. However, the Challenging Behaviour Foundation says ‘these experiences are not unique to the 6 families interviewed and are consistently raised by family carers who contact the Challenging Behaviour Foundation, often in crisis, for information and support’.	

44. McGill P, Tennyson A, Cooper V (2006) Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: their perceptions of services received and expectations of the future. The British Journal of Social Work 36: 597–616

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To gather information from parents of children with severe	**Participants** Carers/family members.	**Satisfaction with care** Respondents gave generally positive ratings of	**Overall score**

learning disabilities and challenging behaviour attending 52-week residential schools about 3 main topics: (i) The support they received prior to their child's placement at residential school. (ii) The suitability and quality of their child's current residential school placement. (iii) Their concerns and hopes for their child's future. **Service aims – explicit** 1. Residential schools provide an intensity of educational support not typically available in local special schools (McGill et al. submitted for publication). 2. Provide year-round respite for the families of children and young people who, in a context of inadequate or non-existent local support, may have found their situation unsustainable. 3. More controversially, by providing a 24 hour service or 'curriculum', they ensure a consistency of provision which facilitates the development and management of their pupils.	**Sample characteristics** Adults（respondents). **Age** Respondents survey: had an average age of 45.3 years (range: 28–61). Respondent's telephone interview: had an average age of 46.2 years (range: 35–57). Children and young people had an average age of 15.2 years (range: 8–19; 86%13 years or over). - Children and young people：direct service users. **Gender** Children and young people (54 male, 19 female); parents questionnaire: 59 female 14 male; parents telephone interview: 13 female, 1 male. **Health status** In most cases, children had an identifiable diagnosis, with the majority (59% of the total sample) having an autistic spectrum disorder. 66% of the children and young people were reported to have at least 1 additional disability or persistent medical problem including physical disability (26%), visual impairment (26%), epilepsy (19%) and hearing impairment (14%). Many children (42%) had more than 1 additional disability. **Ethnicity**	their child's current placement. They perceived it as generally meeting their child's needs (average rating of 4.1 on a 5-point scale) and providing good quality direct care (average 4.2). One parent said that 'care staff have a good attitude and knowledge of our son's needs, they also phone us at home if unsure about his behaviour' (p608). Although positive overall, parents did express concerns, especially about the rate of turnover of care staff, the youth and inexperience of care staff, and the quality of care (not education) and communication between the school and family. **Caregiver burden/distress** Parents of children who were further away from home visited very significantly less frequently ($\chi2=71.3$, df = 30, $P < 0.0001$), with almost half of children placed more than	++

<table>
<tr>
<td>Country
UK.
Source of funding
Not reported.
Methodology
Survey.
Services of interest
- Residential school.
- 52-week residential school.
Content/components of service
- Assessment reports and intervention plans.
- Family counselling and support.
- Placement development.</td>
<td>Total 90% of respondents were White, 6% Asian, 1% Black, 3% other. Telephone interviewees: 2 out of 14 coming from a minority ethnic background.
Level of need
All except 2 children were rated as displaying a number of challenging behaviours. Aggression, the most commonly reported challenging behaviour, was rated as a ‘serious’ problem for 22 children. On average, children were reported to be displaying 10.5 different forms of challenging behaviour (range: 0–14). See table under ‘Characteristics of behaviour’ for further detail.
Relationship: Survey respondents: were completed mainly by birth parents (97% in a 4:1 ratio of mothers to fathers), the remaining 2 being completed by a grandmother and an adoptive mother. Telephone interview respondents: 12 mothers, 1 father and 1 grandmother.
Characteristics of behaviour
<table>
<tr><th>Behaviour</th><th>% of sample reporting</th><th>Mean rating</th></tr>
<tr><td>Aggression</td><td>90</td><td>3.4</td></tr>
<tr><td>Social disruption</td><td>88</td><td>3.6</td></tr>
<tr><td>Destruction</td><td>85</td><td>3</td></tr>
<tr><td>Non-compliance</td><td>84</td><td>3.2</td></tr>
</table></td>
<td>100 miles away seeing their parents less than monthly while the majority of children placed less than 50 miles away saw their parents fortnightly or more frequently; 66% of parents reported that there were constraints on how often they could visit, the most common being distance from home (63% of those noting constraints), cost (35%), work (33%) and other family commitments (31%).
Person -centred outcomes
Choice and control
The majority (73%) of placements were more than 50 miles from the family home; 84% would have liked their son or daughter to attend a school that was closer to home. One parent put this particularly graphically: ‘I wish my son could have stayed at the school that he was at with 1:1 and 52 week school and</td>
<td></td>
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Temper tantrums	82	3
Self-injury	80	3.3
Physical disruption	79	3.1
Sleeping problems	79	2.8
Hyperactivity	78	3
Rituals	77	3.1
Wandering	73	3.2
Inappropriate sexual behaviour	73	2.4
Stereotypy	68	3
Other	15	4.3

Ratings of severity were made on a 5-point scale where 1='displays the behaviour but cause minimal problems' and 5='displays the behaviour and causes a serious problem'.

Sample size

Survey questionnaire responses: n=73; telephone interviewees: n=14.

living at home but there was no provision. What a waste of money that my son has to go miles and miles away and his social worker and goodness knows who else has to go visit him all paid for by the tax payer' (p608).

Qualitative themes

Access to support

Challenging behaviour was, for other parents, manifested as a failure of support, e.g. 'Our daughter did not sleep more than an hour or 2 at night, we were awake and on duty 24/7, no help offered' (p604).

Family life

Total 66% of parents reported that there were constraints on how often they could visit related to cost, other family commitments and work. These were likely to be exacerbated by social and economic disadvantage. One parent said 'I am on my own, I can't afford the

		fare I wish my child could be closer to me and I could visit more often' (p609). Others mentioned the difficulties arising from their own disability or poor health. **The future** 'It's like the local authority think that when they are 19 they are OK and they are going to get up and go off to university' (parent of 18 year old whose post-school placement has yet to be planned) (p609). Parents rated their concern about a number of aspects of their child's future on a scale from 1 ('not worried') to 5 ('extremely worried'). Responses on all ratings indicated high levels of worry, e.g. 75% were 'extremely worried' about the availability of suitable, future services. The worries described by parents related mainly to the absence of planning for the future, their concern that	

		their son/daughter would be placed inappropriately because of funding limitations and concerns that it might be expected that their son/daughter returned to live with them. ‘In many cases, parents reported that no future placement had been arranged despite the date for the end of residential school being imminent.’ ‘In the absence of a plan, or even where such exists, many parents expressed concerns about the nature of their son/daughter’s future placement.’ Parents also expressed clear views about a more desirable future. This typically involved their son/daughter living closer to them, receiving continued educational input and living with or interacting with other young people. The mother of an 18 year old said ‘Ideally I would like him to be half an hour from home in a very small home	

		.looked after by familiar people where he is loved' (p611). **Impact on carers** Prior to their current school placement, 15% of respondents had attended at least 3 (the questionnaire asked only about the 3 most recent schools) schools. Further investigation of the group of 12 children who had attended at least 3 previous schools showed an increasing pattern of residential provision further away from the family home. Distances from home to school were recorded in ranges. Notional distances were calculated using the mid-point of each range (e.g. 25 when the range is 0–50) and 250 when the range is 250+ miles. On this basis, median distance from home to school increased from 25 to 125 miles over the 4 placements, with the percentage that were	

		residential gradually increasing from 10 to 100%. **Inclusion/isolation** Other parents reported similar experiences at school both in terms of exclusion, ‘our child was excluded from day school 4 months before leaving home, during this time we received no help whatsoever’ (p604), and quality of provision, ‘day school only useful because it gave him a routine’ (p605). **Navigating care services** Page 10: The process of obtaining a placement at residential school was also characterized by parents as a negative and stressful experience. Most reported a lack of knowledge amongst professionals about what schools were available and might be appropriate for their son or daughter. Consequently, parents often took on the task of ‘finding	

		out what provision was available on our own, no one offered direction or advice' (p606). Many remarked on the apparent incompetence of the process, e.g. 'Then I would find out that the agency meeting met and that the wrong person would go with the wrong piece of paper for the wrong signature' (p606) and some suggested that such incompetence served a purpose: 'basically I think the education department were not overly motivated because of the money' (p606). **Respite care** Often difficulties in coping with challenging behaviour led to services breaking down. Even though 50% of respondents gave an 'excellent' rating to the usefulness of respite care (average rating of 4.0), many concerns were raised about its availability which over 30% rated as 'very	

		poor’ (average rating of 2.7). Many parents described their child’s exclusion from respite care or about the poor quality of what was provided, e.g. ‘respite was desperately needed, but staff were not knowledgeable about his behaviour’ (p604). Many parents reported frequent instances of neglect. Most reported high rates of change both amongst carers in respite services and amongst professional staff such as social workers. **Staff skills** A small number of parents noted positive experiences with supportive and collaborative professionals, e.g. 1 parent described her son’s social worker, ‘she is just so hard working, so on the ball, so in tune, so supportive of me and my son, she takes people to task’ (p606).	

		Transition Most had less happy experiences: ‘we have tried to get them on board since he has been 16 and a half asking why we had no input from the young adult team he is 19 soon and we have heard nothing’ (p610). Such experiences were sometimes accompanied by parents’ fears that they would be left to pick up the pieces: ‘I do know children who haven’t been found a placement and they have gone home and it was a horrendous experience for the family and the young adult’ (p610). **Cost information** Two main (non-financial) costs are identified in the study. First, the study shows the considerable impact of distance between residential school and family on the maintenance of family contact. Second, this reduction in family contact which is, of course,	

		a cost in itself, also increases the vulnerability of children to abuse and neglect. **Barriers identified** **NHS–local authority interface** Parents reported very limited assistance or support from their local authorities (both education and social services) to maintain higher levels of contact with their child. Only 3 parents mentioned having travel/ accommodation costs paid or partly paid by their local authority. 'When the possibility of a residential school placement is suggested or sought, it is not surprising to find that the responsibility of identifying a particular school and convincing the (often reluctant) local authority and local education authority of the case for funding also falls to parents' (p612).	

		Facilitators identified **Service design** The evidence presented in this study suggests that given the widespread poor quality of family support, if such support included, much more than it does currently, focused and effective approaches to managing and improving behaviour at school and at home, this may help to prevent the need for residential school. **Summary of findings** - Family experiences prior to the current residential school placement were, almost universally, extremely negative and stressful. - Professional advice was reported to be often ill informed. - Parents were generally very positive about their child’s current residential school placement, albeit with some concerns about	

		the quality of care, the extent of staff turnover and the training/experience of junior care staff. - Main concern with current placement: its distance from home, this reducing the amount of contact families were able to have with their child. - Parents expressed great concerns about the future and reported a lack of local planning for their child. - The evidence suggests that given the widespread poor quality of family support, if such support included, much more than it does currently, focused and effective approaches to managing and improving behaviour at school and at home, this may help to prevent the need for residential school. - Main impacts of distant 52 week residential education: on parent–child relationships, significant	

		costs to families and an increase risk of abuse to vulnerable children and young people are significant. **Study limitations** The views reported are those only of parents. These should not be interpreted as a proxy for the views of children and young people in 52-week residential schools especially in respect of direct experiences of such schools. ’Apparent parental satisfaction with residential school placements may reflect the substantial improvement in their family situation rather than, necessarily, being a comment on the school and may not be consistent with the experience of their children (Morris, 1997; Abbott et al., 2001)’ (p611). While the questionnaire sample is relatively large, it is self-selecting and caution should be exercised in	

		concluding that the findings reflect the population of parents having children at such schools. Findings based on qualitative comments either to the questionnaire or by the much smaller sample of telephone interviewees should be treated with similar caution.	

45. McGill P, Vanono L, Clover W et al. (unpublished) Preventing the challenging behaviour of adults with complex needs in supported accommodation.

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim While challenging behaviour is often managed as though it were a problem of individuals, there is widespread recognition of its frequent relationship with the quality of social care. This project set out to evaluate the impact of a strategy for improving social care on challenging behaviour and associated outcomes (p2).	**Participants** Professionals/practitioners Adults with learning disabilities and behaviour that challenges. **Sample characteristics** **Adults** **Age** Adults with learning disabilities at baseline. Mean=39.7.	**Social care outcomes** **Social care standards** Standards set and achieved in experimental group setting- Mean percentage achieved Activities and skill development, 84.0%. Communication and social interaction 56.4%. Health 77.3%.	**Overall score** ++

Service aims Improvement programmes were operationalised as standards to be achieved during intervention. Their achievement was supported through a range of activities centred on coaching managers and staff to enhance their performance and draw more effectively on existing resources (p2). **Country** UK. **Methodology** Comparison evaluation. **Services of interest** Positive behavioural support. **Components of service** Regular review: monthly meetings with manager to review progress against the standards initially set. Progress chasing. Researchers played a local leadership role in which they encouraged the achievement of the standards using a variety of means. Protocols: developing and supporting the development of documentation	Range: 19–84 years. Characteristics of staff participants at baseline Up to 25 13.0% 26-35 26.7% 36-45 27.4% Over 45 33.0%. **Gender** Characteristics of adults with learning disabilities at baseline Male 43%. Characteristics of staff participants at baseline Male 28.1%. **Ethnicity** Characteristics of adults with learning disabilities at baseline White 90.1%. Characteristics of staff participants at baseline White 73%. **Sample size** Comparison numbers: characteristics of adults with learning disabilities n=43 Characteristics of staff participants n=170 in 13 residential settings. Intervention number: characteristics of adults with learning disabilities n=38 Characteristics of staff	Physical environment 73.8%. Relationships with family and others 77.2% Service staff 75.7%. Service management 80.3% Wider organisation 68.0%. Overall 75.2%. **Clinical outcomes** **Behaviour that challenges** In the experimental group, the mean percentage score changed from 42.22 (sd=5.85) at T1 to 54.58 (sd=21.31) at T2 while, in the control group, the change was from 46.67 (sd=16.37) to 42.22 (sd=18.18). Difference scores were significantly different between groups ($t=7.63$, $df=40$, $p<0.005$, 1-tailed, Cohen's $d = 0.94$, 95% CIs 6.44-29.91) Experimental and control group difference scores were significantly different ($t=2.13$, $p<0.025$, 1 ailed, $df=42$, Cohen's $d=0.66$, Mean difference = 20.23, 95% CI .02-38.45). ABC Irritability. Mean (sd) Experimental T1 - 13.95 (7.43), T2- 5.65 (4.57) Control T1-16.54 (9.12), T2-16.54(9.12) $p<0.025$, $d=0.61$.	

Links to other services: Utilisation of existing, local professional resources from outside Dimensions (the service provider). They were encouraged to seek the input of staff from local community learning disability teams and other sources of potential support. Staff skills: coaching staff and manager, staff and manager training. Utilisation of existing Dimensions resources - Where appropriate, managers were encouraged to draw in support from other parts of the organisation. This included a coaching resource which enabled managers to receive support with difficult supervision or management issues and a training resource which provided training for staff specifically related to active support. **Time to follow-up** Follow-up: 12–18 months.	participants n=100 in 11 residential settings. **Sampling frame (if any) from which participants are chosen?** Dimensions (a service provider) was asked to identify 25–30 residential settings with an average of 4 adults with learning disabilities living in each setting of whom (on average) 2 had a recent history of displaying frequent and/or serious challenging behaviour. **Treatment of groups** Prospective allocation into more than 1 group. **How do the groups differ** Explicitly stated. Geographical location: North of England –experimental group 6, control 7 South of England – experimental group 5, control 6. Average number of staff (range) experimental group 9.8 (5–18) control 12.9 (5–30) Number of adults with challenging behaviour Experimental group 24, control 30 Number of adults without	ABC Lethargy Experimental T1-9.80 (6.69), T2-3.25(3.32) Control T1-9.54(6.31) , T2-7.87(8.52) $p<0.05$ d=0.53. ABC Stereotypy Experimental T1-4.50(3.95), T2-1.15(1.72) Control T1-4.87(4.29), T2-4.62(5.05) $p<0.025$ d=0.65 ABC Hyperactivity Experimental T1-11.10(8.35), T2-4.25(3.81) Control T1-15.12(7.65), T2-11.75(9.96). ns.d=0.32 ABC Inappropriate speech Experimental T1-3.30(4.31), T2-0.45(1.05) control T1-2.92(3.37), T2-2.92(3.50). $p<0.025$ d=0.70. **Satisfaction** **Staff satisfaction** Means and standard deviations. Satisfaction (all) Experimental T1-3.82 (1.04), T2-4.05(0.85) Control T1-3.82 (0.98), T2-3.73 (1.13) Satisfaction (only those present at both T1 and T2) Experimental T1-4.06 (0.54), T2-4.33 (0.59) Control T1-3.91 (0.83), T2-3.72 (1.14). Mean Dyer score (all) Experimental T1-89.60 (15.60), T2-92.18 (11.59) Control T1-93.57 (15.53), T2-88.14 16.43) Mean Dyer score (only those present at both T1 and T2)	

	Challenging behaviour Experimental group 14, control 13. Mean total score on ABC across settings for adults described as challenging (range) Experimental group 43.5 (21–89) control 57 (22–135). Mean total score (weighted by number of service users) on cohort ABS across settings (range) Experimental group 21.3 (5-55), control 41.9 (13–71.6). Number (percentage) of adults with autism diagnosis Experimental group 13 (34%), control 11(26%). **If prospective allocation into more than 1 group, what was the unit of allocation?** Groupings, or clusters of individuals **If prospective allocation into more than 1 group, was the allocation sequence concealed?** Yes. **If prospective allocation into more than 1 group, which**	Experimental T1-93.63 (9.19), T2-95.44 (9.41) Control T1-94.87 (14.37), T2-89.42 (16.05) Difference scores for overall satisfaction were significantly different between groups for the whole group comparison (t=1.84, df=164, p<0.05, 1-tailed, 95% CIs: -0.01 to +0.65, Cohen’s d=0.29) but not for the comparison of these present at both T1 and T2 (t=1.40, df=70, ns, 95% CIs: -0.17 to +1.09, Cohen’s d=0.33). Significant differences were also found in modified Dyer scale scores where, in both comparisons, staff in experimental settings showed higher satisfaction at T2 while staff in control settings showed lower satisfaction (All: t=1.71, df=176, <0.05, ne tailed, 95% CIs: -0.40 to +8.48, Cohen’s d=0.26; those resent at both T1/T2: t=1.98, df=78, p<0.025, 1-tailed, 5% CIs: +0.31 to +14.22, Cohen’s d=0.26). In both sets of comparisons the comparison for the larger groups involved comparing T2 scores only. **Staff stress** (The maximum score is, 24. A score of 5 or more is normally regarded as outside of the normal range and indicative of stress. Mean (all) Experimental T1-3.54 (3.92), T2-3.22 (4.08) Control T1-3.98 (4.12), T2-4.31 (4.27) Perc of 5 or more	

	method was used to generate the allocation sequence? Random. Residential settings were allocated by the Principal Investigator to experimental or control group using the computer programme MINIM this minimises differences between groups	Experimental T1-26%, T2-22% Control T1-36%, T2-41%. Mean (only those present at both T1 and T2) Experimental T1-2.70 (2.60), T2-3.33 (5.21) Control T1-4.02 (4.41), T2-4.52 (4.70). Perc of 5 or more Experimental T1-24%, T2-24% Control T1-32%, T2-38%. At T1 the difference in stress scores between staff in the experimental and control groups was not significant (t=0.79, f=257, ns, 95% CIs: -1.46 to +0.59, Cohen's d=0.10) but became so at T2 (t=1.72, df=188, p<0.05, 1-tailed, 95% Is: 2.32 to +0.16, Cohen's d=0.25). The comparison of staff in lace at both T1 and T2, however, found no significant difference in change scores between the groups (t=0.15, f=85, s, 95% CIs: -1.59 to +1.85, Cohen's d=0.03). **Service use** **Staff contact/assistance** All staff contact. Mean (sd) Experimental T1 - 30.67 (21.89), T2 -54.67 (33.24) Control T1-30.80(25.53), T2 - 40.82 (33.29). t=1.14, ns, df=50, 95% CIs - 9.38-37.35, Cohen's d=0.32. Assistance. Mean (sd) Experimental T1- 3.34(4.73), T2-6.23(7.42) Control T1- 2.53(3.73), T2- 3.00(3.89). t=1.45, ns, df=41, CIs: -0.85- 5.69; Cohen's d=0.45.	

		Barriers identified **Capacity** High turnover found in social care does make comparison over time difficult as measures are often being completed by different people at T1 and T2. This could be addressed in future research by a greater focus on the use of measures that do not depend upon social care staff for their completion **Summary of findings** Staff views of impact of intervention - Positive impact on ... Health Strongly Disagree and Disagree n (%) 6 (8.3%) Neutral n (%) 25 (34.7%) Agree and Strongly Agree n (%) 41 (56.9%) Conclusions: some challenging behaviour in social care settings may be prevented by relatively simple interventions which attend to the quality of social care support, especially with respect to communication, health, activities, relationships and the wider social and physical environment.	

46. McKenzie K, Paterson M (2010) Evaluating an assertive outreach team for supporting clients who present behaviour that challenges. British Journal of Learning Disabilities 38: 319–27

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study evaluates an assertive outreach team which aimed to help support people with a learning disability who displayed challenging behaviour in their own environment. The main aims of the service is to prevent out-of-area placements and delayed discharge if individuals were admitted to hospital. **Service aims:** Explicit – the remit of the assertive outreach team (AOT) was to provide assessment and support to individuals who were in danger of their community placement breaking down because of severely challenging behaviour. **Country:** Scotland. **Source of funding** Not reported. **Methodology**	**Participants** Professionals/practitioners; administrators, commissioners, managers. **Sample characteristics**: Adults. **Age** Clients average was 36 (range 22–65). **Gender** Of the 30 clients referred to the AOT, 21 were men and 9 women. **Level of need** Many individuals displayed more than 1 behaviour that challenging, with the most common reason for referral being for verbal or physical aggression (18), followed by self-injurious behaviour (6), antisocial behaviour (5) and	**Clinical outcomes** **Behaviour that challenges** The effectiveness of the service was evaluated purely in terms of a reduction in challenging behaviour: the service was considered by the AOT staff to be effective at significantly reducing or elimination challenging behaviour. Referrer ratings of the effectiveness of the service varied, but in general the input was rated as being ‘quite useful’ and was reported as having led to a reduction in challenging behaviour in 71% of clients. **Satisfaction with care** From the referrer’s perspective, not the service user. Overall referrers were satisfied with the AOT, although 2 respondents noted that the input had been variable and that they had been satisfied with the input of some staff and very dissatisfied with the input of others. In terms of the strengths of the AOT, nearly half of the respondents	**Overall score** +

Mixed methods. **Services of interest** Behavioural support. **Content/components of service** - Assessment reports and intervention plans: The AOT was to provide assessment and support to individuals who were in danger of their community placement breaking down because of severely challenging behaviour. - Crisis prevention and management. - Person centred support. - Staff skills.	sexually inappropriate behaviour (1). The average period of input from the team was 7.9 months per client (range: <1–26 months). **Sample size** AOT staff and service managers (6), members of the CLDT (11) and staff from support services who had received input from the team (7). Total n=47 questionnaires distributed, and 24 were returned, giving a response rate of 51%. At the time of the evaluation, the service had received 30 referrals (mean per month = 2.1), all of which were considered to be appropriate by the AOT staff.	referred to the expertise and approach to work. (p8) **Qualitative themes** **Access to support** Of the 30 clients referred to the AOT, 21 were men and 9 women. The average age was 36 (range 22–65). Referrals were received from all geographical areas of the health board area. Over half of the referrals (16) were received from community nursing, with the remainder being received from a mixture of other health professionals (10) and social workers (4). - The average AOT waiting time was 2.6 days (range 0–19 days). The mean rating by referrers of how quickly they felt the AOT had responded to their referral was 3.6. - Total 3 respondents were unsure about the referral route into the service. - The service was also viewed as accessible and able to provide intensive input. **Navigating care services** The most common area of dissatisfaction was in relation to a lack of clarity about the role and remit of the AOT, the relationship with the wider learning disability service and communication issues. These constituted	

		81% of all responses in relation to negative aspects of the team. **Stress and strain** In a 1-year period, the AOT service experienced 330 h of short-term staff sickness. This compares with an average figure of 422.5 h per month) 1 for the decommissioned inpatient unit (Murray et al. 1999a). Only 1 staff member had left the service, and the average rating of staff satisfaction indicated that the staff were, on the whole, reasonably satisfied with their work. This suggests that the AOT is a less stressful and more satisfying working environment for the staff compared to the inpatient unit. **Staff skills** The time spent by the AOT in providing staff training was an average of 1.5 days per month, comprising 40 training sessions to a total of 67 staff. The impact of this training had not been formally evaluated at the time of writing, however, and this was highlighted as a goal for the service. In terms of the strengths of the AOT, nearly half of the respondents referred to the expertise and approach to work. The AOT staff were seen as professional, objective and keen to help, as well as having the skills and knowledge required.	

		Working together Multi-professional working Total 13 respondents indicated that they had worked jointly with the AOT, and the mean rating relating to the usefulness of this joint approach was 3.5. 5 of the AOT members had worked jointly with other professionals in relation to clients, and their mean rating of the usefulness of this joint approach was 4.8. In relation to liaison with other members of the learning disability services, the mean rating from non-AOT members was 2.8. This compared with a mean rating of 3.7 by AOT members. The composition of the AOT was constrained by the need to re-provide for the staff from the de-commissioned inpatient unit and therefore comprised solely of nursing staff. Joint working took place with 13 staff members in relation to vet clients. In addition, AOT staff attended the learning disability team meetings and had developed a clear pathway for involving CLDT members. This joint working was seen as useful overall; however, AOT staff rated the contact more highly than other respondents. **Costs?** No. **Service use**	

		Length of hospital stay. There had been no delayed discharges since the establishment of the AOT. **Barriers identified** **Knowledge and skills** Limited knowledge/skill of staff. **Organisational structures/ cultures** Communication was a theme under the weaknesses of the service: Lack of communication with others in LDS. Lack of representation at meetings' 'not a lot of communication given unless asked for' 'little or no attempt made to gather my views or to feedback on their involvement' (p322). Other issues included: need to improve communication; response time to accept cases; variable service experience of AOT; relationship with wider LD service and team, e.g. 'Could the AOT be merged with our other nurses to make work more integrated?' (p323;) 'Lack of dedicated input from other disciplines e.g. psychology' (p323). **Roles and responsibilities** Two main issues identified from respondents: - Clarity/expectations of role and remit.	

		- Unrealistic expectations regarding role of team. Example quotes: ‘I’m still not clear about all the areas that AOT work in’. ‘Need more coordination and clarity of roles and responsibilities. Gave some advice but no practical involvement.’ ‘Need to review type of work accepted and prioritisation processes.’ ‘Used inappropriately e.g. to replace service providers.’ ‘LD team expectations of outreach role-used to plug gaps.’ ‘Value given in our role.’ ‘Too much time spent shoring up 1 other service and crippling the AOT.’ ‘Management focus drawn away from main purpose of AOT.’ ‘Lack of self-promotion: informing other disciplines/services of AOT purpose’ (p322). **Facilitators identified** **Collaborative team working** Teamwork/liaison. Ability/time to work alongside carers ‘Working alongside support agencies’; ‘Working collaboratively with all parties involved. **Multi-agency–interdisciplinary involvement** **Staff skills** Expertise/approach to work was a common theme expressed in these quotes. ‘Level of	

		skills/knowledge beneficial to completing pieces of work.’ ‘Objectivity in ongoing situations which are challenging.’ ‘The AOT is professional and willing to help.’ ‘Great enthusiasm to work with others.’ ‘Time for more in-depth work – Ability to look at wider issues affecting behaviour.’ ‘Ability and time to look at the wider picture of CB.’ ‘Having the time to spend completing process and research involved’ (p322). **Speed of response** Team was seen as a facilitator as it was: ‘On-site’ ‘Availability to engage’ ‘ability to respond quickly to crisis’ ‘reduce patient admission to hospital’ – intensive input. The ability to provide more intensive assessments/observations (p322). **Ways of working** The team worked in evidence-based/methodical way. **Roles and responsibilities** Distinct from learning disability team. Separate team within wider learning disability team. **Summary of findings** - Referrer ratings of the effectiveness of the service are reported as having led to a	

		reduction in challenging behaviour in 71% of clients. - The results indicated that the AOT provided a locally based service that was generally effective, efficient, accessible, equitable and appropriate. - The main strengths of the team were staff skills and professionalism, whereas the most frequently cited weaknesses centred on issues of liaison, communication and the role and remit of the team.	

47. National Audit Office (2015) Care services for people with learning disabilities and challenging behaviour. London: NAO

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Examine the challenge the government faced and the performance against the commitments in Transforming care: A national response to Winterbourne View Hospital and the accompanying DH Winterbourne View Review – Concordat: Programme of Action (the Concordat) (2012). The study also identifies	**Participants** Professionals/practitioners, clinicians, nursing staff, managers, directors and board members at the mental health hospitals. Administrators, commissioners, managers. Adults with learning disabilities and behaviour that challenges. Focus group and individual	**Cost information** The 2013 published learning disability census data was used to estimate the cost of treating people in inpatient hospital services. In 2012–13, the NHS spent £557 million on this care for people with learning disabilities within the 58 NHS and 49 independent hospitals, with assessment and treatment centres. In addition, 2013-14, local authorities spent £5.3 billion on services for all adults with learning disabilities. However, there is no	**Overall score** -

barriers to transforming care services. **Service aims** Implicit. By 1 June 2014, if anyone with a learning disability and challenging behaviour would be better off supported in the community, then they should be moved out of hospital. **Country** UK. **Methodology** Qualitative evaluation. **Source of funding** Government department.	interviews with people with learning disabilities and behaviour that challenges services and their advocates in hospitals and living in the community. **Sample characteristics** **Residence** The average length of continuous inpatient stay (including transfers between hospitals) in the 4 hospitals visited in the study was 6 years and 4 months. The average length of stay, including admissions and readmissions, in the 4 hospital visited in the study was 17 years and 4 months. **Legal status** In September 2014, of the 2,600 people in mental health hospitals, 83% had been sectioned under the Mental Health Act, with 46% receiving a civil section and 37% receiving a criminal section. A further 11% were admitted under normal referral procedures, and 5% fell into	separate cost breakdown for community services for those with a learning disability and challenging behaviour. **Summary of findings** The government did not achieve the central goal of moving all people, where appropriate, out of hospitals by 1 June 2014 because no mechanisms existed for the systematic pooling of resources to build sufficient capacity in the community to enable it to happen. The nature and pace of joint working between health and social care commissioners will require a step-change if the commitments are to be achieved (p38). ‘Government faces 3 challenges in improving the care available: to determine the most appropriate place for people’s assessment and treatment; to reduce the number of people with learning disabilities in inappropriate settings; and to create a sustainable system that minimises the need for inpatient care settings’ (p38). **Study limitations** Despite the efforts made to seek the views of different stakeholders including service users and carers and to see the issue from different viewpoints, it is difficult to ascertain in the report how strong different themes were or who the views belonged	

	various ‘other’ categories for placement in a mental health hospital. **Service use** Inpatients with a learning disability and challenging behaviour in mental health hospitals in England. **Sample size** Cohort n=2600 inpatients with learning disabilities in mental health hospitals at September 2014. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).	to. Barriers and facilitators section is limited and the conclusion doesn’t match the findings – e.g. 1 of the main conclusions is ‘to determine the most appropriate place for people’s assessment and treatment’ yet this isn’t a finding discussed elsewhere in the report.	

48. National Audit Office (2017) Local support for people with a learning disability. London: NAO

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim To look at how much the government spends on	**Participants** Professionals/practitioners.	**Costs** For most people it costs £3,500 per week (£180,000 per year) to	**Overall score** -

supporting people with a learning disability and to find out if support is improving outcomes for this group. The study also examines the progress the government has made with its transforming care programme to provide community services and reduce mental health hospital beds for people with a learning disability. The study also identifies barriers to transforming care services. **Service aims** To move some of the 2500 people with a learning disability and/or autism out of mental health hospitals. **Country** UK. **Methodology** Qualitative evaluation. **What is the sampling frame (if any) from which participants are chosen?** Cohort of people with learning disabilities still living in mental	Carers/family members. Interviews and focus groups with carers and people with a learning disability were held with at each of the 6 case study sites and also held with family and carer groups. Administrators, commissioners, managers. **Sample characteristics** **Adults** **Age**: Under 18 n=160 (6%) 19-65 n= 2305 (92%) Over 65 n=45 (2%) Children and young people. **Disability** People with a learning disability and/or autism residing in an inpatient setting as at December 2016. **Residence** Of the 2510 people with a learning disability and/or autism in an inpatient setting in December 2016, they were located in: Non-secure: n=1,235 (49%) Low secure: n=735 (29%) Medium secure: n=475 (19%) High secure: n=65 (3%) Non-secure covers a range of inpatient beds including specialist learning disability units, generic mental	support the majority of people with a learning disability in secure and non-secure mental health hospitals. (NHS Digital Data from September 2015 was used for this analysis). **Service use** **Community service use** Between October 2015and September 2016, 33% of people discharged from mental health hospitals went into residential care. 31% went into supported housing and 26% into the family home with support. However, for the cohort of all people with a learning disability, and not just those leaving hospital, the proportion of people living in the community with family or with their own tenancy, has increased from 70% in 2011–12 to 75% in 2015–16. **Length of hospital stay** In December 2016, the average length of stay in a mental health hospital for a person with a learning disability was 5.47 years. The average length of stay has continued to increase since March 2015, when it was 5.09 years. This data is only for people that are still	

health hospitals in December 2016. **Details of data collection instruments or tool(s)** Not stated. Basic data collection and audit. Clear about methods used and purpose of each one, no detail on the data collection and tools. **Mechanism for change** Increase capacity. Pooled budgets. **Source of funding** Government department.	health, rehabilitation beds and psychiatric intensive care unit. **Legal status** In December 2016, 24% of people in mental health hospitals overall were under restrictions by the Ministry of Justice and therefore not free to leave. **Sample size** The study looks at the cohort of 2510 inpatients with learning disabilities still living in hospitals in December 2016. **Services of interest** **Inpatient category 5**: complex continuing care and rehabilitation beds. **Inpatient category 2**: category 2: acute admission beds within specialised learning disability. **Community support**: learning disability intensive support team. **Content/ components of service** Service planning. Pooled funding. Placement development.	in hospital and does not include people who have been discharged. The number of people who were in hospital for more than 5 years reduced from 930 people in March 2015 to 890 people in December 2016, this means that people discharged had lower than average lengths of stay. **Legal status** In December 2016, 24% of people in mental health hospitals overall were under restrictions by the Ministry of Justice and therefore not free to leave. **Out of area** In November 2016, 20% of people in mental health hospitals were 10 kilometres of less from home and 46% being 50 or more kilometres from home. The distance from home remains unchanged from what it was in December 2015. **Barriers identified** **Delayed discharges** Some of the families and patients consulted as part of the audit said that while care and treatment reviews were a good starting point,	

		‘without a single point of contact to effect change and coordinate resources, families found the process of discharge from mental health hospitals to be incomprehensible and emotionally draining’ (p35). **Lack of care plan** Care and treatment reviews became mandatory in October 2015. Without them, the process to discharge people and get them appropriate support in the community cannot work to best effect. In December 2016: 63% of people admitted that month did not have a pre or post admission review. 28% had never had a review. 39% of people had had a review in the past 6 months. **Risk management** Data in risk registers is particularly poor on people in the criminal justice system and on children about to enter the adult system so they are not identifying all people at risk or waiting to be admitted into mental health hospitals. **Resources**	

		As of summer 2016, only a third of clinical commissioning groups had pooled their budgets with individual local authorities (taken from a survey of clinical commissioning groups). The other main funding mechanism to help transfer money from mental health hospitals to community support is ‘dowry payments’. These are for people who have been in mental health hospitals for more than 5 year. There are 900 patients potentially covered by dowry payments. The audit found that these had not been working as intended. ‘Although 105 people eligible for these payments were discharged between April 2016 and December 2016, there is poor understanding about how these payments will work in practice’ (p39). **Summary of findings** The main finding from the audit is that the transforming care programme is making progress in reducing the number of people in mental health hospitals, but the programme partners consider it likely that the programme will not deliver the 35% to 50% reduction in	

		bed numbers by 2019. There has been little progress in achieving the other main objectives of the programme which are that patients in mental health hospitals are closer to home and that that the length of time people stay in mental health hospitals reduces. **Study limitations** Overall the quality of the audit is limited. However, the authors have made efforts to seek the views of different stakeholders including service users and carers and to see the issue from different viewpoints. Yet, it is difficult to ascertain in the report how strong different themes were or who the views belonged to. While the report points to some of the things that are getting in way of transforming services and these seem valid we don't if implementing them would be effective.	

49. National Development Team for Inclusion (2015) Informing the service model: a report about the experiences of people with learning disabilities and families. Bath: National Development Team for Inclusion

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To find out what people with learning disabilities and families who have experience of inpatient services in each of the 4 regions of England think about services. The findings from this study were to be used to inform the development of a new service model for commissioners. **Service aims** Not stated, are not relevant to this study, as it is a views study about services in general. **Country:** UK. **Source of funding** Not reported. **Methodology** Qualitative. **Services of interest**	**Participants** Professionals/practitioners. - Focus groups with service users, supporters also attended n=12 supporters from n=13 organisations participated in the focus groups. - Carers/family members n=11 telephone interviews with family carers n=6 focus group for families n=10 family carers present at meeting about the service model and discussion noted; n=1 questionnaire (family member that couldn't attend the focus group in person, completed the questionnaire). - Adults with learning disabilities and behaviour that challenges; n=26 servicer users or people with learning disabilities attended 4 focus groups. **Sample characteristics**	**Qualitative themes** **Access to support** There was a lack of skilled and timely support on offer to stop difficult situations escalating and the young person/child or adult being admitted into inpatient provision. Many families had been through this experience and the child/person had been admitted to a service out of their community and for some that provision was many miles away. Families have experienced difficulties in accessing support from CAMHS, Speech and Language and OT, as well as social workers and psychologists. Often the waiting lists are over a year long. **Choice and control** There is a lack of choice for families regarding the services they can access through social services. Personal budgets and personal health budgets should be much easier for families to access. There is also a lack of choice	**Overall score** -

Inpatient services − inpatient/ATU. **Content/ components of service** Family-centred planning activities. Multicomponent support.	**Level of need** Service users and supporters: a majority of service users had personal experience of inpatient services. 4 had experience of being Sectioned. One had helped to produce a report on ‘Locked Hospitals’; 1 was an Experts by Experience (ExEs); 1 had (a bad) personal experience of inpatient services. One had been on several CTRs and one had been involved in a programme of staff training for the local NHS Foundation Trust. **Residence** Each of the 4 focus groups with service users were held in different regions of England: NHS East and Midlands (Birmingham) NHS South (Oxfordshire) NHS London(Hammersmith and Fulham, Greenwich) NHS North (Newcastle) Focus group with families was held in Oxford. **Sample size** Service users (focus groups) n=26 Supporters (focus groups)	for people with complex needs to provide the person centred care they require to stay safe and well in the community, and a lack of small local provision. **Family life** Families said that placements were often remote, making it very hard to visit, and there was no interaction with the community. It was difficult to communicate with family members in these units. There should be access to Skype so families can be contacted privately. **Human rights** The use of Mental Health Act sections is a cause of concern. One family commented that ‘it seemed to overrule direction of policy to keep people in their own community…we asked CAMHS for help and he ended up being sectioned’ (p13). Another family were concerned that section 2 rather than section 3 (with 117 aftercare) was used, and the follow-up by the psychiatrist and the MLDT (with no input from the social worker) was not useful. It was also thought to be ‘too easy to renew section 3 without listening to the parents’ voice’. Overall there was a	

	n=12 Families (telephone interview) n=11 Families (focus group, other consultation) n=17 Total n=66.	feeling that our children are not valued and denied basic human rights, opportunities and skills. 'The bewilderment of being in such a poor human rights care system in a modern democratic EU country and not knowing where to turn to for help, feels like XXXX and I have been shipwrecked for years on our own land. Six years after his transition we are now getting nearer to him having a reasonable quality of life by asking for a "home based programme" funded by the Direct Payment Scheme' (p18). **Health and wellbeing** Families were almost unanimous in their condemnation of the experience of their relatives' health in inpatient provision. For 1 young man, the anxiety caused by the placement led to behaviours that had a detrimental and permanent effect on his health. **Information** Families said: 'services and schools promised things they couldn't provide' (p12). Families are not given information on what is available – including advice on use of a direct payment. Families also said 'it was hard to get information on how to get help	

		and even if you found out, hard to access it' (p12). **Stress and strain** Too many people are getting sent out of their local communities, away from family and neighbourhood and this causes great distress. **Staff skills** 'The crisis was precipitated by the lack of skills and knowledge of the people around him. This includes - diagnostic overshadowing – they don't always see the mental health issues assume the behaviour is because the person has a learning disability. It took us a long time to get his mental health needs recognised' (p11). **Transition** Hospital to community Some service users reported that there were good links between the hospital staff team, the community team, the person and their family which showed how someone could be supported to have a very different life after many years 'inside'. 'Going out places. Meeting new people. Going to Drama Group (which started in the hospital and includes people still living there as well as people who are now out in the	

		community)' (p11). However, for others there wasn't coherent, consistent communication locally between the various organisations and individuals that could help support people's 're-entry' better. Service users thought that there needs to be good support ('the right kind for me') managing day to day living, connecting up with local people and places – 'to prevent me from going back into hospital' (p11). For example: 'prescriptions aren't in Easy Read telling you about the side effects. There should be pictures on it and on the packaging' (p11). Families also thought that transition planning is poor ... For example, one family reported that no adult social worker was allocated and the young person was not known to the health learning disability team. In one case, there was a failure to communicate with the young person regarding a change of school so he was unable to say goodbye or adjust' (p11). **Working together** Families reported that services didn't work well together, and did not engage when needed. In 1 area the learning disability team would not work with the individual until he moved in, as he wasn't registered with the GP. Failure to	

		share information meant that medication had to be prescribed by the psychiatrist without access to medical history. There were problems getting input from social services. There were arguments between health and social services about placements and funding, and examples of the families being left to sort things out for themselves. One family reported that the psychiatrist’s ‘service specifications’ for their relatives discharge was ignored by the social worker, who responded that there was nothing in the ‘service specifications’ that meant they had to be followed. Not following the ‘service specifications’ for my son’s discharge lead to further and ongoing detrimental care after he was already traumatised from his hospital experience **Costs?** No. **Barriers identified** **Capacity** There is a lack of person centred support services in both the community and ATU/inpatient provision. Those families that have managed to achieve person centred support for their family members have done so because they	

		have been proactive, determined and well resourced. One family bought the house their son now lives in. Another had to do all the work to find a local provider and Housing Association for his accommodation in order for him to be discharged. Services should facilitate the use of personal budgets and personal health budgets (p11). **Knowledge and skills** All the families emphasised the real problems they experienced because of unskilled and often under-valued front line workers. Families recognise that these workers are crucial in managing the day to day wellbeing of their family member. Without the right skills, knowledge and values these staff can precipitate a crisis by escalating behaviour that is then deemed so challenging that the person is sectioned or excluded. There are also huge issues with the use of agency staff – lack of continuity and consistency, which also generates problems (p12). **Organisational structures/ cultures** For families, there was a fundamental issue around the culture of professionals within these services – too often families are actually perceived	

		to be the problem, rather than an integral part of the solution (p11). **Roles and responsibilities** There were many examples of procedures and systems not working. These included safeguarding, complaints, tribunals, MHA manager meetings, care programme approach meetings (treated as a tick box exercise), CQC inspections and advocates that were ‘in house’. There may be a perverse incentive for private providers not to discharge. **Facilitators identified** **Brokerage and advocacy** Some service users thought having an advocate can be very helpful: ‘My advocate spoke for me after I told her what I wanted to say. I didn’t have the courage to speak myself (in the Review meeting)’ (p8). ‘The advocacy service helped me get a solicitor (who challenged my Section). However, in hospitals, advocates can come across (to the patient) more like just another member of the group of medical professionals in charge’ (p8). **Commissioning**	

		Service users suggested that 'Commissioners could include performance indicators in contracts to show how well support providers enable people to make friends and develop relationships' (p10). Services need to be jointly commissioned and there needs to be joint ownership, including families. Health and social care services need to work together and disagreements about funding should not result in failure to provide timely and appropriate support. Currently there is a sense from children's services that they are only planning up until 18 years of age. There needs to be planning for life and better transition. **Family involvement in care planning** Services need to work collaboratively with families. There is a culture of seeing families in a negative light rather than recognising the important role they can play in promoting the wellbeing of their family member. Families should have more power and need to be involved on a day-to-day basis and at an operational and strategic level. There should be written agreements with families as to the length of time their relative will be admitted for. This	

		should be reviewed jointly if things change. **Family support** The only things families mentioned that worked well to help them was support from external agencies such as the Challenging Behaviour Foundation. **Regulation** There needs to be better monitoring of services and accountability. Those who monitor services are too ready to listen to clinicians at the moment. Robust safeguarding procedures need to be in place. **Service design** Families say there should be local, small and specialist inpatient provision for those people who might need it. Too many people are getting sent out of their local communities, away from family and neighbourhood and this causes great distress. This provision needs to be part of an integrated pathway of support for people that links prevention, support and returning to the community. There also needs to be small, local, low stimulation accommodation for people with complex needs and challenging behaviour, where family and friends can	

		continue to give support and maintain relationships, staffed by people trained to work with people with complex needs and challenging behaviour. **Multi-agency–interdisciplinary involvement** Families said in relation to inpatient/ATU services that a good multi-disciplinary team who are knowledgeable about PBS, are well managed and avoided using medication is crucial. Also teams that did not use restraint. It is important for teams to ‘stick with the person’. These teams listened to family and other people close to the individual. Being in a place that was relatively local, so that the environment was familiar, is important. **Staff skills** Staff need to be skilled in working with people who challenge and people with autism, and work in a person centred, family friendly way. Particularly, social workers need to be trained to work with people with autism and people who challenge. The training should involve families – and listening to families, so that people get the right placements. Staff who have good communication skills, and understand sensory	

		overload, and who can use social interaction programmes such as intensive interaction, gentle teaching. 'Professionals working with autistic people and not knowing that autism is a 'triad of social impairments', is a bit like finding a builder who does not know how to mix cement' (p18). **Summary of findings** - People with learning disabilities and families raised many common issues that should be addressed by the new service model. - Prior to people being admitted to assessment and treatment services, families found they were not listened to, their relatives were not adequately assessed or understood, there was a failure to plan ahead, and lack of appropriate services. - The experience of inpatient services for families and for people with learning disabilities was often traumatic and damaging. People with learning disabilities said that communication in the units was often very poor. People were not valued and got stuck in the system. - Inpatient services – worked well when people felt safe, were supported to get	

		well, had things to do, were enabled to stay in touch with home, and there was good advocacy. Families also mentioned skilled staff teams who avoided using medication and restraint where possible, and who listened to families and others who knew the person well. - Local services were important. - Returning to the community – worked well when there were good links between the hospital and the community, and good planning, but this was quite rare. There needs to be good forward planning, jointly commissioned services and joint ownership, appropriately skilled teams, and good listening to families and to people with learning disabilities, including self-advocacy. - The most important message from people with learning disabilities and families was – 'please listen, and work with us!' (p20).	

50. Oxley C, Sathanandan S, Gazizova D et al. (2013) A comparative review of admissions to an intellectual disability inpatient service over a 10 year period. British Journal of Medical Practitioners 6(2): a611

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To analyse trends in admissions to an intellectual disability unit over a 10-year period. A retrospective review of the case records of all inpatient admissions to the Seacole Centre was completed over a 3-year period – from 1st January 1999 to 31st December 2001. **Mechanism for change** Identification of needs. **Service aims** Implicit. Specialist inpatient assessment and treatment units. Valuing People and the Mansell Report recognises that NHS specialist inpatient services are indeed necessary on a short-term basis for some people with intellectual disabilities and complex mental health needs.	**Participants** Adults with learning disabilities. Some were young people 14 to 19 years. **Sample characteristics** **Age** Average (mean) age/years 1999–2001 29.58, 2009–11 36.16 Age range/years 1999–2001 14–63, 2009–11 19–72. **Gender** M:F ratio 1999-2001 1.4:1 2009-2011 3.1:1. **Residence** Total number of boroughs from which patients admitted: 1999–2001 (n=10) 2009-2011 (n=7) **Other** Data collected included age on admission, gender, borough,	**Service use** **Community service use** Most patients in 1999–2001 study were discharged to either the same residential home or back to the family home, where as in 2003–11 patients were most frequently discharged to either a different residential home or to supported living. **Characteristics** Reason for admission In both time periods, the most frequent reason for admission is challenging behaviour (62%, n=37 between 1999–2001; 63%, n=29, between 2009–11), followed by psychosis (22%, n=13 between 1999–2001; 11%, n=5, between 2009–11. Social admissions were the third most common reason for admission in the recent study (0% between 1999–2001; 4%, n=2 between 2009–11). The range of psychiatric presentations was widest during the original time period. **Inpatient service use**	**Overall score** -

Methodology Cross-sectional. **Source of funding** Not reported.	diagnosis, psychotropic medication on discharge, date of admission and discharge, length of stay, legal status on admission, delays on discharge, and reason for delay, and living arrangements prior to and after discharge. **Sample size** Numbers of admissions 1999–2001 n=60 2009–11 n=41 Number of patients 1999–2001 n=46 2009–11 n=40. **Treatment of groups** No prospective allocation-use of pre-existing differences to create comparison groups. **How do the groups differ?** Explicitly stated – time of admission to hospital.	Admissions : 1999–2001 n=60 ; 2009–11 n=41 Number of readmissions: 1999–2001 n=16 ; 2009–11 n=1 Number of delayed discharges: 1999–2001 n=40 (67%); 2009–11 n=24 (59%). **Length of hospital stay** Average (mean) length of stay / days 1999–2001 n=198.6; 2009–11 n=244.6 The length of stay over the 10-year period has slightly increased from an average of 198.6 days up to 244.6 days, which demonstrate that admissions are considerably longer than in more generic medical settings. **Summary of findings** Throughout this study spanning 10 years, challenging behaviour followed by psychotic disorder remained the most common cause for admission. The number of readmissions significantly reduced from 24% (14 patients) to 2% (1 patient). During 1999–2001 a large proportion of patients were discharged to their original place of accommodation (often the family home) whereas in 2009–11, it was more common for patients to be discharged to a new place of living more suited to managing	

		increasing complex needs and behaviours. Services created by the private sector are used very widely and seen as at time as an economically viable option in the current climate of credit crunches. Increasing capacity can be achieved by reducing length of stay: requires proactive planning throughout the whole process of care, as well as active discharge planning, with a need for clearly defined pathways of care. **Study limitations** Other than simple counts and percentages there is no further analysis as the real, significant differences to compare the 2 groups to, or compared to national data. Given the differences in sample sizes for the 2 years, it's difficult to see whether differences are within the range of probability or unlikely to be due to chance. The study takes place in a greater London borough which is likely to experience more out of area placements, and difficulties in securing alternative placements in the community due to costs of accommodation with support.	

51. Pearson GS (2012) The transition experience of developmentally impaired young adults living in a structured apartment setting. ANS. Advances in nursing science 35: E73-89

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim To ascertain the specific experiences of adolescents and young adults with a childhood diagnosis of pervasive developmental disorder (PDD) who were receiving state-funded transitional clinical and living services and had transitioned into a supervised apartment setting associated with an adult mental healthcare services provider. **Country:** USA. **Source of funding** Not reported. **Methodology** Qualitative. **Services of interest** Semi-independent living.	**Participants** Adults with learning disabilities and behaviour that challenges; 10 people aged 18–24. **Age** Age range: 18–24. **Gender** Male: n=9 Female: n=1. **Ethnicity** Not reported. **Level of need** A diagnosis of pervasive developmental disorder and other high/risk behaviours such as aggression or sexually inappropriate behaviour. However, all participants assessed as capable of living independently in a supervised environment. **Residence**	**Qualitative themes** **Choice and control** Presentation of self that most participants appeared 'unkempt and messy' (pe79). It further reports that 8 of the participants appeared depressed and dissatisfied with their living situation. The study reports that participants had 'mixed' opinions about residential treatment programmes. One participant said '... when I was in [another program site] and I was always relying on staff there to give me rides and stuff. You know, to help me out with stuff and whatever. But now, you know, because I don't rely on them so much anymore. Sometimes I do but when I moved to [a new town] I'll need them less and stuff. I'll need to be on my own and I basically ask, why should I have staff do stuff? When I can do it on my own?' (pe82). Two participants talked about how the transition had affected their relationships with their mothers. One said: 'Like, um, when I'm upset and I know my mother isn't there to hold me and to tell	**Overall score** -

	Supervised independent apartment provided by an adult mental health service provider. **Sexual orientation** Not reported. **Socioeconomic position** Not reported. **Sample size** N=10.	me 'there, there' everything is going to be OK' and like she used to when I was little. You know ... you're alone, you can't rely on your mother anymore ... You've got to live on your won for once and do you know, grow up. You can't be a big baby anymore. You've got to clean your own apartment, you've got to take care of yourself, you've got to do everything on your own...learn how to pay bills eventually...learn how to pay the rent' (pe82). One participant was more dissatisfied with the transitional living programme and said 'Pretty much I've lived independent you know and that's why when I see staff come in and you know I've been on my own for a while and come and go as I please, I'm used to, you know freedom, actual freedom' (pe82). **Defining behaviour that challenges** One participant said: '[Residential program] kicked me out. Because I mean I hated it. You lived in this room with like sex offenders and just kids with real problems. And I was sitting there and man, I was so pissed off. I would just jump out the window and just go out and spend the day outside in the fresh air. And they call it running away ... You know I just needed some space' (pe80). **Environment**	

		Living environment – the study reports that ‘all apartments appeared run-down and physically dirty’ (pe79). The majority of participants did not appear to be ‘emotionally connected’ (p.e79) to their apartments. **The future** The study reports that 5 participants reported events about increasing independence, e.g. getting their own apartment, opening a bank account, or doing their shopping independently – 1 talked about looking after himself, and opening his own bank account – 1 mentioned the freedom he felt in his own apartment, saying that one Saturday ‘I felt like I was born again. I felt like people actually respected me ... I was a citizen of this country ...i t felt good’ (pe82). The study notes that many of the participants did not have plans for the future, although one person had the clear goal: ‘My eventual goal is to move out of this program and be on my own, to live in this apartment, to support myself and pay my own bills’ (pe83). Several other participants also talked about wanting to become independent of the programme. **Health and wellbeing**	

		Participants frequently described poor physical health – 8 participants were ‘significantly overweight’, 9 were taking 2 or more psychotropic medications, which had side effects including impact on movement, obesity and difficulty concentrating. **Inclusion/isolation** Relationships with others were ‘defined as all relationships identified by participants’ (pe80). The study reports that 6 participants expressed negative feelings in relation to their families, whereas 4 were more positive. Four participants said they had made friends ‘within the program’ (unclear which programme this refers to). One participant discussed his relationship with his pet cat. 4 participants had ‘roommates’ in the apartments in which they lived, but generally did not have positive relationships with them. The study notes that only 2 participants reported having a romantic relationship. The study reports that, at the time of the interview: 6 participants were attending a formal school programme – 1 was volunteering – 1 was involved in an adult therapeutic day programme – 1 was working at a restaurant – 1 was unemployed and searching for work. Most participants, except the 1 person working at a restaurant, were not enthusiastic about their work or school activities. The author notes that it	

		was unclear how much the participants felt that they were missing out on 'normal' life and development. The study notes that 'for 8 of the participants, the researcher ended each interview with the sense that the individual was aware of missing social normalcy, which could be defined as a clean, home-like environment with caring family' (pe86). **Staff skills** The study reports a mixture of positive and negative relationships with transitional living staff. Four participants said they found help with budgeting helpful, 2 found staff intrusive, whereas 1 thought they were not available enough. **Trust** Another participant said of a residential placement: 'I liked it and I went through a lot there ... had some bad times ... at first when I go there I kind of hated it, you know because of the rules and stuff and all the things with staff. I wasn't really used to the place but now that I'm gone actually I love the place and I miss it big time. And all the people there' (pe80). **Summary of findings** That participants' experiences of making the transition to adulthood was characterised by a theme of loss, including of positive family	

		relationships, ‘normative’ adolescent and young adult experiences and loss of independence. The author further notes that participants appeared to be developing the skills necessary for adult independent living, but questions whether they were just ‘going through the motions’ required by the independent living program? (pe86). - The research illustrates the importance of planning for all aspects of wellbeing, including managing psychiatric medication management, nutrition and exercise, and emotional wellbeing. - A more extensive knowledge base about each of the participants in the study would have been helpful. - Emphasises need for consumer voice in planning care. **Study limitations** Limited access to participants – unclear if this was a representative sample. - Lack of researcher query in to sexuality as an aspect of adolescent development. - The need for the researcher to balance their role as a clinician with their role as a researcher.	

52. Perry J, Allen D, Pimm C et al. (2013) Adults with intellectual disabilities and challenging behaviour: the costs and outcomes of in- and out-of-area placements. Journal of Intellectual Disability Research 57: 139–52

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study compares both cost and outcome for in-area placements and out-of-area placements for people with severe challenging behaviour. **Methodology** Comparison evaluation Our approach to assessing costs followed the comprehensive costing approach recommended by Beecham and Knapp (1992). **List/add services of interest** Residential placement.	**Participants** Professionals/practitioners Case managers were asked about commissioning arrangements; service administrators were asked for financial information; service managers were interviewed about settings, staffing, staff training, working methods and routines; individual participants were interviewed for their subjective appraisals of outcome (provided they passed screening for response bias); and paid carers who knew the person well were consulted about objective information on participant characteristics and lifestyle outcome. Adults with learning disabilities and behaviour that challenges; 76 adults with intellectual disabilities and challenging behaviour living at in-area and out-of-area placements; 38 people with intellectual disabilities and challenging	**Summary of findings** Effect sizes Total, accommodation and non-accommodation costs were significantly higher in-area. This was mainly due to significantly higher direct staff costs (95% CI=£368 to £875) but costs of day activities were also substantially higher. The difference in accommodation costs remained significant even after an analysis of covariance was conducted. The 2 groups did not differ significantly with respect to day activities except that more in-area participants attended social clubs than out-of-area participants (32% compared to 8%) and attendance at day centres was a more common mode of provision among out-of-area participants (51% compared to 34% respectively). However, much out-of-area day activities was organised on-site using accommodation staff. Hence, the	**Overall score** -

	behaviour living in-area and 38 similar people living out-of-area were compared. **Sample characteristics** Adults. Mean ages were 46 years and 35 years respectively. **Age:** Mean ages were 46 years and 35 years respectively. Disability: people with intellectual disabilities and challenging behaviour **Gender**: 23 men and 15 women and out-of-area participants were 25 men and 13 women. **Ethnicity**: All participants were White. **Level of need:** 76 total (2 groups of 38) people with intellectual disabilities and challenging behaviour. **Residence** The out-of-area group represented 2-thirds of the total number of people who originated from the territory served by the largest specialist health service in Wales and were placed in residential	additional costs of in-area day activities were higher, as reported above. **Narrative findings** The study concludes that both in-area and out-of-area have positive and negative effects for people with behaviour that challenges. No overall conclusion as to whether or not in-area or out-of-area placements are better or worse, in terms of either outcomes or costs, is provided. The study says that its findings should be treated very carefully as it was (i) only for 1 area of the UK (ii) the eventual sample size for out-of-area placements was smaller than expected at 38 people. The latter means that this study can only classify as showing large differences but non-significant (due to size) the differences between in-area and out-of-area placements for the following measurements: – social networks containing friends without intellectual disability (better in-area) – frequency of visits from friends and family (better in-area) – loneliness – use of seclusion (better out-of-area) – satisfaction with	

	settings at least 10 miles beyond its boundaries. Two exclusion criteria were applied: (1) people in placements which they or their family had requested the authority to commission and (2) people in placements less than 10 miles outside of the research territory which might on this basis be considered as local to the individual and family. **Sample size** Comparison numbers n=38 people with intellectual disabilities and challenging behaviour living in-area and 38 similar people living out-of-area were compared. The sample lived in 49 settings: 26 in-area and 23 out-of-area.	residential activities (better out of area) The study notes that looking at quality of life, quality of care and costs means that many statistical calculations have been run as part of the study. This creates risk of type 1 errors in the study – e.g., counting differences as actual that are not. Precautions were carried out to avoid such issues but the study notes caution should be used when interpreting the findings EXCEPT that out-of-area placements were cheaper but in-area placements were linked to many other benefits. The researchers also state that 'matching' participants for the comparative study for in-area and out-of-area is imperfect. The study states that the policy to move out-of-area people in-area in recent years may have targeted out-of-areas placements with higher than average costs meaning that those still out of area are generally not high cost. **Qualitative themes** **Choice and control**	

		There were no significant differences in household participation or choice. **Environment** In-area settings were generally smaller. This was identified as an advantage by the writers of the study. **Family life** Visits from friends were more frequent and costs of maintaining contact for families and friends were lower. Families and friends of participants living out-of-area had significantly greater costs when seeing their relatives or friends (mean =£8.3/week, sd=£12.7) than those in-area (mean =£1.9 /week, sd=£3.2; mean difference =-6.7, 95% boot- strapped 95% CI=-11.8 to -3.1). There were non-significant trends towards more frequent visits to and from family among the in-area group. Visits from friends occurred significantly more often among in-area participants (2.8 compared to 0.3, z=-2.12, p<0.05). **Health and wellbeing**	

		Advantages of out-of-area placement (3) day centre attendance was more common; (4) sedation was less frequent; and (5) more people had had their sight tested in the previous 2 years. There were no significant differences in the proportions of participants who were underweight, overweight but not obese, or obese. In-area participants undertook activities involving moderate or vigorous physical exercise significantly less frequently than out-of-area participants (mean=6.4, sd=9.8 compared to mean= 11.5, sd=12.0; z=-2.4, p<0. 05). However, type of placement ceased to be significant when the effect of age was taken into account using a general linear model with age as a covariate (r2=0.06, F1, 66=0.3, p=0.58). Using 12 bouts of moderate or vigorous exercise in the preceding 4 weeks as a definition of inactivity (Emerson 2005), significantly more in-area participants were inactive (86% compared to 60%, c2=6.17, p<0.05, control for age not possible because inactivity is a nominal variable). There were no significant differences between setting types in terms of receipt	

		of health-related services apart from significantly fewer in-area participants having had a sight test in the previous 2 years (63% compared to 90%, c2=7.3, p<0.05). There were no significant differences between the 2 groups on the Health Care Scale and its sub- scales. Nor were there significant differences on the Risks Scale or Safety Inventory. **Inclusion/isolation** Day centre attendance was greater (and therefore better) for out-of-area placements). Attendance at daytime social clubs was more common; community activities were undertaken more frequently; day centre attendance was more common. There were no significant differences between groups on any aspect of the Index of Community Integration or in the composition of social networks. Despite an indication of lower reported loneliness in-area, the difference between the groups was not significant. **Staff skills**	

		Were more common; (4) contact from specialist psychiatrists and clinical psychologists was greater; (5) procedures for behavioural assessment and writing teaching programmes were more common as was functional analysis of challenging behaviour; (6) staff distance between staff and residents was less; turnover of living companions in the previous 3 years was lower. There were significant differences in relation to the presence of: (1) procedures for behavioural assessment of residents and writing teaching programmes, and (2) induction training, regular in-service training and supervision, which were both more common in in-area settings. In addition, there was significantly greater staff distance between staff and residents in out-of-area settings. Setting types did not differ in extent and recency of staff training in managing challenging behaviour. Advantages of in-area placement were: (2) staffing per person was higher; (3)	

		staff induction training and regular in-service training and supervision. **Costs** Economic evaluation – full or partial Costs were assessed from a societal perspective to include costs to the caregiving agencies, the NHS, local authorities and families of residents. Data were collected on site-specific staff and non-staff costs and services provided independently of the residence: external daytime, hospital and community services.	

53. Perry J, Beyer S (2009) The impact on objective technology of life outcomes of assistive technology in residential services for people with learning disabilities. Journal of Assistive Technologies 3: 5–14

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This paper describes an evaluation of a sample of settings in which various assistive technology (AT) devices have been installed	**Participants** Professionals/practitioners. Data were collected by interview with staff members who knew participants well. Adults with disabilities.	**Summary of findings** **Study limitations** This study was limited by the lack of a matched control group. This means that any changes may have been due to the	**Overall score** -

following the assessment of individual residents' needs. **Service aims** The objectives of the TATE (Through Assistive Technology to Employment) Equal Development Partnership was to demonstrate how assistive technology could support people with learning disabilities and allow them to take a full and active part in the communities in which they live. **Country** UK. **Methodology** Single group, before and after. **Services of interest** Supported independent living/ single tenancy houses in which a residential service is provided **Source of funding** Research council European Social	Adults with learning disabilities. **Sample characteristics** **Adults** **Gender** Total 19 were male and 11 were female. **Ethnicity** The ethnic origin of the entire sample was white (English). **Residence** On average, people had lived in their current settings for 111 months (range =4–384, sd=90.6); 30% of residents had lived in the family home before moving to their current settings; 7% had lived in group homes; 14% in specialist learning disability hospitals or hostels; 11% in residential special schools; 15% in residential or village communities and 23% in other types of settings. On average, 7 people lived in each of the 10 settings (houses in which a	passing of time, and not the intervention itself This study had a small sample and may have not been powered to detect differences. The questionnaires used may not have been able to capture all the qualitative outcomes that may have taken place as a result of the new AT. **Qualitative themes** **Barriers** Criticism related either to teething problems with particular devices, or to false alarms or equipment malfunctions. For example, in 1 instance a fingerprint recognition door entry system was found to require too much dexterity from the individual it was supposed to help. It was adapted so that it could recognise the individual's hand. This required far less dexterity. **Facilitators**	

Fund under the Equal Community Initiative Programme. **Time to follow-up** One month before and nine months after AT installations.	residential service is provided) (range=1–17, sd=4.4). **Characteristics of behaviour**: The average score on the Adaptive Behaviour Scale was 190 (range=59–281, sd=65.0). Challenging behaviour was reflected in the Aberrant Behaviour Checklist (ABC). Scores on the ABC averaged 20.1 (range =0–75, sd=18.6). **Sample size** A convenience sample of 10 of the 32 sites in which AT was to be installed was selected for the study, 30 residents. **Treatment of groups** N/A (not more than 1 group). **What is the sampling frame (if any) from which participants are chosen?** Explicitly stated A convenience sample of 10 of the 32 sites in which AT was to be installed was selected for the study.	Unobtrusive methods of monitoring individuals' whereabouts through devices like exit sensors, together with the facility for staff to receive automated alerts on their mobile phones, was claimed to have reduced intrusion by staff and afforded residents greater independence. Increases capacity: a member of staff might now be able to leave 1 resident at home for longer periods, giving him or her greater privacy and independence, while accompanying another resident on a community activity.	

	What methods were used to collect the data? Structured interview.		

54. Perry J, Felce D, Allen D et al. (2011) Resettlement outcomes for people with severe challenging behaviour moving from institutional to community Living. Journal of Applied Research in Intellectual Disabilities, 24(1): 1–17

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The aim of this study was to evaluate the quality of care and lifestyle outcomes arising from the resettlement of adults with severe challenging behaviour from a traditional learning disability hospital to new purpose-built bungalows. **Service aims** Provide homelike accommodation in the community, coupled with staff training in positive behavioural support and	**Participants** Professionals/practitioners. Adults with learning disabilities and behaviour that challenges. **Sample characteristics** **Adults** **Age**: Range =36 to 67 years, mean=47 years. **Gender** Male n=13 Female n=6. **Health status** N=4 epilepsy n=2 infrequent seizures n=2 seizures controlled by medication n=3 autism n=7 mental ill-health (reached threshold level of the PAS-ADD checklist	**Social care outcomes** **Social interaction or support** **Social contact** There was a marginal, non-significant increase in contact with neighbours in the community (see Table 7a and b in the paper). There was no significant change in family contact for the Stayers T1–T2 or the Movers Pre-Post. However, there was a significant increase at follow-up (chi ^2=9.6, p<0.05). The Full-Pre versus Full-Post comparison of change was also significant (chi ^2=7.4, p<0.05). There were no significant changes in contact with friends. No significant differences were found in the proportion of participants having particular forms of contact with family and friends. Community integration	**Overall score** +

the development of individual plans. **Country** UK. **Services of interest** **Positive behavioural support** All staff were trained in positive behaviour support and used this approach in the community setting. **Inpatient category 2**. Category 2: acute admission beds within specialised learning disability. Before resettlement participants lived in a variety of settings within the grounds of a hospital. Including ward, villa, semi-detached and mobile home. See resident characteristics for more. **Dispersed housing** The community settings to which participants were resettled were newly built and designed specifically	(Moss et al. 1998)). N=6 detained under Mental Health Act in past 10 years, n=3 detained under the Act at the time of the study. N=19 regularly took some form of psychotropic medication All participants had been seen at least once by a doctor in the previous year. The mean frequency of being seen by a doctor was 4.2 times per year. **Level of need** People whose challenging behaviour has resulted in them being the last to leave institutional provision and also classified as requiring ongoing specialist professional input in the community. **Relationship**: The majority of staff in the new setting had worked previously in the hospital. **Residence** On average, people had resided in the hospital for 22 years, range =7–50 years. Participants lived in a variety of settings within the hospital boundary; n=6 males ward n=5 females ward n=4 males semi-detached house n=3 males villa within hospital grounds n=1 female mobile home (alone) in the grounds. People living in the wards and villa were with other service users not in the study because they were due to be resettled to other authorities.	The range and frequency of social activities were reported to increase significantly for the Stayers T1–T2 (z=-2.19 and -2.59, p<0.05 and 0.01, respectively). There was no significant increase arising from moving to the community or at follow-up. The range and frequency of community activities were also reported to increase significantly for the Stayers T1–T2 (z=-2.45 and -1.99, respectively, both p<0.05). There was no significant increase arising from moving to the community or at follow-up. **Engagement in meaningful activities** There was a significant increase in scores on the Index of Participation in Domestic Life (IPDL) for the Movers Pre-Post (z=-2.26, p<0.05) whereas there was no change for the Stayers T1–T2. There was no further change at follow-up. Full-Pre versus Full-Post change was significant (z=-2.07, p<0.05). There was no significant change for the Stayers T1–T2 in any category of observed activity. There was a significant increase in the time spent by participants interacting with staff immediately after moving to the community (Movers Pre-Post: z=-2.42, p<0.05), although a subsequent non-significant decline resulted in the Full-Pre versus Full-Post comparison not being significant.	

to meet the needs of people with intellectual disabilities and severely challenging behaviour. Typically, they were located towards the edge of small towns or villages. All community settings were built to the same design. Accommodation for up to 5 people was on the ground floor which was split into 2 wings. One wing comprised 4 bedrooms accommodation and the other, 1 bedroom, for individuals who were considered to require separate living space. The first floor comprised offices and a meeting room.

Content/ components of service

Training: staff were trained in positive behavioural support.

Source of funding

Health authority: this research was supported by a grant from the then

Characteristics of behaviour

Challenging behaviour was the main reason for admission to hospital for 13 participants, and it was 1 of several reasons for a further 4. Participant scores on the ABC (Aman and Singh 1986) are summarized in Table 2. All 19 participants had some form of challenging behaviour and all were considered to exhibit behaviours classified under at least 3 of the 5 ABC subscales, 74% under at least 4 subscales and 26% under all 5 subscales. The challenging behaviour of all of the sample included forms which disrupted other activities. In particular, their challenging behaviour sometimes or frequently prevented n=16 from participating in activities:

Table Aberrant Behaviour Checklist (p4)

Subscale	Minimum	Maximum	Mean	sd
Irritability	0	42	21.05	12.20
Lethargy	0	42	14.47	11.87
Stereotypy	0	21	4.42	5.59
Hyperactivity	0	44	19.89	12.43

Social interaction with service users occupied a small minority of the time. However, there was a significant increase for the Full-Pre versus Full-Post comparison (z=-2.80, p<0.01). Otherwise, there was a significant increase in total engagement in constructive activity for the Movers Pre-Post (z=-2.20, p<0.05), associated with a non-significant tendency for greater domestic activity as well as the higher level of interaction with staff. The Full-Pre versus Full-Post comparison of total engagement in activity just failed to reach significance (z=-1.77, p=0.08). However, the comparison of domestic activity did (z = -2.58, p=0.01).

Table 9 extract

	Hospital			Community		
	Full-T1 (n = 19)	Stayers-T2 (n = 17)	Full-Pre (n = 19)	Movers by T3 (n = 14)	Follow-up (n = 14)	Full-Post (n = 19)
Index of Participation in Domestic Life (%	25.5 (19.8)	30.4 (17.8)	35.1 (18.1)	49.2 (19.7)	48.9 (13.7)	43.9 (17.1)

Bro Morgannwg NHS Trust Learning Disabilities Directorate (now Abertawe Bro Morgannwg University NHS Trust). One of the authors is employed by the Trust and helped design the study and interpret the results. Data collection was independently conducted.

Voluntary/charity

This research was supported by grant from the Baily Thomas Trust. The Trust had no involvement in the study or decision to submit the paper for publication.

Methodology

Comparison evaluation.

Inappropriate speech	0	9	2.26	2.64
Total	13	125	62.4	34.0

Sample size

Total n=19. Comparison numbers n=0; Intervention number:
Group 1 (n=2) Group 2 (n=12) Group 3 (n=5). The intention was to have a 2 group design, an experiment group and control group, but due to delays with the new accommodation being ready, individuals were resettled at different time periods, which relate to the 3 groups.

Sampling frame

Adults with severe challenging behaviour, who lived in a hospital in South Wales just before final closure, were deemed to require continuing healthcare.

Treatment of groups

Prospective allocation into more than 1 group.

How do the groups differ?

Length of time residing in hospital before move. Group 2 (n=12) 6 months more before resettlement Group 3 (n=5) 12 months more before resettlement.

maximum score)						
Interaction with staff (% time)	17.2 (15.9)	13.5 (12.2)	13.9 (10.1)	26.5 (16.7)	20.5 (16.2)	17.7 (15.0)
Interaction with service user (% time)	1.3 (2.37)	0.5 (0.86)	0.4 (0.82)	1.13 (2.23)	2.95 (3.69)	2.25 (3.26)
Domestic activity (% time)	4.0 (6.1)	4.0 (5.73)	3.6 (5.05)	9.6 (12.6)	10.0 (8.15)	7.9 (8.0)
Personal activity (% time)	5.0 (4.9)	6.0 (4.87)	6.8 (5.1)	8.3 (6.5)	7.4 (6.84)	7.0 (6.06)
Other activity (% time)	16.8 (15.3)	12.3 (11.5)	12.6 (9.62)	24.4 (17.2)	25.4 (21.8)	20.8 (21.7)
Total Constructive Activity (% time)	37.1 (29.7)	37.4 (25.8)	34.3 (24.5)	52.5 (23.1)	57.1 (28.3)	48.4 (29.9)

Social care standards

Perception of risk

Time to follow-up

Follow-up: 12 months (T3) after n=14 had moved 24 months (T4), 12 months after everyone n=19 had moved.

There was a tendency for perceived risk to be lower in the community. However, for those variables related to abuse and exploitation where it was possible to compute chi-square statistics, there were no significant differences. This was true even for the Full-Pre versus Full-Post comparison.

Table 6 The mean percentages of participants perceived to be at risk ; % participants perceived to be at risk (perception based on solid evidence)

	Hospital		
	Full-T1 (n = 19)	Stayers-T2 (n = 17)	Full-Pre (n = 19)
Accidents in the home	95 (37)	82 (24)	95 (26)
Accidents out of the home	84 (58)	88 (41)	90 (42)
Abuse[1] by service users	95 (58)	71 (18)	68 (16)
Abuse[1] by local community	90 (26)	47 (0)	47 (0)
Abuse[1] by staff	6 (0)	12 (0)	0 (0)

Abuse[1] by others	11 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Exploitation by service users	47 (5)	35 (18)	32 (16)	29 (0)	14 (7)	11 (5)
Exploitation by local community	58 (5)	47 (0)	42 (0)	36 (0)	36 (0)	26 (0)
Exploitation by staff	16 (0)	25 (0)	11 (0)	7 (0)	0 (0)	0 (0)
Exploitation by others	21 (0)	12 (0)	11 (0)	7 (0)	0 (0)	0 (0)

[1] Physical or sexual abuse.

Clinical outcomes

Physical health

There were no differences in the frequency of activities per month involving physical exercise between the settings or over time.

Behaviour that challenges

There were no changes in observed challenging behaviour arising from moving to the community. However, ABC scores declined over time and were significantly lower in the community. The Full-Pre versus Full-Post comparison was significant (z = -2.64, P < 0.01). Lower ABC scores were found for 14 of the 19

participants (74%).
Extract from table 9, p11

	Hospital		
	Full-T1 (n = 19)	Stayers-T2 (n = 17)	Full-Pre (n = 19)
Challenging Behaviour (% time)	17.5 (27.7)	24.3 (33.6)	19.8 (30.8)
Aberrant Behaviour Checklist scores	62.4 (34.0)	51.6 (39.2)	47.1 (35.1)

Satisfaction

Life satisfaction

Only 4 individuals were able to respond without bias to all subjective measures in the Comprehensive Quality of Life Scale (ComQol). No statistical tests were performed because of the small sample size. There was a tendency for the 4 participants to report high levels of satisfaction according to the ComQol in hospital and be less satisfied after moving to the community. However, scores on the Lifestyle Satisfaction Scale (LSS) showed the opposite; satisfaction with home and community and with recreation and leisure increased following resettlement.

Table 10 Reported satisfaction with different areas of life (n = 4) p12

	Hospital
ComQol— Satisfaction with:	Full-T1 (n = 19)
Health	75
Safety	100
Material well-being	88
Community activities	75
Close relations (intimacy)	100
Productivity	100
Emotional well-being	88
Lifestyle Satisfaction Scale:	
Home and community	8
Recreation and leisure	30

Physical environment
The community settings were more homelike according to the Characteristics of the Physical Environment Scale. The difference for the Movers Pre-Post was statistically significant (z=-2.57, p<0.05)

whereas there was no change for the Stayers T1–T2. There was no further change at follow-up. Full-Pre versus Full-Post change was significant (z=-2.75, p<0.005). There were no differences in Group Home Management Scale scores between the settings or over time. The GHMS was used as a measure of social milieu. Specifically, it provides an indication of the extent to which management practices are institutionally or individually oriented in 4 areas: rigidity of routine, block treatment, social distance between staff and service users and depersonalisation.

Person-centred outcomes

Choice and control

There were no changes in Choice Questionnaire scores arising from moving to the community. See table 9. Table 9 extract, p11.

	Hospital			C
	Full-T1 (n = 19)	Stayers-T2 (n = 17)	Full-Pre (n = 19)	M s T (r 1
Choice Questionnaire	32.2 (11.9)	27.1 (17.9)	36.7 (17.0)	3 (2

		(% maximum score) **Costs** None. **Service use** **Organisation and staffing** Working practices (RSWPS) concerned with individual planning, assessment and teaching, activity planning, supporting resident activity, and staff training and supervision tended to be improved in the community compared to the hospital. The difference for the Movers Pre-Post fell just short of statistical significance (z=-1.96, p=0.06) compared to no change in the Stayers T1–T2. The Full-Pre versus Full-Post change was significant (z=-2.19, P < 0.05). **Summary of findings** There were almost no areas of significant deterioration in quality of care or lifestyle outcome arising from moving to the community. The quality of care and lifestyle outcomes associated with new NHS community settings for adults with learning disabilities and severe challenging behaviour assessed as requiring continuing healthcare were generally equivalent or superior to previous hospital levels. In this,	

		findings were similar to other more general deinstitutionalisation studies. The community provision was: 1. More homelike. This is not a surprising finding in that it is consistent with the broad deinstitutionalisation literature (Emerson and Hatton 1996; Felce 2000), and, comparison in this particular case was to wards and villas in the final period of their functional life. 2. Associated with some improvement in working methods and staff contact received by participants. 3. Associated with increased family contact, greater participant involvement in household activity and constructive activity generally and reduction in staff-reported challenging behaviour. 4. Associated with an increases in the range and frequency of social and community activities over time, but such increase also occurred while people remained in the hospital. This might have been due to the training staff were given in positive behavioural support in preparation for the move and also the possible greater orientation to community activity that followed the closing of the hospital day centre which occurred between T1 and T2 as part of the contraction of the hospital.	

		The authors suggest that for active support, the evidence is reasonably strong that the training had an impact. Compared to the pre-resettlement level, receipt of assistance from staff after resettlement doubled and engagement in constructive activity increased by 50%. However, longer-term follow-up is needed to see whether sustained implementation of such approaches as Positive Behavioural Support and AS bring long lasting behaviour change. **Study limitations** There is a major flaw in this study that means that the actual move out from the hospital setting may not have been the critical event in this particular change process. This is because staff received training in new working methods while participants were still in hospital, so we don’t know how much of the impact on participant behaviour might have been due to the training, rather than the change in residential setting. This suggests that longer-term follow-up is needed to see whether initial improvements are maintained or enhanced and to see whether sustained implementation of such approaches as positive behavioural support and AS bring enduring behaviour change. There are also a number of	

		weaknesses in the study methodology. First, the inability to establish the experimental design as originally intended meant that statistical analysis investigated significant change over time within groups but did not directly compare an experimental group living in the community with a control group in hospital. Therefore the interpretation is based only on comparing the impact of resettlement on participants’ quality of life against pre-move stability while remaining in hospital. Also the sample size is small, which means that there is a risk of Type 2 error, namely a lack of power to identify actual differences between the groups. Differences which fell just short of significance may have been shown to be significant if the sample size had been larger. Moreover, the evaluation of quality of care and lifestyle outcomes is necessarily multi-faceted. This means using multiple statistical tests in examining differences and an increased risk of making Type 1 error (accepting as ‘real’ differences that are not). The authors could have tried to restrict the alpha level to compensate for this, but chose not to do this because of exacerbating the risk of Type 2 error arising from the small sample size. Another thing that may have impacted on the results is the way the data was collected. It was not possible to ensure that	

		data collectors were blind to the service differences evaluated. Nor were staff respondents. It is possible that this knowledge could have influenced their ratings. Due to the many limitations of the study, the interpretation must necessarily be cautious.	

55. Phillips N, Rose J (2010) Predicting placement breakdown: Individual and environmental factors associated with the success or failure of community residential placements for adults with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 23: 201–13

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study seeks to test the validity of a proposed framework for placement breakdown that incorporates elements of Weiner's theory of helping behaviour, in particular, staff attributions of control about the causes of an individual's challenging behaviour. **Service aims** Not stated.	**Participants** Professionals/practitioners: residential staff who worked closely with each of the individuals with intellectual disabilities. **Sample characteristics Adults** N=43 all aged over 20 years. **Age** Breakdown group: 47.9 mean, 25.3–65.7 range	**Social care outcomes** **Adaptive behaviour** According to ABS-RC2 equivalent scores, individuals whose placements broke down were significantly more able overall and in terms of their personal (Factor A) and community (Factor B) self-sufficiency skills. There were no significant differences however in personal-social responsibility (Factor C). **Clinical outcomes** **Behaviour that challenges** There was no significant difference in the overall frequency and severity of challenging behaviour between the individuals in the breakdown and maintained groups (as	**Overall score** ++/+

<table>
<tr>
<td>Country
UK.
Services of interest Nursing and medical team
N=35 had a psychiatrist involved in their care (n=15 breakdown; n=20 maintained).
Supported independent living/ single tenancy
N=1 was living independently and they belonged to the breakdown group.
Semi-independent living
N=4 lived in a supported living service. n=3 breakdown, n=1 maintained.
Fully staffed group home: Not enough information is provided to tell how many people in the study were living in the ‘fully staffed group’ home. We know that: n= 7 lived in a group home (n=2 breakdown, n=5 maintained) n=3 lived in a</td>
<td>Maintained group: 43.2 mean, 22.7–79.2 range.
Gender
Breakdown group: n=15 male; n=5 female Maintained group: n=17 male; n=6 female.
Level of need
The subjects in the study were adults with intellectual disabilities and challenging behaviour, the criterion for which was set as a score of 35 or below on the behavioural items of the Disability Assessment Schedule (DAS-B; Holmes et al. 1982).
Residence
Group home breakdown n=2 (10.0%) maintained n=5 (21.7%) Supported living service breakdown n=3 (15.0%) maintained n=1 (4.3%) Residential home breakdown n=11 (55.0%) maintained n=17 (73.9%) Nursing home breakdown n=3 (15.0%)</td>
<td>measured by the total scores on the DAS-B). The scores for: frequency breakdown group 26.3 (sd=5.0); maintained group 28.0 (sd=3.9) severity breakdown group 26.3 (sd=4.9); maintained group and 29.7 (sd=3.9). There was also no significant difference in the levels of physical aggression, with 85.0% of the breakdown and 82.6% of the maintained group displaying it. There was a difference in the level of antisocial behaviour. The breakdown group were found to be more challenging in terms of the frequency and severity of antisocial behaviour (χ2=22.40, p<0.001 and χ2= 23.06, p<0.001 respectively), the severity of ‘temper tantrums’/‘verbal abuse’ (χ2= 9.19, p=0.010) and the severity of ‘sexual delinquency’ (χ2= 9.78, p=0.008), as measured by individual items on the DAS-B. In accordance with the guidance, antisocial behaviour was only rated as present if judged to be ‘intentional’ by the respondent.
Table 3: Raw DAS-B data for the items found to differ significantly between the breakdown and the maintained groups. (p207)
<table>
<tr><th></th><th>Breakdown group(n = 20)</th><th>Maintained group (n = 23)</th></tr>
<tr><td>Frequency of intentional antisocial behaviour</td><td></td><td></td></tr>
<tr><td>Marked</td><td>15</td><td>2</td></tr>
<tr><td>Lesser</td><td>1</td><td>0</td></tr>
</table></td>
<td></td>
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nursing home (n=3 breakdown).

Residential placement

N=28 lived in a residential home. n=11 breakdown group; n=17 maintained group.

Source of funding

Not reported.

Methodology

Quantitative evaluation.

Time to follow-up

No follow-up.

maintained n=0 Living independently breakdown n=1 (5.0%) maintained n=0 No. of co-residents breakdown n=10.1 (1–25) maintained n=4.9 (2–7).

Sample size

N=43. Comparison numbers n=23 (maintained group); Intervention number n=20 (breakdown group).

Sampling frame

Individuals were sought from populations served geographically by 5 NHS trusts across the West Midlands, representing both rural and urban populations. The population was adults with intellectual disabilities and challenging behaviour, the criterion for which was set as a score of 35 or below on the behavioural items of the Disability Assessment Schedule (DAS-B).

None	4	21
Severity of intentional antisocial behaviour		
Severe	14	1
Lesser	2	1
None	4	21
Severity of verbal abuse		
Severe	14	6
Lesser	4	7
None	2	10
Severity of sexual delinquency		
Severe	7	0
Lesser	1	1
None	12	22

Mental health

Individuals experiencing placement breakdown were significantly more likely to have received a psychiatric diagnosis than those remaining in the same service (35.0% compared to 4.3% respectively; $\chi 2=6.64$, $p=0.010$). In

	Treatment of groups Prospective allocation into more than 1 group based on clear criteria. **How do the groups differ** One group had experienced a placement breakdown during 2006 (the 'breakdown' group), and the other had remained successfully in the same community residential service for 3 years or more (the 'maintained' group). The study found: Individuals in the breakdown group displayed higher rates of 'intentional' antisocial behaviour and were more likely to have had at least 1 acute behavioural or psychiatric admission.	contrast, the numbers prescribed antipsychotic medication were high in both groups (55.0% and 56.5% respectively). **Costs?** None. **Service use** **Risk of hospital admission** Individuals in the breakdown group were significantly more likely to have experienced 1 or more acute admissions to an acute psychiatric or behaviour service (60.0% compared to 13.0% for the maintained group; $\chi 2=10.38$, $p=0.001$). **Organisation and staffing** Attributions of control Staff overall in the breakdown group rated the cause of the individual's challenging behaviour as being more under their control, but this was not significant at $p<0.01$ (breakdown mean 21.7, sd=5.3; maintained mean 17.5, sd=7.0; t=2.19, $p=0.034$). However, the difference was more significant if you considers just the views of the most senior member of staff that completed the CBS in each home. Those in the breakdown group judged individuals to be more in control of their challenging behaviour (mean score 22.2, sd=6.7, compared to a mean score of 14.2, sd=6.7 for the maintained group; t=3.90, $p<0.001$). Organisational functioning services in the breakdown group were rated as being of poorer overall quality than the maintained placements, as indicated by the total score on the SSA (mean 35.2, sd=5.2 compared to 39.6, sd=2.9 respectively; t=3.34, $p=0.002$). More specifically, placements that broke down were found to be significantly poorer in terms of the: - adequacy of their staff	

		resources (χ2=6.64, p=0.010) - energy levels of staff to implement interventions (χ2= 11.71, P = 0.001) - physical environment (personal space, light, ventilation etc.; χ2=6.93, p=0.008) - the social environment (amount of staff contact, assistance, interaction styles etc.; χ2=10.14, p=0.001) - effectiveness of the administrative systems (χ2=8.02, p=0.005). **Staff contact/assistance** Differences between the groups A clinical psychologist was involved with 45.0% of the breakdown group, and a behavioural specialist with 20.0%, meaning that a total of 55.0% of the group had involvement from 1 or both of these services. **Summary of findings** Effect sizes: A power calculation was conducted to obtain an estimate of group size that would have appropriate power at a fixed alpha level if a large experimental effect is expected (power = 0.8; alpha = 0.05). Using Cohen's (1988) conventions for non-matched groups it was determined that approximately 23 participants would be required in each group. **Narrative findings** **Individual characteristics** No differences were found between the groups in overall levels of challenging behaviour, although the breakdown group displayed higher rates of 'intentional' antisocial behaviour. Individuals at greater risk of breakdown appear to be more able to look after themselves and to cope with more complex concepts such as the use of money, but in	

		comparison find it difficult to get on with those around them. Individuals experiencing breakdown were more likely to have had at least 1 acute behavioural or psychiatric admission. **Service characteristics** Services in which a breakdown occurred were of poorer overall quality, particularly in terms of staff resources and energy levels, the physical environment and administrative systems. This study provides some evidence in support of the proposed framework for placement breakdown. The framework suggests that the risk of placement breakdown is increased if the individual has mild intellectual disabilities and displays outwardly-directed behaviour, as staff are then more likely to judge that the individual is in control of their behaviour and (following emotional reactions such as anger) are therefore less willing to offer help. It is suggested in the model ‘that risk of breakdown is greatest when such attributions are made by staff with the authority to decide whether an individual must leave. There are also other factors in the individual’s environment which impact on the likelihood of breakdown, but what these are is currently unclear’ (p203).	

		‘In this model, placement breakdown is best predicted by an individual who is more able in terms of community self-sufficiency, is judged by the most senior respondent as being more in control of their challenging behaviour, and is living in a poorer social environment in terms of staff assistance and interactions. Although the contribution from the CBS scores is not significant individually, in combination with the other factors it accounts for enough variance to be included in the model’ (p208). **Implementation issues** To enable more accurate identification of those at risk of placement breakdown, services will need to consider a broader range of factors, such as the severity of an individual’s intellectual disabilities, the extent to which staff in positions of authority attribute their challenging behaviour to controllable causes, and the willingness of staff to interact with and help them. The authors suggest that interventions to reduce this risk will need to address the way that staff think about challenging behaviour and the beliefs that they hold about its causes. They also suggest that service managers may want to improve the functioning of the residential service, particularly in terms of the provision of appropriate training, and perhaps by working with service managers to improve the quantity and quality of staff supervision. **Study limitations** While the study includes the total breakdown population that could be identified, it is still slightly smaller (n=20) than recommended by the power analysis (n=23). But the researchers say it would have been impractical to do that	

		as it would mean extending the geographical area or extending the research window for the study. Another limitation is the way that the maintained group was identified (individual referred to a behavioural or psychological service during the same 12 month period), which introduced a confounding variable. Whilst psychological or behavioural specialist services were not involved with any of the members of this group initially, most of those in both groups (75.0% and 87.0% respectively) were receiving some support. Any interventions, whilst not preventing breakdown, could have impacted on the individual and environmental factors measured. Caution should also be used with reference to interpreting the scores used in the Service System Assessment (Allen 1999) as it is a relatively untested questionnaire and has not be used in this context previously. To think about With regard to the statistical analyses used, no causal direction or temporal sequence can be inferred from the results of the logistic regression. This limits the evidence for the proposed framework as the 3 factors implicated can only be said to be linked by their combined predictive ability. The tendency for stepwise regression analysis to overinflate the predictive value of some variables further emphasises the tentative nature of the framework.	

56. Pratt K, Baird G, Gringras P (2012) Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme. Child: Care, and Health and Development 38(6): 789–97

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Authors note that admission can be distressing, uncomfortable and can lead to increased behaviour that challenges, additional nursing staff input and use of medication. The audit aims to see if these experiences are preventable. **Country** UK. **Question areas** 1. Types of service provision. **Methodology** Qualitative study. **Services of interest**	**Participants** Professionals/practitioners: nursing staff, carers/family members. **Population** Children, young people, families/carers. **Sample size** Total 20 staff and 4 families were interviewed.	**Qualitative themes** **Barriers** Parents felt that a lot of the problems they encountered could have been overcome with 'adequate modification of a planned admission and increased awareness of both process and the individual's needs' (p790). Page 4: a) Car parking – 'no spaces outside the hospital or cannot park for more than an hour. We need the car to bring the child/YP to hospital as behaviour is too difficult for public transport'. b) 'Our child is not able to wait around for long periods'. c) 'We are anxious about the noise of the ward and how our child will react'. **Facilitators** Parents/carers preferred (the checklist) and more information was gained, if it was completed in outpatients or during a home visit. Authors asked families what might trigger behaviour that challenges – sometimes the children	**Overall score** -

Inpatient Setting comprises both a secondary and a tertiary inpatient service with a large paediatric intensive care unit.		are very sensitive to noise, some may have rigid likes and dislikes, sensitivities to various stimuli, or may have routines and rituals. If these can be determined in advance, then strategies can be employed to overcome this, such as providing a quiet cubicle to minimise noise (p791). **Personalisation of care** Selection of quotes 'Our child does not like to be touched. To do so increases anxiety and challenging behaviours, especially in environments and with people they are not familiar with' (d)(p792). 'He has sensitivities to certain materials and does not like getting undressed' (participant) (p792). **Staff skills** Nursing staff stated that they felt the challenging behaviour caused them anxiety, they felt deskilled, and that they had a lack of knowledge about ASD because of a lack of basic training. There was expressed a need for additional staff who had mental health training (p790). **Summary of findings** Authors conclude: each child/YP with developmental problems and challenging behaviour needs a different strategy and person-centred planning. A specific pre-admission check- list	

		completed with the parent/carer and a specialist member of staff who understands the difficulties and how the system works are essential. Changing this process of care saves time in the long run with huge improvement in the quality of experience of care for both the families and young people, and staff, as outlined in Domain 4 of the NHS Outcomes Framework for 2011/12 (Department of Health 2010: 793).	

57. Pritchard A, Roy A (2006) Reversing the export of people with learning disabilities and complex health needs. British Journal of Learning Disabilities 34: 88–93

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim To look at the extent to which people with learning disabilities who have mental health needs, severe challenging behaviour, autism and offending behaviour originating from the West Midlands were being placed locally or out of area to have their support needs met. **Service aims** Not stated.	**Participants** Administrators, commissioners, managers. Commissioning authorities in the West Midlands region of the UK. **Sample characteristics** **Adults** Total 72% range 19–45. Complex needs group: n=152 (75%) in the 19–45 age range	**Service use** **Out of area** The majority of people (74%) placed out of area were in the 19–45 age range. Complex needs group n=202 (41%) were placed out of area. Of the people placed out of area the most significant group was the age range 31–45 (39.5%) of this range placed out of area. Severe learning disability group n=213 (29%) were placed out of area. Of the people placed out of area the most significant group was the age	**Overall score** -

Methodology Mixed methods. **Source of funding** Not reported.	with an average age of 20 years. Severe LD group: n=162 (76%) in the 19–45 age range. Age: 13 to over 65. **Children and young people** Aged 13–18. For people with complex mental health needs (n=494) only n=14 were between 13–18. For people with severe learning disabilities (n=745) only n=3 were between 13–18. **Disability** 2 groups considered in the study: (p89) (1) Complex mental health needs (n=494). People in this group typically had a mild or moderate learning disability accompanied by offending or extremely challenging behaviour often associated with autism and mental health problems. (2) Severe learning disability (n=745). People in this group had a severe learning disability and high dependency needs often associated with additional physical and behaviour problems.	range 31–45 (45%) of this range placed out of area. **Provider type** Complex mental health needs group For people who were placed out of area, the authorities contracted with 67 providers between them with a very high reliance on the private sector. n=54 (80.5%) were private, n=8(12%) were in the voluntary sector and n=5 (7.5%) were NHS providers. For clients placed within area there were 42 providers of whom n=19 (45%) were private, n=13 (31%) were in the voluntary sector and n=10 (24%) were NHS providers. 'The analysis of the very complex cases revealed that not one placement out of authority areas was in a supported living service. All placements were either in a hospital, nursing, or residential home' (p90). Severe learning disability group Analysis of numbers of clients placed with various types of providers indicated a higher reliance on the private sector for the out of area placements than for local placements (68.5% and 45% respectively) and a lower reliance on the voluntary sector (19% and 43% respectively). When analysing the nature of the accommodation	

	Gender Complex needs: n=156 (77%) male; n=46 (23%) female. Severe LD: n=339 (64%) male; n=193 (36%) female. **Ethnicity** Data not reported for the complex needs group. Severe LD group: data available for n=204 (27%). 181 (88.5%) were white, 14 (7%) were black Caribbean, 7 (3.5%) were Indian and 2 (1%) were Pakistani. The range of white clients ranged from 73% in urban areas to 100% in rural areas. Conversely black Caribbean clients ranged from 0% in a predominantly rural authority up to 27% in an inner city authority. **Sample size** N=1239 total participants with complete data available (10 people incomplete data for age and gender analysis but costs analysis included) n=494 (complex mental health needs)	over 80% of the placements in and out of area were residential homes (p90). **Qualitative themes** **Choice and control** From discussions with commissioners a theme emerged (don't know how strong) about the lack of choice, lack of control over cost of placement and the difficulties in monitoring quality of services some distance away. **Resources** From discussions with commissioners a theme emerged (don't know how strong) about resourcing in relation to local issues. The commissioners noted that there were: difficulties in completing resettlement; difficulties in disposing of surplus land and developing sites and difficulties in managing transitional costs (double running costs). **Staff skills** From discussions with commissioners a theme emerged (don't know how strong) around workforce issues. Local service development limited by availability of skilled staff and a gap between numbers of professionals required and numbers trained.	

	n=745 (severe learning disabilities). **Treatment of groups** Prospective allocation into more than 1 group. **How do the groups differ?** Explicitly stated. One group defined as having 'complex mental health needs' - typically had a mild or moderate learning disability accompanied by offending or extremely challenging behaviour often associated with autism and mental health problems. The second group 'Severe learning disability' – people in this group had a severe learning disability and high dependency needs often associated with additional physical and behaviour problems.	**Transition** From discussions with commissioners a theme emerged (don't know how strong) about resourcing in relation to transition. Commissioners noted that there were: poor transition arrangements for children entering adult services; lack of information on population delaying planning; expensive individual placements and problems in providing local adult services for children in distant placements. The authors also suggest that there was strong support from commissioners for the adoption of a pathway approach to transition with clear milestones with specific roles for agencies thereby empowering clients and developing partnership working (p93). **Working together** From discussions with commissioners a theme emerged (don't know how strong) about the: evidence of patchy joint interagency commissioning; poor coordination between mental health and learning disability services for commissioning and provision; lack of critical mass in individual commissioning areas and lack of clarity about funding responsibilities due to difficulties in interpreting guidance. **Capacity**	

		From discussions with commissioners a theme emerged (don't know how strong) about capacity. There was mention of: blocked inpatient beds due to lack of community placements; local services unresponsive to new crises leading to out of area placements often in the private sector; and severe shortage of local forensic beds. **Cost information** Costs (2002–03 prices) Complex needs group Cost packages were available for n=504, n=212 (42%) of which were out of area. Less than 3% of the packages cost less than £30,000 per year while a significant proportion (25.4%) cost over £90,000 per year. Over 80% of this client group needed packages costing in excess of £60,000 per year. In the most expensive range (over £90,000 per year) 71 of 212 people (33.5%) were placed out of area compared with 57 of 292 people (19.5%) of those placed locally. The average cost of a care package in this group n=504 £84,433. Of this, the average cost for an out of area placement £97,509 and average cost of local placement £74,767. Severe learning disability group	

		Cost packages were available for n=740, n=208 (28%) of who were receiving services out of the area. In this client group nearly 90% cost <£60,000 per year. There were no differences in the proportion of clients placed out of area and locally for any of the cost bands. Similar proportions were spent out of area compared with local placements. The average cost of a care package in this group n=744 £43,829. Of this, the average cost for an out of area placement £46,524 and average cost of local placement £42 829. Costs for all people The average cost of all people n=1244 £60,239. Of this the average cost for an out of area placement £72,259 and average cost of local placement £54,112. **Summary of findings** Out of area placements were common place and expensive compared to local provision especially for people with complex mental health needs. A higher proportion of young people were being placed out of area which suggests that unless local services are urgently developed this will continue to rise in the future. **Implementation issues** The high proportion of young people being placed out of area means high levels of	

		long term funding. To reduce the flow of high cost clients out of area, there is a need to develop joined up commissioning and monitoring of services and partnerships with local providers to increase capacity and improve quality. One of the benefits from the project was the development of a database to collect information about the needs of people and cost of care packages. If the information gaps were filled in the database it could help commissioners to develop appropriate local services. The authors suggest that to create capacity for this population people would need support to progress to less intensive services when appropriate. **Study limitations** The study is dependent on the rigour of responding authorities and the accuracy of their data. Two authorities (15%) did not participate, but we don't know how significant they might have been to the study. However, the researchers say the authorities not supplying data did not differ significantly from the responding authorities. The numbers of clients and the costs of their placements therefore were an underestimate. Another limitation of the study is that the classification of the 2 client groups was not subject to clinical validation. The researchers say that 'most authorities	

		however, had on record comprehensive historical and diagnostic data on clients to help in determining support needs in prospective and existing placements' (p93).	

58. Purandare K, Wijeratne A (2015) Reflections on the use of a specialist acute assessment and treatment unit for adults with intellectual disability. Advances in Mental Health and Intellectual Disabilities 9: 132–8

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim To evaluate the impact of a changing commissioning landscape on the provision of specialist acute inpatient care from the perspective of a small category 2 unit in London. The authors looked at records of hospital admission between 1 January 2012 and 31 December 2013. **Service aims** People are admitted to the unit if they can no longer be looked after by community teams. A small but significant source of referrals is the criminal justice system.	**Participants** Adults with learning disabilities and behaviour that challenges. Adults with intellectual disability, 78% of people admitted were because of behaviour that challenges. **Sample characteristics** **Adults** **Characteristics of behaviour** 78% of people had a diagnosis of problem behaviour (ICD 10 F7x.1) Other Demographic details were not collected. **Sample size**	**Costs?** No. **Service use** Inpatient service use. During the 2 years studied there were 2 admissions of adolescents to the unit this was because there was a lack of specialist in patient provision for this age group within the region. **Length of hospital stay** The average length of stay reduced from 205 in 2012 to 117 in 2013 (t=0.793023; p=0.431512; result not significant at $p<0.05$). **Number treated**	**Overall score** -

People are assessed for admission in the unit by a multidisciplinary team. **Country** UK. **Methodology** Cross-sectional study. **Details of data collection instruments or tool(s)** Not stated. **What is the sampling frame (if any) from which participants are chosen?** All referrals to The Kingswood Centre a 16 bed specialist acute inpatient unit (category 2) between 2012 and 2013. **Source of funding** Not reported. **Mechanism for change** N/A **Time to follow-up** No follow-up.	N=79 referrals to the unit (Jan 2012 - Dec 2013) Intervention number: n=52 admissions to the unit. **Services of interest** **Inpatient category 2.** Category 2: acute admission beds within specialised learning disability; 16 bed specialist acute inpatient unit in Brent, London.	In 2012, 23 out of 35 referrals (65%) led to an admission to the unit. In 2013 this was 29 out of 43 referrals (67%). Over half of the admissions during the study period (54%) had been first admitted to a mainstream mental health ward but then needed to be transferred to the specialist unit. **Reasons for transfer included** The need for specialist behavioural assessment and treatment lack of appropriate training the need for environmental adaptations to suit the needs of patients with autism. **Out of area** The average distance to the hospital from the borough of origin increased from 8.7 miles in 2012 to 12.3 miles in 2013(t=1.081475; p=0.146881; not significant at p<0.05). **Summary of findings** 'There has been an increase in the referrals and admissions to the unit with referrals covering a wider catchment area. This has resulted in a doubling of the	

		average distance between the unit and the respective catchment areas that patients and their relatives have to travel. The majority of admissions were transfers from mainstream mental health services. There has been a reduction in the mean length of stay' (p132). **Study limitations** The study looks at the hospital records in 1 area and relies on the accuracy and detail of reporting at the time. Demographic data were not collected at the time so it is not possible to see if there were differences for different people. It is not able to say anything about people who were not admitted, for instance people who were admitted to mainstream services or private services in the area at the same time, so it can't be used to work out the overall need for patient care in each community. Differences in length of time of admission and increases in distance from home were not statistically significant, but this could be because there were not	

		enough people to detect statistically significant differences.	

59. Raghavan R, Newell R, Waseem F et al. (2009) A randomized controlled trial of a specialist liaison worker model for young people with intellectual disabilities with challenging behaviour and mental health needs. Journal of Applied Research in Intellectual Disabilities 22: 256–63

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The aim of this study was to evaluate the effectiveness of a liaison worker in helping young people and their families from Pakistani and Bangladeshi communities' access appropriate intellectual disabilities and mental health services. **Mechanism for change** **Liaison worker** Families receiving input from the liaison worker would have more contact and better outcomes from services. **Service aims**	**Participants** Carers/family members. Children with learning disabilities and behaviour that challenges. **Sample characteristics** **Age** Age range 13–25. Mean age of control n=19; mean age of the intervention n=17. Children and young people. **Disability** Degree of intellectual disability Control: mild n=5; moderate n=5; severe n=4 Intervention: mild n=5; moderate n=3; severe n=4.	**Social care outcomes** **Quality of life** Measured using the SF12.This is a standardized and validated 12-item quality-of-life questionnaire. There was no difference between the 2 groups at baseline: SF12 physical: z=-1.068, p=0.286; SF12 mental: z=-0.046, p=0.963). There was no difference between the groups at follow-up SF12 physical: z=-0.789, p=0.430; SF12 mental: z =-0.650, p=0.516). However, differences on the physical subscale of the SF12 just failed to reach significance [z=-1.950, p=0.053 (NS)], which suggests a strong non-significant trend for carers to experience better physical quality of life in the intervention group. There were no differences between	**Overall score** +

Explicit. 'The liaison worker's role was to broker services and help young people with intellectual disability and their families to access services' (p257). Broadly, the role of the liaison worker was to: - visit and/or telephone participants at least once every fortnight - provide advice about the availability of particular services and help participants access these services (e.g. by helping them with making initial contacts, by discussion of participants' difficulties with appropriate professionals). - liaise with people providing services, making them aware of the family and young person's needs and discussing how service providers can take action to help them' (p259) **Methodology** RCT including cluster. Non-blinded. **Source of funding** Voluntary/charity. Foundation for People with	**Health status** Autism n=1 control n=0 intervention Downs syndrome n=2 control n=0 intervention Cerebral palsy n=0 control n=1 intervention Joubert's syndrome n=1 control n=0 intervention Epilepsy n=2 control n=2 intervention. **Ethnicity** Control: n=14 Pakistani families Intervention: n=12; n=9 Pakistani families; n=3 Bangladeshi families. **Level of need** All the participants were receiving services for challenging behaviour and/or mental health problems from the health service. (p258) **Residence** Bradford, north of England. Metropolitan area. Characteristics of behaviour Challenging behaviour known to families control n=3 intervention n=4 Some language/some communication control n=9	treatment and control groups on the SF12 mental subscale. **Clinical outcomes** **Behaviour that challenges** Two standardized measures were used to measure challenging behaviours: Strengths and Difficulties Questionnaire (sdQ) and the Problem Behaviour Inventory (PBI). The sdQ is a validated screening questionnaire with 25 items under 5 scales consisting of emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behaviour. The PBI is a simple checklist to measure the frequency of challenging behaviour at home, school and day-care settings. There was no difference between the 2 groups at baseline: (sdQ: z=-1.025, p=0.305; PBI: z=-1.138, p=0.255). There was no difference between the groups at follow-up: (sdQ:z=-1.522, p=0.128; PBI: z= 0.154, p=0.877) There were no differences between groups over time in terms of their scores on the PBI, which suggests that there was no difference in participant challenging behaviours as a result of the intervention of the liaison worker. However, there was a significant difference between the 2 groups on the	

Learning Disabilities and the Baily Thomas Charitable Fund.	intervention n=10 No language control n=5 intervention n=2. **Sample size** Comparison numbers n=16. Intervention number n=14. Sample size n=30. **Treatment of groups** Prospective allocation into more than 1 group. **How do the groups differ?** Implicit 2 more people in the control group; no Bangladeshi families in the control group. However, there were no differences on any of the outcome measures at baseline (sdQ: z=-1.025, p=0.305; PBI: z=-1.138, p=0.255; GHQ30: z=-1.138, p=0.255; SF12 physical: z=-1.068, p=0.286; SF12 mental: z=-0.046, p=0.963).	other measure of challenging behaviours (sdQ total score) (z=-2.555, p=0.009), indicating that young people allocated to the specialist liaison worker had decreased problems over time as measured by the sdQ, when compared with those in the control group. **Mental health** Measured using the General Health Questionnaire (GHQ30) Is a standardized measure of mental ill health for use in non-psychiatric settings. It is a validated 30-item self-completion questionnaire which examines general psychological distress. There was no difference between the 2 groups at baseline: GHQ30: z=-1.138, p=0.255. There was no difference between the groups at follow-up: GHQ30: z=-0.283, p=0.777. So there was no difference in the mental health of carers over time. **Service use** **Staff contact/assistance** Participants in the intervention group, who had the additional help of a liaison worker had statistically significantly more frequent contact (z=-3.620, p=0.001), with more services (z=-3.335, p=0.001) and with more outcomes from such contacts (z=-3.579, p=0.001) than did	

		controls No. contacts with services n=40 control; n=111 intervention No. different help required n=17 control; n=47 intervention No. outcomes achieved n=9 control; n=33 intervention. **Qualitative themes** **Access to support** Responses from the focus group suggest: The treatment group ‘felt better equipped in obtaining contact with appropriate services’ (p262). The control group felt that they had not progressed much in achieving help during the RCT they ‘reported continuing difficulties in gaining necessary access to services, help and support’ (p262). **Seeking help** Responses from the focus group suggest: The treatment group ‘felt better equipped in obtaining contact with appropriate services’ and ‘felt better equipped to help their son or daughter’ (p262). The control group felt that they had not progressed much in achieving help during the RCT they ‘reported continuing difficulties in gaining necessary access to services, help and support’ (p262). **Costs?**	

		No. **Summary of findings** **Effect sizes** Typically, it is difficult to find differences between small groups of participants unless the intervention offered is very powerful in effecting change. The authors suggest that ‘the fact that some significant differences were found in our study suggests that a relatively modest input which helps families to access services is, in fact, very powerful’ (p261). **Narrative findings** ‘Families receiving input from the liaison worker had more frequent contact with more services than did families not receiving this input and had more results from such contacts. There was also some indication that young people with intellectual disabilities had less challenging behaviours following intervention than controls. There was a trend towards greater quality of life in the physical domain among carers, but this did not reach significance’ (p261). **Study limitations** The researchers used a number of methods to try limit bias in the study, including: randomised allocation of	

		participants – independent researcher recording the post-treatment measures - all data was analysed by a researcher not connected with delivery of the intervention – double recording of the contacts of participants by liaison worker and retrospectively by families (providing a means of checking the probable accuracy of self-reports). However, the liaison worker undertook pre-treatment measurements, thus introducing some potential for bias in the data collection. Another potential source of bias in the study is the retrospective data reporting on ‘contacts’ by families, however the findings with regard to number of contacts is congruent with other findings which suggests we can have some level of confidence in the findings with regards to contacts. Another limitation of the study is that there were 4 dropouts which were not followed up and due to the small study size may have affected the results of the study.	

60. Reid C, Sholl C, Gore N (2013) Seeking to prevent residential care for young people with intellectual disabilities and challenging behaviour: examples and early outcomes from the Ealing ITSBS. Tizard Learning Disability Review 18: 171–8

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The purpose of this paper is to present early outcomes and case examples from the Ealing Intensive Therapeutic and Short Break Service. **Service aims** Providing intensive support and short breaks will prevent residential placements. **Country** UK. **Services of interest** SHORT TERM ACCOMMODATION Short breaks/respite services SUPPORTING PEOPLE IN THEIR COMMUNITY Short breaks (at home). **Components of service** ASSESSMENT	**Participants** Carers/family members. Children with learning disabilities and behaviour that challenges. **Sample characteristics** **Age** Between the ages of 7–17. **Children and young people** Young people. **Gender** Total 9/11 male. **Ethnicity** 1- White British 2- Asian British 3 - Mixed race 4 - Mixed race 5 - Asian British 6 - Mixed Race 7 - White British 8 - Asian British 9- Somali 10- Asian British 11- Black British. **Residence**	**Clinical outcomes** **Behaviour that challenges** DBC was found to improve between pre (median 89, range 99) and post-intervention (median 78, range 76). This difference was found to be statistically significant (z=-2.045 , p=0.041) A moderate to large effect size (0.44). **Satisfaction** **Caregiver burden/distress** Changes in Parental concerns was found to be statistically significant (z=-2.84, p=0.005). A composite score was also created for each participant by averaging ratings across all 3 of their concern areas. found to change significantly between pre- (median 5, range 1) and post-intervention (median 3, range 3.6) z=-2.848, p=0.004. **Summary of findings**	**Overall score** +/-

Functional behavioural assessment (FBA) SPECIALIST STAFF Agency carers: an increased package of agency carers trained to work in the home and community with the young person and their family, an increase of existing direct payment carers Clinical/educational/behavioural psychologists Training: whole network training is delivered to support implementation of interventions to staff and families as required family link foster carers: who take the young person into their own home for overnight stays and support. **Source of funding** Not reported. **Methodology** Single group, before and after. **Time to follow-up** At the point of discharge. In practice therefore, the length of time between data points is varied.	Length of time in intensive service for each participant: 1 n=2 years 3 months; 2 n=7 months; 3 n=2 years 11 months; 4 n=5 months; 5 n=4 months; 6 n=2 years 1 month; 7 n=1 year 9 months; 8 n=1 year 7 months; 9 n=9 months; 10 n=1 year 4 months; 11 n=11 months **Sample size** N=11 young people. **Sampling frame** Referrals to The Ealing Intensive Therapeutic and Short Breaks Service (ITSBS), September 2008 and March 2012. **Treatment of groups** No prospective allocation – use of pre-existing differences to create comparison groups. **How do the groups differ?** Not stated.	The ITSBS is a multi-component service and it remains to be seen whether all its elements are critical to the outcomes obtained. Our experience suggests, however, that the combination of extended, tailored short breaks and intensive behavioural, systemic and therapeutic input from clinical psychologists, provides a range of benefits. Families get time out to recover, consider new ways of supporting their child, assess their wishes for the future and re-organise the home environment. Families and professionals are also enabled to work together to find shared solutions to supporting young people in their local communities (p176). **Study limitations** The service outcomes presented here should be considered with caution as they relate to initial and emerging data gathered within the realms of usual clinical practice. As noted, there was variation in time between data points. There was also no control group or follow-up data.	

61. Richings C, Cook R, Roy A (2011). Service evaluation of an integrated assessment and treatment service for people with intellectual disability with behavioural and mental health problems. Journal of Intellectual Disabilities 15: 7–19

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim An isolated inpatient ward for people with an intellectual disability and additional mental health and behavioural problems was developed into a more flexible service integrating inpatient beds, day assessment, outreach and the local community learning disability teams. The functioning of the new service is evaluated on the basis of the way it was utilized in its first 2 years (p7). **Service aims** Explicit. Looking at alternative ways to support people referred for admission. In some cases it was felt admission might have been avoided if more intensive intervention had been carried out at an earlier stage. There was some success with this approach and, when the inpatient unit was closed for a year for refurbishment, an	**Participants** Children with learning disabilities and behaviour that challenges. Adults with learning disabilities and behaviour that challenges. People with intellectual disability with behavioural and mental health problems. **Sample characteristics** **Gender** 61% were male and 39% female. **Level of need** Autism spectrum disorder 48% depression 22% epilepsy 18% psychosis 15% personality disorder 15% bipolar affective disorder 11% anxiety disorder 9.5% obsessive compulsive disorder 2.7% alcohol/substance misuse 2.7% adult ADHD 1.4% dementia 1%	**Service use** **Community service use** Total treated placement preserved 2004–05 5/22 (23%) Total treated placement preserved 2007–08 24/40 (60%) Total placement preserved (inpatients) 2004–05 3/20 (15%) Total placement preserved (inpatients) 2007–08 5/14 (36%) This was a statistically significant difference (chi-square 3.15, probability 0.076). This difference was not significant once inpatient care was commenced (chi-square 1.19, probability 0.276). **Number treated** Number treated before BCATS 2004–05 22, Number treated after 2007–08 40 Number of inpatients 2004–05 20 Number of inpatients 2007–08 14 Percentage treated as inpatients 2004–05 91% Percentage treated as inpatients 2007–08 35% Number detained 2004–05 45% Number detained 2007–08 42.8% The length of	**Overall score** -

integrated model was developed further (p9). **Country** UK. **Methodology** Comparison evaluation. **Services of interest** Inpatient services. Behavioural support. Day care services. **Content/ components of service** **Assessment reports and intervention plans** Every person referred to the service would be on the care programme approach (CPA: DH 2008) and in receipt of care coordination. This would ensure that care plans and risk assessments were up to date p9 The BCATS pathway specifies the assessments which must be carried out and how frequently these should be done, and how outcomes should be measured (p9). **Behavioural support plan**	PTSD 1% conduct disorder 1% 53% had mild intellectual disability, 35% moderate intellectual disability and 11% severe intellectual disability. **Sample size** Comparison group for the year preceding the programme not reported Intervention number: 102 people referred to BCATS in the first 2 years of the new service. **Treatment of groups** No prospective allocation-use of pre-existing differences to create comparison groups. **How do the groups differ?** Not stated. **What is the sampling frame (if any) from which participants are chosen?** Explicitly stated. All referrals to the BCATS scheme in the first 2 years, comparison group all referrals to the centre in the 1 year	stay in the new model of service was significantly lower than in the previous model (74 days v. 198 days; chi-square 4.40, probability 0.036) **Barriers identified** **Delayed discharges** **NHS–local authority interface** Funding problems still exist to make the rate of delayed discharges increased over time comparable to the rates before implementation of the new model. **Facilitators identified** **Placement support** Supporting people to remain in their exiting placement can prevent delayed discharges while waiting for funding and finding suitable accommodation. **Summary of findings** The continued challenge of delayed discharge does however serve to underline the importance, where possible, of avoiding placement breakdown. The new service model has been far more successful than the previous model at preserving community placements. This study demonstrates the advantages of greater	

Outreach allows behavioural assessment to be carried out in the service user’s own home environment and enables staff from the assessment and treatment unit to work alongside carers, observing their interactions with the service user, modelling new approaches, communicating confidence and improving morale (p17). **Crisis prevention and management** BCATS specifies an enhanced response to service users in crisis rather than the involvement of a particular group of professionals. **Referral** Once is a referral is made it is discussed in a multidisciplinary referral meeting including the clinical leads from the community teams. The 2 teams agree the most appropriate BCATS service component for the client (p9). **Regular review** The BCATS pathway specifies, the frequency of multidisciplinary reviews. **Links to other services** Supported living outreach team (SLOT) (see (Ayres and Roy 2009)	before implementation of the new service. **What methods were used to collect the data?** Administrative data. **Details of data collection instruments or tool(s)** Health of the Nation Outcome Survey-LD (HoNOS-LD). **Do the authors’ describe any ways they addressed the repeatability or reliability of their tools** No. **Do authors’ describe any ways they have addressed the validity or trustworthiness of their data collection tools/ methods?** Yes. Use of validated tools to measure Scores on the Health of the Nation Outcome Scales for People with Learning Disabilities. **Which methods were used to analyse the data?** Not clear.	integration between community and inpatient services for people with intellectual disabilities, but identifies continuing delays in achieving discharge. **Implementation issues** The option of day assessment seems on the whole to have been underutilized in the first 2 years of BCATS. A possible reason for this may be difficulty accessing the unit on a daily basis, especially for families in crisis or where service users live too far from the unit. With time the numbers of service users for whom discharge was delayed began to rise – in a couple of cases to lengths of stay comparable to those seen under the previous model. It is clear therefore that the service has not been immune to delayed discharge. The problems with agreeing funding and finding suitable alternative placements under which the previous assessment and treatment unit had laboured have not gone away (p17). **Study limitations** The improvements we have seen in outcomes in the first 2 years may of course be in part a result of the enthusiasm for a new approach	

and the Community Forensic Team (see Benton and Roy 2008). Clinical/educational/behavioural psychologists. Occupational therapist. Speech and language therapist. **Time to follow-up** Two years intake after implementation compared to 1 year intake before implementation.		inevitably seen in the professionals who developed it. The measures of quality used in this study are predominantly those from a service provider perspective (symptom control, adverse incidents and duration of stay). Future studies may therefore need to consider utilizing user-oriented measures of service quality. Outcome was also measured using HoNOS-LD scores but this was not done with all participants. Comparing the outcomes for before the service was implemented may over inflate the effect due to the fact that the service was thought to be inadequate and in need of change in the first place. **Mechanism for change** **Care pathway** **Partnership and collaboration** **Services working with other services** The Birmingham Community Assessment and Treatment Service (BCATS) integrates assertive outreach, day assessment and inpatient components and in turn is integrated with the existing community learning disability teams. BCATS consists of 3 components: assertive outreach, day assessment places and inpatient beds. BCATS staff may attend a CLDT	

		meeting before a referral is made. Once is a referral is made it is discussed in a multidisciplinary referral meeting including the clinical leads from the community team. If it proves necessary to commission a bed elsewhere, the BCATS team plays a central role in commissioning that bed, and aims to remain involved in the service user's management and to return them to the BCATS service as soon as a bed becomes available (locally) Enhanced response times were agreed upon for the involvement of each discipline for service users in the BCATS pathway.	

62. **Robert M, Leblanc L, Boyer T (2015) When satisfaction is not directly related to the support services received: understanding parents' varied experiences with specialised services for children with developmental disabilities. British Journal of Learning Disabilities 43: 168–77**

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Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study aims to find out and understand parents' experiences of and the strengths and weaknesses	**Participants** Carers/family members: 14 mothers and 1 father. **Sample characteristics**	**Summary of findings** **Positive experience** The analysis of parents' accounts of their experiences with support services	**Overall score** -

of specialised support services. The study also aims to identify the conditions and the perceptions on which parent’s base feeling satisfaction and dissatisfaction. **Service aims** Not stated. **Country:** Canada. **Methodology** Qualitative study. **Mechanism for change** Partnership and collaboration. Some parents want to be more involved in decisions about support services and intervention and thus recognising their expertise and contribution. **Services** Person centred active support (PCAS). **Source of funding** Not reported.	Adults. **Sample size** N=15. Seven parents who had at least 1 child (target child) diagnosed with autism spectrum disorder and 8 parents who had at least on1e child (target child) diagnosed with intellectual disabilities. **What is the sampling frame (if any) from which participants are chosen?** The study was conducted in a city in Quebec, Canada, where healthcare services and treatments are publically funded. The recruitment strategies were directed at selecting parents of children with developmental disabilities. The parents were recruited, on a voluntary basis, by a team of professionals who provide specialised support to children. Recruitment took place over a 15-month period, until a total of 15 parents of children with	finds that parents are most positive about the concrete support offered by professionals and value the commitment, dedication, and compassion of the support workers. A large number of parents are satisfied with their experiences with specialised services. The services that are most appreciated by these parents are those that address ‘working with’ their child to improve communication with him or her, understanding his or her issues and managing difficult behaviours. **Negative experience** There are 5 themes that parents identify as negative experiences. These include: (i) a change of support worker, (ii) wait time before having access to services, (iii) the services offered are not suited to the child’s needs or the family situation, (iv) access to certain services based only on diagnostic criteria and (v) failure to recognise parents’ contribution and expertise in the intervention process. **Satisfaction/dissatisfaction**	

Content/ components of service Family counselling and support. **Time to follow-up** No follow-up.	developmental disabilities was reached. **What methods were used to collect the data?** One-to-one interview (face to face or by phone). Open-ended, in-depth qualitative interviews, approximately 60 min in length. A semi-structured question guide was used to ensure that a range of issues were covered. The open-ended interview gave parents the opportunity to discuss, in their own words, what is important to them.	The conditions and the perceptions on which parents base their feeling satisfaction and dissatisfaction on relate to their perception of themselves being experts or no experts and parents' opinions on the purpose or goal of the service or intervention they are using. Parents that are satisfied with services tend to see support workers as experts on their child's situation and their goal is to improve daily life with their child and they are less positively invested in the future. Parents that are dissatisfied with services tend to think they are experts on their child and want a bigger decision making role in the intervention plan. **Study limitations** The sample size is small, which means there may be a lack of diversity in the parents' experiences. Participants were recruited from only 1 site, which makes it likely that the sample is homogeneous. It is therefore difficult to be certain that the results show a trend: that certain characteristics of parents' experiences correspond to satisfied parents and others to dissatisfied	

		parents. Sample size is an important consideration for a mainly transversal qualitative analysis (usually 25 cases are required for data saturation). Since a vertical analysis was also used, it allowed the researchers to establish commonalities among participants and to determine ‘essential’ elements that divide parents fairly clearly into 2 groups, a satisfied and a dissatisfied group. **Qualitative themes** **Access to support** 1.Wait time before having access to services. 2. Access to certain services based only on diagnostic criteria. Parents have a hard time accepting that certain services are removed or inaccessible because of diagnosis. **Choice and control** The services offered are not suited to the child’s needs or the family situation. The intervention methods (behavioural or cognitive) suggested by professionals do not always work for a given child or may be unsuitable for a family situation.	

		One parent said, ‘You know, sometimes they told me to do one thing or another, and I refused because it wasn’t beneficial for my child’ (p45). Another case of this issue is parents who would like to receive extra services that are not included in their child’s programme in order to better meet what they believe are their child’s needs. In other cases, the parent found the proposed intervention measures unrealistic, that is, too demanding, given the family situation (e.g., they have other children who also require their attention or have a demanding job). **Family life** The main goals of parents who are satisfied overall are to improve daily life with their child and to maintain a good family atmosphere. **Stress and strain** A change of support worker. Some parents consider this change as a gap in support services and a step backwards, since a new professional and personal relationship (trust,	

		empathy, etc.) has to be built between the parent and child and the support worker. **Staff skills** The positive aspects of parents' experiences are centred on the concrete support offered by the professionals. For example, 'practical tips' to help them manage their child's challenging behaviour, which has a positive effect on the family atmosphere (p43). **Working together** Failure to recognise parents' contribution and expertise in the intervention process. **Costs**: No.	

63. **Robertson J, Emerson E, Pinkney L et al. (2004) Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. American Journal on Mental Retardation 109, 332–44**

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim	**Participants**	**Social care outcomes**	**Overall score**

The aim of the study was to examine the quality and costs of community-based residential supports to people with mental retardation and challenging behaviour. Study compares outcomes for congregate and non-congregate settings. **Country** USA. **Services of interest** Residential placements. Residential care in non-congregate facilities (in which 50% or fewer of residents had challenging behaviour) and congregate facilities (in which over 50% of residents had challenging behaviour). **Methodology**	A member of the care staff who knew the participant well. **Sample characteristics** **Age** Between 18 and 65 Non-congregate (mean years) 34.4. Congregate (mean years) 36 No significant difference **Gender** % Men Non-Congregate 52 Congregate 76 **Health status** Mental health Non-Congregative 54 Congregative 36 Autism Non-Congregative 44 Congregative 39 **Ethnicity** % White non-congregate 100 Congregate 92 No significant difference **Level of need** Adaptive behaviour a Non-congregative 97.5 Congregative 113 (No significant difference) Challenging behaviour Non-congregative 45.7 Congregative 47.5 **Residence** Residential history - Mean age entering residential care (years) Non-congregate 11	**Quality of life** Participant choice, family contact, social networks, and activity by time. Choice (mean score) Non-congregate time1 63.9 Time2 71.0 Congregate time1 72.9 Time2 71.0 Family contact (mean contacts in past 3 months.) Non-congregate time1 6.9 Time2 7.2 Congregate time1 9.0 Time2 9.3 Social networks (mean number of people identified) Non-congregate time1 7.4 Time2 6.4 Congregate time1 4.4 Time2 6.1 Size **Composition (%)	+

Quantitative evaluation.	Congregate 18.2 Residential history - Mean years in current setting Non-congregate 6.9 Congregate 4.5 % who have lived in NHS Mental Handicap Hospital Non-congregate 48 Congregate 52 significantly longer in non-congregate than those in congregate settings t(48) = 2.43, p < .05. **Sample size** Comparison numbers: 2 points in time separated by a period of approximately 10 months (mean gap of 9.6 months). **Sample size**: n=50; n=25 in each group	Family members Non-congregate time1 68 Time2 70 Congregate time1 80 Time2 84 People who are neither staff/formal services nor family and who do not have intellectual disabilities Non-congregate time1 36 Time2 48 Congregate time1 20 Time2 24 Participant activity (%) Disengaged Non-congregate time1 36 Time2 37 Congregate time1 44 Time2 39 Engaged Non-congregate time1 5 Time2 4	

		Congregate time1 5 Time2 5 Personal activity Non-congregate time1 14 Time2 13 Congregate time1 14 Time2 14 Other activity Non-congregate time1 13 Time2 15 Congregate time1 11 Time2 13 Total non-social engagement Non-congregate time1 32 Time2 33 Congregate time1 31 Time2 32 Mean hours per week of scheduled activity Non-congregate time1 17.8 Time2 17.2	

		Congregate time1 6.4 Time2 7.1 No. of community activities in last 4 weeks Non-congregate time1 15.7 Time2 20.8 Congregate time1 15.8 Time2 17.3 Variety of community activities in last 4 weeks Non-congregate time1 4.8 Time2 5.5 Congregate time1 4.9 Time2 4.7 Co-tenant no. of community activities in 4 weeks Non-congregate time1 23.0 Time2 17.6 Congregate time1 15.7 Time2 10.1	

		Co-tenant variety of community activities in 4 weeks Non-congregate time1 5.9 Time2 4.6 Congregate time1 4.6 Time2 3.9 **Clinical outcomes** Behaviour that challenges Participant activity (%) Stereotypy Non-congregate time1 31 time2 30 Congregate time1 25 time2 29 Challenging behaviour Non-congregate time1 3 time2 1 Congregate time1 2 time2 1 **Service use** **Service quality** Working practices- mean scale score 1 is low quality, 4 high quality.	

		Person-cantered planning Non-congregate 3 Congregate 3.7 Assessment and teaching Non-congregate 2.7 Congregate 3.2 Activity planning Non-congregate 2.7 Congregate 3.5 Staff support to residents Non-congregate 2.4 Congregate 3.0 Training and supervision of staff Non-congregate 3.3 Congregate 3.8 Social climate (mean percentage of maximum institutional score) Depersonalisation Non-congregate 36 Congregate 33 Rigidity of routines Non-congregate 11 Congregate 16	

		Block treatment Non-congregate 36 Congregate 35 Social distance Non-congregate 19 Congregate 23 Contact received from staff (mean percentage participant time receiving contact over 1% of time) Total nonnegative contact Non-congregate 10.5 Congregate 17.3 Other interaction Non-congregate 6.8 Congregate 11 Verbal assistance Non-congregate 3.1 Congregate 4.9 Nonverbal/physical assistance combined Non-congregate 1.4 Congregate 1.8 Contact received (%)* From residents	

		Non-congregate 0.7 Congregate 0.5 From visitors/others Non-congregate 0.7 Congregate 1.7 **Costs** Economic evaluation – full or partial Cost information **Summary of findings** • People living in congregate provision were reported to experience greater choice over aspects of their lives at Time 1, t (48) =2.43, p<.05, this was not evident at Time 2. • Those living in non-congregate settings received significantly more scheduled hours per week of day activity at Time 1 than those in congregate settings, t(47)=3.68, p < .001, and at Time 2, t(46)=3.08, p < .01 • Outcomes Time 1. Having a greater proportion of residents with challenging behaviour in a house was associated with more frequent use of physical restraint, r=.44, p < .001, and greater number of injuries received from fellow residents	

		(participants and co-tenants), r=.24, p < .005. - Outcomes Times 2. Having a greater proportion of residents with challenging behaviour in a house was associated with greater number of injuries received from fellow residents (participants and cotenants), r=.26, p < .005, less choice, r=.26, p < .1 (trend), fewer hours per week scheduled activity, r=.42, p < .05, greater likelihood of receiving antipsychotics by depot injection, r=.33, p < .05, and smaller social networks, r=.37, p < .01.	

64. Royal College of Psychiatrists (2013) People with learning disability and mental health, behavioural or forensic problems : the role of in-patient services. London: PCPsych

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim Inspection reports on so called ‘assessment and treatment units’ (Care Quality Commission 2012) tend to group bed categories 2, 3, 4 and 5 together. Consequently, it is not surprising that there is a very	**Participants** Professionals/practitioners. **Sample size** Authors extrapolate from local (Leicestershire) data that between 22 000 and 26 000 people with a learning disability	**Service use** **Case load** Thirteen years ago, research suggested that the total bed requirement (in all the 1–6 categories) was 14–29 per 100,000 population (Bailey and Cooper 1997). Based on our survey and consultation, we would now estimate that the total bed	**Overall score** -

wide range in the length of stay mentioned in these reports. This in turn leads to stringent criticism about the inappropriate use of assessment and treatment beds (Department of Health 2012a, 2012b; Scottish Executive Joint Improvement Team 2006). This study aims to imperative to tease out these differing categories of beds using the typology we describe, to inform appropriate commissioning. , targets that aim solely on cutting the numbers of 'assessment and treatment units for challenging behaviour' will result in significant gaps in service provision that will disadvantage the very patients it is meant to help. This report sets out, with representative case examples, 6 categories of inpatient beds and their close relationship with each other. Although all these categories do involve some assessment and treatment, they serve different functions. **Mechanism for change** **Identification of needs**	in England are likely to have some form of behaviour that challenges. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).	requirement taking all 6 categories of inpatient beds together is only about 6 to 7 per 100,000. This number represents a substantial reduction from before and has been possible because of significant improvements in community learning disability services and better working arrangements with generic mental health teams. **Inpatient service use** Using data obtained from the Faculty of Psychiatry of Intellectual Disability's regional representatives, we found that at present there are around 3954 beds within the 10 strategic health authority regions of England. This is made up of approximately 2393 category 1, 814 category 2, 622 categories 4/5 125 category 6 beds (no specific data available for category 3 beds). This includes some, although not all, beds in specialist units designated for autism spectrum disorders. These figures include all National Health Service (NHS) and independent sector provision for forensic and non-forensic services and represent an almost 90% reduction from a high of over 33,000 NHS beds in 1987–88 (p12). **Organisation and staffing**	

A survey of forensic learning disability beds (i.e. category 1) estimated that there were 48 high, 414 medium and 1356 low secure beds for people with learning disability in 2009 within the 10 strategic health authority regions of England (Alexander et al. 2011). It showed a very uneven distribution of these beds, with some regions not having any medium or low secure unit within its borders. The survey (2012/13 by the Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists) showed that there were about 3954 beds in England: 2393 category 1, 814 category 2, 622 categories 4/5 and 125 category 6 beds. The occupancy figure of the currently available beds, is estimated to be about 80%. **Service aims** Implicit. Inpatient services. People with a learning disability have high rates of mental health comorbidity (Deb et al. 2001). Epidemiological studies have		Authors recommend that commissioning for inpatient services should therefore include all 6 categories of beds, be focused on care pathways from hospital to the community and may have to be regional (covering neighbouring health districts). **Out of area** Close monitoring and review of 'out-of-area' and indeed 'within area' placements by health and local authorities is required, not just as a guarantee for preserving standards but also to tackle any issues around delayed discharges that may compromise the optimal use of inpatient beds. **Summary of findings** From a patient care perspective, the narrative should be that of inpatient services complementing community teams to achieve good treatment outcomes and being part of the pathway of care for those who present with complex needs. Indeed, depending on patient needs, an admission to an inpatient bed can sometimes be appropriate and beneficial early on in the care pathway, to undertake a multidisciplinary assessment and provide early interventions to prevent rapid deterioration (p11).	

suggested a prevalence rate of 31–41%, For those who are treated within hospital settings, (Alexander et al, 2001;Hall et al. 2006a; Hurst et al. 1994; Raitassuo 1999; Singh et al. 1994; Tajuddin et al. 2004; Trower et al. 1998; Xeniditis et al. 2004) show rates of major mental illness comorbidity ranging from 50 to 84%. Their clinical presentations are often a complex mix of learning disability, mental illnesses, other developmental disorders, personality disorders, substance misuse, and physical disorders including epilepsy. **Country** UK. **Methodology** Mixed methods. Based on discussions with stakeholders (service users, family members, carers, general practitioners, psychiatrists in various subspecialties, nurses, psychologists, speech therapists, social workers, occupational therapists,		The 2 models (category 2 and 3 – specialist and generic) serve different types of patients and generic psychiatric care may be unpopular, especially with carers and families. Category 3 care can be suitable if there is substantial specialist support available to facilitate this from community learning disability teams. Authors recommend: Lack of awareness about the 6 different categories of inpatient beds results in all of them being described incorrectly as ‘assessment and treatment units’. When undertaking reviews of inpatient placements, service providers, commissioners and policy makers should be aware of these different categories and monitor their function against these categories. 2. A choice of both generic mental health and specialist learning disability mental health beds should be available for people with learning disability and mental health or behavioural problems who require acute inpatient treatment. 3. Regional commissioning strategies should focus care pathways on well-developed community services and a spectrum of inpatient care as described by the 6 categories in this report 4. There should be discussion between patients, carers, professionals, providers and commissioners in each area about local	

physiotherapists and service commissioners) we describe 6 categories of inpatient beds for people with learning disability and mental health and behavioural difficulties		need as part of a joint strategy in developing pathways of care for people with learning disability. 5. Commissioners and providers should plan from day 1 of admission to inpatient services for the person with learning disability to move back to community services 6. There should be regular monitoring of the availability of multidisciplinary therapeutic input through the care programme approach and other reviews 7. All inpatient units should be able to show evidence of having gone through an external accreditation process 8. All inpatient units should be able to show evidence of a minimum data-set of treatment outcomes that includes baseline descriptions of quality of care, measures for effective treatments, appropriate use of medication, patient safety, compliance with Mental Capacity Act, and patient experience. 9. A number of patients in category 4 and 5 beds (forensic rehabilitation and rehabilitation and continuing care) stay for very long periods in hospital because apart from therapeutic input, they also need continuous supervision for the protection of the public. If this type of continuous supervision was legally enforceable in the community, without it amounting to the legal standard for deprivation of liberty, then they could	

		very well be managed outside hospitals. Recommend further scrutiny of this issue. **Barriers identified** High medium and low secure forensic beds (category 1.) The decision whether a person becomes a ‘forensic patient’ or not often depends on both clinical judgements about risks and the attitudes of professionals working in the criminal justice system. Both of these are inevitably shaped by the availability of services, and if less restrictive inpatient facilities are unavailable, more patients can end up in these restrictive settings.	

65. Seaward S, Rees C (2001) Responding to people with a learning disability who offend. Nursing Standard 15: 36–9

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim This study aims report on a small survey conducted in 1 NHS trust to establish the number of people with a learning disability known by staff to have committed, or be	**Participants** Professionals/practitioners, members of staff likely to be in contact with people with learning disabilities who have offended, **Sample characteristics**	**Summary of findings** Approximately 1.24% of those with a learning disability in the trust’s catchment area might have committed, or have been alleged to have committed, an offence over a 2-year period (p38). There was a high proportion of incidents that involved	**Overall score** -

alleged to have committed, an offence (p36). **Mechanism for change** Identification of needs. **Service aims** Not stated. **Country** UK. **Methodology** Survey.	**Disability** Disability level. # (%) Borderline 5 (16) Mild 21 (68) Moderate 5 (16) Severe 0 (0). **Residence** Accommodation # (%) Alone 10 (32) With parents 8 (26) Residential accommodation 6 (19) With carers 5 (16). **Characteristics of behaviour** Offending behaviour Number of offences, known or alleged # (%) 1, 8 (26) 2-4, 5 (16) 5+, 11 (35) not known 7 (23) Types of offences # (%) Nature of offence Sexual assault 12 (39) Physical assault 12 (35) Inappropriate sexual behaviour 10 (32) Theft 3 (10) Arson 1 (3) Other 8 (26) Action taken # (%) Health intervention 14 (45) Caution 8 (26) Probation 5 (16) Sentence 2 (6) No action taken 2 (6). **Sample size** Reponses relate to 31 individuals who have or have been suspected of committing an offence.	sexual assault or inappropriate sexual behaviour (p38). The size of the problem might be larger because of the possible numbers of unreported incidents. For more serious offences, the police and the courts favour referral to local forensic services. In a survey of 135 NHS trusts in England and Wales, Bailey and Cooper (1997) found that only 54.8% provided forensic services for those with learning disabilities. This means that some trusts have to purchase expensive out of authority placements. Where placements are made outside the individual’s geographical area, clients can become separated from family and social support networks. This makes continuity with family relationships difficult to maintain. A number who are frequent offenders, and a small majority who have, to the health professional’s knowledge, offended once. Offending might not be a one-off event for some, but could lead to a pattern of offending behaviour. This emphasises the importance of early appropriate intervention, to prevent this behaviour from becoming an established pattern. **Study limitations** Although the study lists its limitation in terms of generalisability, and it is not clear	

	Treatment of groups No prospective allocation-use of pre-existing differences to create comparison groups. **How do the groups differ?** N/A (not more than 1 group).	whether the pattern of offending is different to the non-disabled population, or other characteristics of the area that may be unique to the region. It does gather data from sources more likely to present realistic estimates of local prevalence, The numbers and characteristics seem to be similar to those in other studies. Survey reached its objective of providing an overview of the local situation The nature of offending behaviour means that the accuracy of the results cannot be estimated with any certainty. The size of the problem might be larger because of the possible numbers of unreported incidents. Similarly, it is important to remember that the figures are based on staff's knowledge and recollections, which might be open to inaccuracies (p38). not all data collected was reported, for instance age, Other professionals involved and services received, e.g., day care.	

66. Sergeant EV, Brown G (2004) Housing people with complex needs: Finding an alternative to traditional service models. Housing and Care and Support 7: 25–30

Research aims	Study characteristics	Outcomes and findings	Overall validity rating

Study aim The aim of the research was to examine the failure of the traditional models of supported housing to meet more complex and challenging needs and to explore Solutions that allowed for choice and which are cost-effective, provide high levels of support and have flexibility. Key to this was the housing and support model. **Service aims**: Explicit. A single-model (group home) solution was felt to create difficulties. The council wanted first to plan for those with challenging behaviours and autistic spectrum disorders, while retaining the flexibility to accommodate a larger group of people in the future. **Country** Scotland. **Methodology** Qualitative study. **Source of funding** Not reported.	**Participants** Professionals/practitioners. Adults with learning disabilities and behaviour that challenges. **Sample characteristics** **Residence** Service user status: acute admission (delayed discharge) Admission from group setting - 7, admission from parental home - 2, admission from other setting - 1. Long stay hospital Admission from group setting - 4, admission from parental home - 12, admission from other settings – 4. **Sample size** Total 55. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group). **What is the sampling frame (if any) from which participants are chosen?** Implicit.	**Costs:** No **Facilitators identified** **Multi-agency-interdisciplinary involvement** - External agencies can provide valuable special expertise which will help ensure a more effective solution to individual needs. - Thinking and working across professional boundaries need to cross statutory and voluntary agencies. - Resettlement and community developments are intrinsically linked, so must not occur in isolation. **Service design** Individual assessment and planning are central to planning. The development of appropriate housing models in Aberdeen needed to incorporate a variety of living environments, with inclusive, flexible support packages. **Summary of findings** The construction of some sheltered and very sheltered developments is beginning to complement existing resources, providing for single tenancies with high-level yet unobtrusive support. As part of the city's portfolio of accommodation for people with learning	**Overall score** -

Services of interest Supported independent living/single tenancy. **Content/components of service** **Environmental assessment** A specialist autism and environmental assessment was needed to advise on commissioning of care, specific staff training needs, the living environment, building and assistive technology needs. **Assistive technology** No further details given what assistive technology was recommended, except that: The scope of such technology for service users with dementia and physical disabilities was examined as part of the research, with the conclusion that such technology would be of significant value in meeting the needs of people with a wide range of learning disabilities and challenging behaviour. **Person-centred support** Own tenancy. **Time to follow-up** No follow-up.	Residents in Grampian LD hospitals with no discharge plans 2000-–01. **What methods were used to collect the data?** **Expert testimony** Council Learning Disability Strategy Implementation Group, advice and specialist assessments were obtained from housing providers, Lancaster and Robert Gordon Universities, National Autistic Society and the Scottish Society for Autism. Ark Housing Association, Hanover Housing Association and Margaret Blackwood Housing Association. **Details of data collection instruments or tool** Not stated. **Do the authors' describe any ways they addressed the repeatability or reliability of their tools?** No. **Do authors' describe any ways they have addressed the validity or trustworthiness of**	disabilities, this development extends the range of choice for the whole community. **Facilitators identified** **Implementation issues** Stakeholders had to be aware of the resource constraints, the need for best value and the need to develop a coherent network of provision, as part of this planning process. **Study limitations** This study describes the process of consultation to design housing solutions that meet the needs and preferences of the residents of acute hospitals and long stay hospitals. The study was not able to say whether the programme was successful or cost effective. **Mechanism for change** **Personalised support** **Services working with other services** The living environment needed to be responsive to individual need, offering independence, privacy and safety, and that support had to be flexible, responsive and provided by skilled staff who were consistent in approach and had the appropriate training to meet	

	their data collection tools/methods? No. **Which methods were used to analyse the data?** Not clear.	diverse needs. Individual assessment and planning are central to planning. External agencies can provide valuable special expertise which will help ensure a more effective solution to individual needs. Thinking and working across professional boundaries need to cross statutory and voluntary agencies. **Services working with the person – co-production** The initial point of the design process is the individual assessment of need by the care manager, who should assess and collate information, with the multi-disciplinary team, parents, carers and the service user. The assessment defines the type of service rather than the other way round.	

67. Shared Lives Plus and KeyRing (2012) Closing the Winterbournes. Liverpool: Shared Lives Plus

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim	**Participants**	**Qualitative themes**	**Overall score**

The Shared Lives sector and KeyRing Living Support Networks are 2 models which have been used successfully to enable people labelled as ‘challenging’ or who have ‘complex needs’ to move out of institutional settings into ordinary family homes and communities. This briefing outlines how these successful approaches, along with other community-based approaches should be used as part of person-centred support planning to consign the vast majority of assessment and referral units to history. **Country:** UK. **Services of interest** KeyRing. Shared Lives: an adult (16+) who needs support and/or accommodation becomes a regular visitor to, or moves in with, a registered Shared Lives carer. Together, they share family and community life.	Adults with learning disabilities and behaviour that challenges – not clear how many described as having challenging behaviour. **Sample size** Not stated. However, around 1500 people at any one time live in 150 ‘assessment and referral units’, The make-up of providers in 145 units (from CQC report): 68 NHS trusts providing assessment and treatment and secure services, including 2 services that were residential care homes. 45 independent healthcare services (IHC) providing assessment and treatment and secure services. 32 adult social care (ASC) services providing residential care. **Sampling frame** Implicit – 1500 people living in 145 services. **Sample characteristics** Adults: 16 and over. **Treatment of groups** N/A (not more than 1 group).	**Choice and control** Participant A said, ‘I hate it here and want to get out’. Participant B moved into his own accommodation as part of KeyRing Network. Anthony receives some additional one-to-one support from another provider with skills like cooking and shopping. **Inclusion/isolation** Accessing community education and rebuilding relationships within his community, before regaining enough confidence to move to his own tenancy, with occasional support. **Cost information** Annual savings of up to £50,000 per person have been realised. The average saving is £13,000 per person. **Barriers identified** **An ordinary life** The current definition of essential standards in these settings does not appear to match with minimum acceptable standards when it comes to individual choice, experience of ordinary life and promotion of independent living. **Risk management** Poor risk management. It is difficult to achieve the units’ stated aim of	-

Components of service Information use/sharing. Locally based community volunteer training. **Source of funding** Not reported. **Methodology** Single group, before and after. **Time to follow-up** No follow-up.		'assessment' of an individual's social skills and potential for independence in a setting where they experience nothing resembling 'ordinary life'. Some professionals are also risk-averse and a culture of positive risk-taking, in which people are supported to experience less secure and more independent settings, is particularly difficult to achieve where accountabilities are not clear (p3). **NHS commissioning practices** Many of the 1500 people living in 'assessment and referral centres' are using care commissioned wholly or jointly by the NHS, due to their having been assessed as having mental health or other primarily 'medical' needs. The NHS has not embedded a culture of personalisation (unlike local authorities) in its commissioning or provision, nor are personal budgets or Direct Payments, which can give individuals and families control over resources allocated to them, available outside of Personal Health Budget pilot areas. **Facilitators identified** **Brokerage and advocacy** Brokerage and advocacy service to enable people with learning disabilities and behaviour that challenges and their families	

		to make alternative choices, using existing budgets. Care packages should be required to be under constant review in any setting in which an individual is deprived of their liberty, with independent external advocacy freely available. More social care providers should be encouraged to employ people with learning disabilities, as advocates. **Commissioning** Professionals, including NHS consultants, need to be educated about non-traditional approaches, required to explore the most independent option available and empowered to help people to take positive and informed risks in order to have opportunities to develop their independence. **Payment by results and social finance investment** There may be a role for payment by results approaches and utilising social finance investment methods to bring alternative providers into the market, or to allow double-funding of experimental support packages for short periods, with returns on investment realised from the savings when people move successfully into more independent settings. **Personal budgets**	

		Regulation CQC's mandate could be widened and clarified to ensure that any care provided for more than a very short period of time was required to demonstrate that it was enabling individuals to experience ordinary independent, family and community life.	

68. Slevin E (2004) Learning disabilities: a survey of community nurses for people with prevalence of challenging behaviour and contact demands. Journal of clinical nursing 13: 571–9

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The overall aim of the research was to answer the following questions: 1 What are the demographic details of the CNLD? 2 How many clients are there on the nurses' caseloads? 3 How many clients on these nurses' caseloads have challenging behaviours, and what are the contact demands of these people? 4 What qualifications do the nurses possess that help them work with people who have challenging behaviours? (p573).	**Participants** Professionals/practitioners Community learning disability nurses. Employment grade H 2 (5%) G 27 (61%) F 1 (2%) E 13 (30%) D 1 (2%) Professional qualifications RNLD 44 (100%) CNLD 30 (68%) RMN 7 (16%) RGN 15 (34%) BNT 2 (5%) academic qualifications MSc 1 (2%) PG Dip 1 (2%) BSc/BA 9 (20%) Dip. 14 (25%) None 25 (57%) Mean number of years of experience reported by the respondents mean, min, max, sd Qualified nurse 14.53 2.4	**Service use** **Case load** The total number of clients reported to be on the combined caseloads of the CNLD was 1985; of these 642 (32%) were children. The mean caseload size was 45 with the minimum being 10 and the maximum 165 (sd=30.96). Median may be a more appropriate measure of central tendency i.e. 41. Of the total 1985 clients on the CNLD combined caseloads 550 (28%) were reported to have challenging behaviours, 206 (32%) of children were reported to have challenging behaviour 344 (26%) of the adults on the nurses' caseloads were reported to have challenging behaviour. The	**Overall score** +

Mechanism for change Identification of needs. **Service aims** Explicit. The CNLDs were defined in this study as any nurse working in community adult or children's' services for people with learning disabilities, and they included nurses who worked in specialist challenging behaviour support teams (p574). **Country** UK. **Methodology** Survey. **Source of funding** Not reported.	30.00 6.9 RNLD (learning disability nurse) 12.77 2.4 30.00 6.05 CNLD 6.48 0.5 15.00 3.68 A population of 37 (84%) were employed in a full-time capacity and 7 (16%) were employed part-time. The mean hours worked by the part-time respondents was 23 hours and this ranged from a minimum of 8 hours (1 person) to a maximum of 30 hours. The employment positions of the respondents were 2 team leaders (5%), 2 behavioural nurse therapist (BNT) (5%), 6 community learning disabilities sister/charge nurse (14%) and 34 CNLD (77%) (p574). **Sample characteristics** **Adults** **Age** 46–52.8 (18%) 39–45.7 (16%) 32–38.23 (52%) 25–31.4 (9%) 18–24.2 (5%). **Gender** Total 29 (66%) female and 15 (34%) male. **Level of need**	number of clients who had challenging behaviour across all the individual nurses caseloads was mean 12.5, maximum 44, minimum 0 (sd = 9.28). Of the 44 CNLD only 2 (4.5%) reported that they did not have any clients with challenging behaviours on their caseload. P574. Clients with challenging behaviour were more likely then clients without behaviour that challenges to be visited more often, A, visited daily; B, visited every 2–3 days; C, visited weekly; D, visited every 1–2 weeks; E, visited monthly. **Qualitative themes** **Facilitators** Courses or training that nurses said helped them in caring for people with learning disabilities and behaviour that challenges. **Staff skills** Value of courses reported by participants (Table 4, p575) Dip. professional studies (n=1) 'My practice is now more research based and effective' Counselling course (n=3) 'Helps me listen more to carer and client; increases my understanding of triggers for aggression, I am now better able to help parents, and I have more insight into problems'	

	550 (28%) were reported to have challenging behaviours, 206 (32%) of children were reported to have challenging behaviour and 344 (26%) of the adults on the nurses' caseloads were reported to have challenging behaviour. The number of clients who had challenging behaviour across all the individual nurses caseloads was mean 12.5, maximum 44, minimum 0 (sd=9.28). Of the 44 CNLD only 2 (4.5%) reported that they did not have any clients with challenging behaviours on their caseload (p574). **Sample size** 65 eligible out of 69 nurses 44 (68%) returned a questionnaire. **Treatment of groups** N/A (not more than 1 group). **How do the groups differ?** N/A (not more than 1 group).	TEACCH (n=3) 'Helpful to learning disabilities, mental health and challenging behaviour and autism'. Care of violent potentially violent individual (n=3) 'This is helpful to learning disability and mental health, I am now more aware and able to diffuse, I feel more confident following this.' Diploma aromatherapy (n=2) 'Helps challenging behaviour as tactile treatment' Diploma reflexology (n=1) 'It is useful I use it to aid relaxation' Introduction to psychology (n=1) 'This increased my knowledge of challenging behaviour.' Sex education course (n=1) 'a lot of challenging behaviour is related to sexual problems this course was helpful in that' Behaviour modification course (n=4) 'Functional analysis, behavioural interventions better all-round understanding. You know how challenging behaviour develops and what to do about it – the best course I have ever been on.' BILD 4-day conference on challenging behaviour (n=1) 'More able to critically analyse approaches to meeting needs of those who challenge services.' Teacher practitioner course (n=1) 'Heightens awareness and knowledge base so I am	

		better able to plan interventions.' Drama therapy (n=1) 'Developed my communication, useful for promoting healing, and bringing out positive aspects in others.' Family therapy (n=1) 'I now understand family dynamics better and the impact of challenging behaviour on the family.' **Summary of findings** Research evidence would suggest that among nurses who work with people with learning disabilities in community settings a conservative estimate of at least 25% would be expected to be clients with challenging behaviours (p577). The numbers of clients visited on a less than weekly basis are very few, in fact<3% of the total population were visited at these frequencies. There was a higher percentage of clients among those who have challenging behaviours reported to have been visited at the most frequent intervals (p577). The numbers of people with challenging behaviours in the community requires significantly more nurses to support this client group, and more staff who also possess a BNT qualification. **Study limitations** No statistical analysis was undertaken to determine whether the most frequent visits did not also include people with high support needs, and not necessarily challenging	

		behaviour, for instance epilepsy, or sensory impairments. Also authors point out that the frequency of contacts is not always a good indicator of need as it says nothing about the duration of a visit, or indeed what activities are actually undertaken during a visit.	

69. Slevin E, Sines D (2005) The role of community nurses for people with learning disabilities: working with people who challenge. International Journal of Nursing Studies 42: 415–27

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study aims to examine how community nurses for people with learning disabilities help this group of people in their everyday lives. **Country** UK. **Question areas** 1. Types of service provision.	**Participants** Professionals/practitioners. **Sample characteristics** Adults. **Sample size** Total 22 community nurses for people with learning disabilities (CNLD).	**Qualitative themes** **Barriers** There was a lack of respite services for people with challenging behaviours. This led to use of hospitals for respite provision, which goes against contemporary philosophies of community care (p420). **Facilitators** When the nurses and families felt as though they were working together. The development of therapeutic relationships with clients and carers was a valued role for these nurses and they found it to be 1 of the	**Overall score** +

Methodology Qualitative study **Services of interest** Community supports.		most effective things they were involved in. 'It is a joint thing with the carer, the psychologist and myself. We look at all the results we have got from the assessment process and together we decide where we want to get to. We connect families and clients to other professionals and other resources in the community; and liaise not only with the statutory sector but with the voluntary sector as well' (p420). **Access to support** **Timely access to support** **'**I think the important thing is to start with very young children, and young parents. Because we feel that if you get in there and teach them positive strategies in relation to good parenting, you know, preventative work is a very important strategy' (p420). **Inclusion/isolation** There was a consensus among the participants that challenging behaviour was detrimental to the person's life in that it leads to 'social exclusion' and exclusion within services for people with learning disabilities.	

		Personalisation of care A functional analysis approach was frequently indicated: ‘you would be trying to eliminate undesirable behaviour so you would be reinforcing positive behaviours’ (p420). **Staff skills** There was indication from the data of a perception that caring for people with challenging behaviour was a specialist role and the CNLD needed to specialise more in this area: we need to be looking at the issue of challenging behaviour as an entirely specialist area within the community. **Trust** The development of therapeutic relationships with clients and carers was a valued role for these nurses and they found it to be 1 of the most effective things they were involved in. Forming trusting relationships with clients was considered essential. **Working together** Empowerment and sharing was recognised by the CNLD as an essential requirement of	

		care planning. Selection of quotes: 'it's helping people speak up for themselves give the parents the voice that they need because a lot of the parents in this district sometimes feel a bit intimidated by professionals'; 'talking, listening and counselling-being able to allow parents to ventilate their problems' (p420). Teamwork was indicated to be valuable in the care of people with challenging behaviours. **Summary of findings** The findings of this study suggest that without carer (and client when possible) involvement in the total process of care planning and delivery, community care will fail to meet the needs of people with challenging behaviours. Preventive work was usually reactive rather than proactive. The authors suggest 'the "shared" approach to care that the CNLD in the present study were found to utilise should be further promoted and encouraged by learning disabilities services' (p424).	

70. Toogood S, Saville M, McLennan K et al. (2015) Providing positive behavioural support services: specialist challenging behaviour support teams. International Journal of Positive Behavioural Support 5: 6–15

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The article reviews the rise and fall of specialist challenging behaviour support teams (PBSS) and describes an up-to-date replication and innovation of the service model. **Service aims** Explicit. The main aim of PBSS is to help local services improve the life quality of people with intellectual disabilities who engage in challenging behaviour, their family members, and those who provide their support and assistance. **Country** UK. **Source of funding** Consultancy. Author is an independent provider and	**Participants** Not described. **Sample size** Not applicable **Study timing** Not applicable **What is the sampling frame (if any) from which participants are chosen?** Explicitly stated In 2010, three local authorities and their NHS partners commissioned a specialist challenging behaviour support service that has now been operational for just over four years. **Details of data collection instruments or tool(s)** Not stated **Do the authors' describe any ways they addressed the**	**Barriers identified** **Difficulties in upscaling** Reasons for the failure to replicate (this service) are not well understood, but many services tended to copy structural rather than functional aspects of the service model. For example, while services recruited community-based practitioners with a specific brief to support people with behavioural challenges, there was often no clear expectation that they should provide individually tailored, function-based, behavioural intervention. Board Certified Behavior Analysts are practitioners certified by the Behavior Analysis Certification Board (BACB). The number of BCAB practitioners in the UK is small. **Facilitators identified** **Service design** Good service design and development capabilities that complement strategies for crisis prevention and management. For a small number of individuals, services need	**Overall score** -

receives a fee for consulting work with the service described in this article. **Methodology** Single group, before and after. **Services of interest**: Peripatetic specialist challenging behaviour (intensive) support. **Content/components of service** - Assessment reports and intervention plans. - Case management. - Crisis prevention and management. - Data based support. - Function based support. - Least restrictive support. - Minimally intrusive support. - Multi-component support. - Multi-level support. - Placement development. - Peripatetic behavioural advisors. - Person-centred support. - Positive behavioural support. - Staff skills. - Training: training and mentoring for professionals from other agencies.	**repeatability or reliability of their tools** No **Which methods were used to analyse the data?** Not clear	to be able to create bespoke packages that are robust, durable and affordable. **Multi-agency-interdisciplinary involvement** Authors conclusion: 'that BST appears to be a valuable resource from the perspective of services working with them, promoting a multi-agency PBS based approach to support individuals with behaviours that challenge, and steps should be taken in order to ensure this is maintained' (p13). **Summary of findings** - Three local authorities and the NHS Clinical Commissioning Group jointly commission the service, which is provided by a local authority and not the NHS. - The service is staffed and led by board-certified behaviour analysts, who work closely with others to ensure contextual fit. - The service works behaviourally in early intervention, crisis prevention, technical assistance and placement development.	

Time to follow-up No Follow up			

71. Vaughan PJ (2003) Secure care and treatment needs of individuals with learning disability and severe challenging behaviour. British Journal of Learning Disabilities 31: 113–17

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim A survey was undertaken within the catchment area of the Wessex Consortium (population 1.8 million) to identify the number of individuals with learning disabilities and challenging behaviour who were placed in or needed to be placed in secure care. **Mechanism for change** Identification of needs. **Country** UK. **Methodology** Survey. **Source of funding** Not reported.	**Participants** Professionals/practitioners. **Sample characteristics** **Age** Mean age 33 (range 18–63). **Gender** Total 29 males, 6 females. **Ethnicity** One was described as Black Caribbean, all the rest were white. **Sample size** Total 35 individuals were identified as being in or requiring secure care on September 2001.	**Satisfaction** **Satisfaction with care** Learning disability teams said that of the 35 individuals identified as being in or requiring secure care, 24 (69%) thought the placements they were in were suitable, 9 (25.5%) were thought to be unsuitable, 2 (5.5%) were uncertain or did not state an opinion (p31). Of those who said the placement were unsuitable 4 were felt to be in settings with an inappropriate level of security, and 3 people were felt to need a local service. **Service use** **Case load** Cols: Future placement needs low secure, medium secure, special placement Violence/ assaultive behaviour 13, 12,1 Sexual offences 11, 8, 2	**Overall score** -

	Treatment of groups No prospective allocation-use of pre-existing differences to create comparison groups. **How do the groups differ?** N/A (not more than 1 group).	Self-harm 4, 4, 1 Arson 4, 3, - Damage to property 4, 2, - Absconding 2, 2, 1 Theft/Burglary 3, 1, - Murder -, 1, - Hostage taking 1, -, - Abduction -, 1, - (some individuals had more than 1 category). **Characteristics** Women were over-represented for self-harm and fire setting. (56 and 57%), despite representing 17% of the group. **Inpatient service use** Current placements High secure n=2. Private secure (out of area) n=19. NHS secure (out of area) n=6. Private non-secure (local) n=1. Short-stay respite centre (local) n=5. Short-stay respite centre n=1. At home n=1. Total n=35.	

		N=9 (25%) reported were said to need psychiatric input as well as a learning disability service. **Length of hospital stay** Mean length of stay was 3 years and 7 months (range =2 months–12 years) there were 3 exceptionally long placements and the median length of 2 years and 4 months is more representative. **Legal status** Total 21/35 were detained under a civil section of the Mental Health Act 1983. **Out of area** The majority of placements were out of area offering differing levels of security. The majority (19) placements were in private secure settings, many miles from the consortium area. **Summary of findings** Although the majority of placements were outside of the local area, few practitioners gave this as a reason for the placement being inappropriate. Only a minority of offenders for violence and sexual offences were subject to a court order. There are a small number of women in mixed sex wards, that may have different service needs to men, as shown by the over-representation of self-harm and fire	

		setting. There is a consideration of mixed wards where 72% of the men are sexual offenders (60% in this group).	

72. Watson JM, McDonnell V, Bhaumik S (2005) Valuing People: Evaluating Referral Systems. A Study of a Multidisciplinary Single Point of Referral System to Dedicated Adult Learning Disability Health Services in Leicester, UK. The British Journal of Development Disabilities 51(101), 155-70

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim The overall aim of the study was to assess the impact of establishing the SPR system in eastern Leicester PCT. The objectives were to make the following comparisons before and after the new system was introduced: the number and demographic characteristics of individuals referred; the sources of referrals; the reasons for referrals; the appropriateness of referrals; the average number of professions involved in the care of each patient; the mean waiting time between referral and assessment; and the perception of communication between professionals (p158). **Service aims**	**Participants** Professionals/practitioners. **Sample characteristics** Adults. Practitioners included: the project facilitator, single point referral coordinator and representatives. A third of the referrals were people with learning disabilities and also behaviour that challenges. **Sample size** Comparison numbers: old system 98. Intervention number: new system 92.	**Satisfaction** **Staff satisfaction** Single point of referral (SPR) M-most of the time, S-sometimes, O-occasionally, N-ever The reason for the referral is clear Old M37% S33% O30% N0% SPR M74% S22% O4% N0% Referral letters/forms contain sufficient information for you to judge whether the referral is appropriate Old M19% S44% O26% N0% SPR M18% S8% O1% N0% Referral letters/forms contains useful additional information Old M1% S7% O17% N3% SPR M17% S8% O2% N0%	**Overall score** -

Explicit. (To evaluate) a multidisciplinary SPR pilot project for dedicated adult learning disability health services was set up in Eastern Leicester Primary Care Trust (PCT). This used common referral criteria and a streamlined information system (p156) **Country** UK. **Methodology** Mixed methods. **Source of funding** Local authority - Leicestershire Partnership NHS Trust. **Services of interest** Community support Adult learning disabilities health services **Content/components of service** Referral. **Time to follow-up** No follow-up.	**Treatment of groups** No prospective allocation-use of pre-existing differences to create comparison groups. **How do the groups differ?** Explicitly stated. Slightly more males than females were referred to both the old system (54%) and SPR system (53%). There was no statistical difference in the sex, ethnicity or type of accommodation in the 2 study periods. There were significantly more individuals aged <19 referred to the old system (X2=18.5, p<0.001) (p159). **What is the sampling frame (if any) from which participants are chosen?** Implicit. Between 1 October 2002 and 31 March 2003, 92 individuals were referred. Here were 98 referrals between 1 August 2001 and 31 October 2001 (p159). **What methods were used to collect the data?**	Service providers' perceptions of the benefits of the SPR system A-gree, N-eutral, D-isagree It has improved patient care A56% N33% D7% It provides better information for patients/carers A67% N26% D4% It provides a more holistic approach to care A78% N15% D4% It has achieved a coordinated team approach A74% N11% D11% It provides better documentation for professionals A59% N33% D4% It has improved professional satisfaction A56% N33% D7% It has improved professional understanding of the roles of different professions A85% N11% D0% **Costs?** No. **Service use** **Waiting times** The SPR system significantly reduced the median waiting time from 66 to 6 days (z=-5.9, p< 0.001) (p161) and the interquartile range from 15–46 days to 2–9 days, 25% of patients were assessed within 2 days, 50% within 6 days and 75% within 9 days (p162). The	

	Administrative data: casenotes. One-to-one interview (face to face or by phone). Single point of referral (SPR) project facilitator, PR coordinator and SPR representatives. **Self-completion questionnaire** A short postal questionnaire was designed, piloted and used to collect similar information from referrers. **Other documentation** Literature review of published reports on the trusts operating single point of referral systems in learning disability. **Details of data collection instruments or tool** Researcher designed questionnaire. **Do the authors' describe any ways they addressed the repeatability or reliability of their tools?** Yes, the postal questionnaire was piloted.	proportion of inappropriate referrals halved from 26% to 13% (p168). **Facilitators identified** **Single point of referral** Facilitates shorter waiting times to access the right services at the right time. **Summary of findings** The SPR system facilitated prompt allocation of referrals to the appropriate professionals with significantly reduced waiting times from referral to assessment. It reduced the rates of inappropriate referrals and re-referrals and duplication of professional input. It provided a more efficient service for referrers; and better care and information for service users and carers. Multidisciplinary working improved interdisciplinary understanding and communication; collaborative working; and professional satisfaction. The database should be developed as a tool for audit and evidence-based service developments; and the system extended to joint working with social services and integrated care pathways (p169). **Facilitators identified** **Implementation issues**	

	Do authors' describe any ways they have addressed the validity or trustworthiness of their data collection tools/ methods? No. **Which methods were used to analyse the data?** Explicitly stated. Statistical testing was done where appropriate using the chi-square (x2) test for categorical data; and the Mann-Whitney U test for comparison of medians.	The SPR system facilitated prompt allocation of referrals to appropriate professionals, with a significant reduction in the waiting times from referral to assessment. However, the co-existence of 2 referral systems to the same dedicated services caused confusion for some referrers and inequity for service users (p168). **Study limitations** The extent and bias of missing data about the old system limited the comparisons that could be made with the SPR data and valid testing for statistically significant differences. The 54 referrals for which individual data were available were unlikely to be representative of the total 98 referrals. The extent and bias of missing data about the old system limited the comparisons that could be made with the SPR data and valid testing for statistically significant differences. The time scale and other resource constraints of the study precluded obtaining the views of service users and carers. **Mechanism for change** **Multidisciplinary collaboration** **Services working with other services**	

		A multidisciplinary SPR pilot project for dedicated adult learning disability health services was set up in Eastern Leicester Primary Care Trust (PCT). This used common referral criteria and a streamlined information system. A new referral form and an information leaflet about the SPR system were developed and copies distributed to social workers, day centre managers, general practitioners (GPs) and colleges of further education. A representative from each profession attended weekly SPR team meetings, where referrals were assessed and action plans agreed. A social worker attended these meetings about once a month.	

73. Wheeler JR, Holland AJ, Bambrick M et al. (2009) Community services and people with intellectual disabilities who engage in anti-social or offending behaviour: referral rates, characteristics, and pathways. Journal of Forensic Psychiatry and Psychology 20(5): 717–40

Research aims	**Study characteristics**	**Outcomes and findings**	**Overall validity rating**
Study aim As part of a multi-centre study examining the care	**Participants** Adults with learning disabilities and behaviour that challenges.	**Service use** **Community service use**	**Overall score** +

pathways of adults referred as a result of anti-social or offending behaviours to a range of community and special forensic ID services, this paper reports on referrals to CTLDs in 15 districts spread across 3 UK regions (covering a general population of 1.74 million), providing a preliminary portrayal of the operation of core ground-level community ID services in relation to adults with offending or antisocial behaviour (p720). **Mechanism for change** Identification of needs. **Service aims** Implicit. Multi-disciplinary community ID services (typically referred to in the UK as 'community teams for adults with learning disabilities'; 'CTLDs') are a central component in public health and social care	**Sample characteristics** **Age** Inclusion criteria: (3) they were age 18 years by 31 December 2002. The average age was 36 years (ranging from 17 to 82 years). Younger age was significantly associated with CJS group membership, t(235)=72.19, p<.05 reflecting the high age of some referrals in the No CJS group rather than youthfulness of the CJS sample; age (at time of behaviour) No CJS 37.08 (13.19), CJS 32.59 (11.09) total 36.15 (12.19) p=.03. **Disability** Level of learning disability n, % Severe/ profound No CJS 67 35.6%, CJS 5, 10.2% p=.001 Mild No CJS 79 42%, CJS 27 55.1% ns. Borderline/ none No CJS 25 13.3%, CJS 17 34.7% p=.000 Not known No CJS 17 9%, CJS 0, 0 p=0.29. **Gender** Women made up an unexpectedly large proportion of the total sample (41%). referred to CMLD. There was no significant association between gender and CJS group membership, Chi2 (1, n=237) = .37, p<.05. **Level of need** Psychiatric diagnosis N, % Schizophrenia or psychotic illness No CJS 20, 10.6, CJS 8, 16.3 Depression No CJS 20, 10.6, CJS 10,	Origin of referrals to the CTLD The majority of referrals to CTLDs originated from within the community (66%, n=157), which included referrals from family, carers, general practitioners, self-referrals, and community-based health services (including referrals made by professionals within the CTLD). A smaller proportion of referrals came to teams via social services (22%, n=51). The most infrequent source of referrals (12%, n=29) reached teams via forensic and tertiary health, courts, or offender services (psychiatric inpatient, secure ID hospital, or criminal justice services). There were no statistically significant differences between the CJS and No CJS groups in relation to the origin of referrals Chi2 (2, n=237) = 4.946, p<.05. **Summary of Findings** The overall estimate for the prevalence of adults known to CTLD services (0.5% of the general adult population) is in line with comparable surveys of adults with ID known to UK community ID services (estimates range from 0.1% to 0.7%, e.g., Allgar et al. 2008; McBrien et al. 2003). The current study estimates that 0.8% of	

provision for people with ID (Department of Health 2001: 720). **Methodology** Secondary data study retrospective observational case note study. **Source of funding** Health authority. This study was commissioned by the National Forensic Mental Health RandD Programme.	20.4 Bipolar/ manic depressive disorder No CJS 14, 7.4, CJS 1, 2 Severe anxiety and OCD No CJS 6, 3.2, CJS3, 6.1 Personality disorders No CJS 6, 3.2, CJS 2, 4.1 ADHD, ADD, or conduct disorder (in childhood) No CJS 15, 8, CJS 5, 10.2 Autism spectrum conditions No CJS 29, 15.4, CJS 5, 10.2 Epilepsy No CJS 51, 27.1, CJS 5, 10.2 A diverse range of psychiatric conditions were exhibited and overall almost half the sample experienced at least some form of dual diagnosis (n=103, 44%). There was no significant association between presence of a psychiatric condition and CJS or No CJS group membership, Chi2 (1, n=237) = .30, p<.05. **Characteristics of behaviour** Inclusion criteria: (2) the referral related to anti-social or offending behaviour (including: physical aggression, verbal aggression, stalking behaviours, cruelty and neglect of children, sexually inappropriate behaviour, damage to property, fire setting, taking property, inappropriate motor vehicle or traffic-related behaviours, obtaining goods or money under false pretences, and illegal drug-related behaviours, and if the behaviour led to CJS contact, or formal statutory sanction, this was also recorded). Exclusion criteria included referrals related to challenging behaviours which were solely	the established adult ID population were referred annually as a result of behaviour which involved CJS contact. Cases referred annually as a result of anti-social behaviour made up 3.8% of the established adult ID population: a 5:1 ratio of referrals involving antisocial as opposed to offending behaviour. Level of ID did not hold as a significant predictor for CJS contact in the multivariate analysis. people with mild ID seem to be situated in an ambiguous ‘grey’ area in relation to the interpretation of their behaviours as either ‘challenging’, ‘anti-social’, or offending’ (e.g. McBrien 2003). Suggests that a quarter of adults known to community ID services to engage in broadly defined anti-social behaviours might be expected to be referred annually to CTLDs following such behaviour. Involvement with ID residential or day services was also significantly associated with lack of CJS contact. Offenders with ID drawn from ID services, as here, seem less comparable; being more significantly intellectually impaired and older (e.g., Barron et al. 2004; Rose, et al. 2008); with minimal substance abuse issues and a higher prevalence of women	

	self-injurious behaviours, and also solely pica, faecal smearing, stereotypy, and inappropriate verbal acts. Behaviour that triggered referrals: physical aggression (52%); followed by verbal aggression (40%); damage to property (24%); and inappropriate sexual behaviour (18%). (11%) of cruelty and neglect cases (mothers); 89%, n=23 (fathers) 11%, n=3; Chi2 (1, n=237) = 27.87, p< 001. Cruelty and neglect referrals made up 24% of the female sample. Very few cases with more severe impairment were found in the CJS group. The majority of those in the CJS group had mild, borderline, or no ID; 90%, n=44 (vs. 10%, n=5 with severe or profound ID); in the No CJS group 61%, n=115 had mild, borderline, or no ID (vs. 39%, n=67, with severe or profound ID); Chi2 (1, n=220)=14.53, p<.001 (excluding those for whom level of ID was not recorded in health records, n=17). Verbal aggression was statistically significantly associated with No CJS group membership, Chi2 (1, n=237)=12.13, p=5 .001; as was prior physical aggression (n=133, 71%); Chi2 (1, n=237) = 6.81, p<.01. Cruelty and neglect of children was significantly associated with CJS group membership, Chi2 (1, n=237)=11.56, p=5 .005; as was - a recorded history of taking property; Chi2 (1, n=237)=9.45, p<.005 - previous CJS	(compared to 'Offenders with ID' – 'Offenders with ID' drawn from CJS settings). **Barriers identified** **Study limitations** Accurate figures for community team referrals were not available: CTLDs were typically unable to provide more than approximate figures: computer record systems were unable to generate this information readily). other limitation to the study include: First, the study offers only an approximate base-line estimate of adults known to CTLDs; second, it is unlikely that all adults with ID would be known to ID services; third, even of those known to ID services, it is unlikely that all cases with anti-social or offending behaviour would trigger a referral to CTLDs. Details of the severity of behaviours and qualitative data on the experience and relevance of circumstances were not sought, given the retrospective case note design. Interpretation of these findings must remain cautious, bearing in mind the exploratory nature of the logistic regression model. The current data do not permit comment on experiences of the quality of the services offered, or	

	involvement Chi2 (1, n=237) = 31.17, p<.001, - a record of prior offences:Chi2 (1, n=237)=22.38, p<.001 Behaviour which led to the referral n, % Physical aggression No CJS133, 70.7, CJS 25, 51 ns. Verbal aggression No CJS 86, 45.7, CJS 9, 18.4 p=.000 Damage to property No CJS 45, 23.9 , CJS 12, 24.5 ns Inappropriate sexual No CJS 34, 18.1, CJS8, 16.3 ns. cruelty/ neglect of children No CJS14, 7.4, CJS12, 24.5 p=.001 taking property No CJS 7, 3.7, CJS 2, 4.1 - substance abuse No CJS 7, 3.7, CJS 2, 4.1 - Fire setting No CJS2, 1.1, CJS 0, 0 - fire setting No CJS, CJS cruelty/ neglect of children No CJS, CJS **Service use** Inclusion criteria: (1) they had been referred to the CTLD in the year 2002. Inclusion criteria for Phase 2(1) they were accepted as eligible to the CTLD service to which they had been referred and (2) they had CJS or formal statutory involvement in their case (at least police contact or detention in hospital under the Mental Health Act following criminal prosecution and court action). **Other** Psychosocial history n, % Abuse or severe deprivation in childhood No CJS 44, 23.4, CJS 13, 32.7 ns. Abuse or severe	on the outcome of service provision in relation to further anti-social and offending behaviour.	

	deprivation in adulthood No CJS 16, 8.5, CJS 7, 14.3. **Sample size** Total 237 people were referred to the CLTD team. N=49 (21%) were referred due to offending behaviour which led to contact with CJS services (the CJS group), and n=188 (79%) people were referred due to anti-social behaviour which did not lead to contact with CJS services (the No CJS group). **Treatment of groups** No prospective allocation-use of pre-existing differences to create comparison groups. **How do the groups differ?** Groups are: (1) the 'No CJS' group includes cases whose anti-social or offending-type behaviour did not lead to contact with the CJS and (2) the 'CJS' group includes cases whose anti-social or offending-type behaviour led to at least a minimal level of CJS contact (the police were at least informed) and includes cases where offending-type behaviour led to arrest, caution, charge, or conviction.		

74. Wong YL, Bhutia R, Tayar K et al. (2015) A five decade retrospective review of admission trends in a NHS intellectual disability hospital. Advances in Mental Health and Intellectual Disabilities 9(3): 108–15

Research aims	Study characteristics	Outcomes and findings	Overall validity rating
Study aim This study will revisit the study by Ganguly et al. (2009) post-Winterbourne View scandal in 2011–13 examining the trend of admission in this NHS intellectual disability hospital. The study will look at the reasons underpinning admissions to hospital and their nature and severity. **Service aims** Not stated. **Country** UK. **Methodology** Retrospective case notes review **Source of funding** Not reported.	**Participants** Adults with learning disabilities and behaviour that challenges. Excluding people admitted to forensic beds. **Sample characteristics** **Age** There were 58 new admissions over the period in 2011–13, of which 15.5% were aged under 16 years old; 81% were between 17 and 64, and 3.4% cent were over 65 years old. **Disability** Admissions related to people with mild, moderate, and severe learning disability accounted for 52, 27, and 21% respectively. **Level of need** Total 86% of admissions had more than 1 reason for admission (Figure 2), of which	**Service use** **Length of hospital stay** Nine out of 58 (67.2%) admissions had stayed over 6 months in 2011-2013, accounting for the majority of total admissions, The number within the shortest admissions (1 to 3 months) category had also increased from 7.8 to 15.5%. **Legal status** There were more detained patients compared to informal patients. In 2011-2013, formal patients accounted for 62.1% being admitted under the Mental Health Act 1983 compared to 37, 26.73, 33, and 10% in the previous study periods. **Out of area** There were 29 out of area admissions in 2011–13, of which there were more male admissions (n=25, 86.2%) than female admissions (n=4, 13.8%). Over 40% of the out of area admissions were from the under 16 age group, compared to 15.5% from admissions within our catchment area. All out of area admissions were related to behavioural problems. The	**Overall score** -

	90% were related to behavioural problems with co-morbid psychiatric illness; 100% of people with severe learning disability who were admitted to hospital also had a diagnosis of autism spectrum disorder (ASD) **Sample size** N/A **Treatment of groups** N/A (not more than 1 group).	number of first time admissions (n=25, 86.2%) were higher than readmissions (n=4, 13.8%); 79.3% of out of area admissions had a diagnosis of ASD, compared to 58.6% of the population within our catchment area. **Risk of hospital admission** Over the past 5 decades, male admissions had been consistently higher than female admissions, accounting for over 70% of the total admissions on average. The number of admissions increased from 51 in 2003-–06 to 58 in 2011–13. The commonest reason for hospital admissions was related to behavioural problems, followed by psychiatric illness. The ratio of first admission vs. those who had previous admissions were approximately 1:9 (1975-–77), 2:3 (1985–87), 5:5 (1995–97), and 9:1(2003–06), respectively, and in the period of 2011–13, the ratio was 3:1. **Summary of findings** Present study has identified that, despite the Winterbourne View scandal, the number of admissions to Brooklands Hospital during the period of 2011-–13 had increased compared to the last decade. More people are entering units than leaving them. The increase demand of admission to hospital in the recent decade can partly be explained by the closure of 2 other local learning disability hospitals in 2008 and 2013, as well as the reduction of emergency	

		respite placements and day centres in the area (p113). Data is not available to know whether the reduction in admission rates is offset with an increase in admissions to private facilities, (p113). Similar to a study carried out in Enfield (Oxley et al. 2013), behavioural problems have consistently been the leading cause of admission. However, 86% of admissions post-Winterbourne View were also associated with additional psychiatric or medical problems. In our study, we found that the commonest psychiatric disorder that associated with hospital admissions was ASD. The increase of diagnosis of ASD could be related to the increased understanding and diagnostic skills in this area of psychiatry. A significant percentage of people (79.3%) referred from out of area region would also have been diagnosed with ASD before or during their admissions. This indicated that a more highly specialist skills units were sometimes required to look after this group of people (p133). Authors conclude that study has clearly highlighted that with the reduction of specialist inpatient facilities, people requiring hospital admissions have increased in both complexity and severity. In order for people to be resettled in the community safely and effectively, robust alternative arrangements in the community are vital (p114). The development of a high-quality community service supported by staffs who have specialist skills and knowledge was associated with	

		reductions in rates of both long- and short-term admissions (Allen 1998) (p114). **Study limitations** Brooklands Hospital has changed from a local tier 3 to a regional tier 4 service accepting referrals from a wide geographical area and from other hospitals. This might impact on the characteristics of patients admitted. It is also not possible to track the impact of the private or voluntary sectors and how it might have affected the trend of admissions to the NHS hospital. (p114).	

75. Xenitidis K, Gratsa A, Bouras N et al. (2004) Psychiatric inpatient care for adults with intellectual disabilities: generic or specialist units?. Journal of Intellectual Disabilities Research 48(1): 11–18

<table>
<tr><th>Research aims</th><th>Study characteristics</th><th>Outcomes and findings</th><th>Overall validity rating</th></tr>
<tr>
<td>Study aim
To evaluate the effectiveness of a specialist unit for people with a learning disability and mental health problems (MHP) and to compare admissions to the specialist</td>
<td>Participants
Adults with learning disabilities.
Adults with learning disabilities that require a psychiatric admission.
Sample characteristics
Adults</td>
<td>Clinical outcomes
Function
Group 1: admission; Group 2: discharge
GAF
<table>
<tr><th>Group 1 N</th><th>Group 2 N</th><th>Group 1 mean</th><th>Group 2 mean</th><th>Group 1 sd</th><th>Group 2 sd</th><th>SMD</th><th>SE</th></tr>
</table>
</td>
<td>Overall score
-</td>
</tr>
</table>

<table>
<tr>
<td>unit and the general psychiatric unit.
Service aims
Provide care and treatment for adults with learning disabilities (LD) that require a psychiatric admission.
Country
UK.
Source of funding
Not reported.
Methodology
2-group before-and-after study
What is the sampling frame (if any) from which participants are chosen?
Adults with (LD) that require a psychiatric admission in 3 inner London boroughs.
Details of data collection instruments or tool(s)
Disability Assessment Schedule (DAS-B).
Global Assessment of Functioning Scales (GAF)</td>
<td>Age:
Mean =34.55.
Disability
Total 81% had mild LD.
Gender
Total 50.7% male.
Health status
Schizophrenia =46.5%; bipolar affective disorder =22.5%; autism =23.9%; epilepsy=8.5%; no additional diagnosis =14.1%.
Legal status
The number of people admitted in both groups detained under the Mental Health Act 1983 was 41.6%.
Sample size
Sample size n=84 total admissions for 54 people.
Comparison numbers
Generic services n=45 total. Admissions: n=10 were transferred from generic to the specialist unit (22%); n=8 were readmissions.
Intervention number</td>
<td>
<table>
<tr><td>33</td><td>33</td><td>37.7</td><td>62.4</td><td>14.8</td><td>16.7</td><td>-1.54</td><td>0.282</td></tr>
</table>
Behaviour that challenges
Group 1: admission; Group 2: discharge
DAS
<table>
<tr><th>Group 1 N</th><th>Group 2 N</th><th>Group 1 mean</th><th>Group 2 mean</th><th>Group 1 sd</th><th>Group 2 sd</th><th>SMD</th><th>SE</th></tr>
<tr><td>33</td><td>33</td><td>4.24</td><td>5.36</td><td>2.87</td><td>2.62</td><td>-0.403</td><td>0.249</td></tr>
</table>
Mental health
Group 1: admission; Group 2: discharge
PASS-ADD
<table>
<tr><th>Group 1 N</th><th>Group 2 N</th><th>Group 1 mean</th><th>Group 2 mean</th><th>Group 1 sd</th><th>Group 2 sd</th><th>SMD</th><th>SE</th></tr>
<tr><td>33</td><td>33</td><td>10.6</td><td>4.24</td><td>5.68</td><td>4.82</td><td>1.2</td><td>0.269</td></tr>
</table>
TAG
</td>
<td></td>
</tr>
</table>

<table>
<tr>
<td>The Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PASSAD)
Threshold Assessment Grid (TAG)
The total TAG score was used as a summary score of severity of MHP.
Mechanism for change
Specialist support people with a learning disability and mental health problems admitted to a specialist unit are less likely to be discharged to an out-of-area placement than people admitted to a generic mental health ward.
Source of funding
Not reported.
Time to follow-up
No follow-up.</td>
<td>Specialist service n=39 total admissions; n=5 were readmissions.
Services of interest
Inpatient category 3
Acute admission beds within generic mental health settings.
Inpatient category 2
Acute admission beds within specialised learning disability.</td>
<td>
<table>
<tr><th>Group 1 N</th><th>Group 2 N</th><th>Group 1 mean</th><th>Group 2 mean</th><th>Group 1 sd</th><th>Group 2 sd</th><th>SMD</th><th>SE</th></tr>
<tr><td>33</td><td>33</td><td>11.9</td><td>6.39</td><td>3.43</td><td>3.01</td><td>1.67</td><td>0.288</td></tr>
</table>
Costs? No
Service use
Length of hospital stay
There was a significant difference in the length of stay of people in the specialist unit remaining inpatients for longer (mean: 23.3 weeks; sd: 14.1) compared to those admitted to generic psychiatric wards (mean: 11.1 weeks; sd: 13.6).
Out of area
People in the specialist unit (3 out of 33) were less likely to be discharged to an out-of-area placement compare to those discharged from general adult mental health wards (10 out of 33).
Summary of findings
People treated in the specialist unit showed significant improvements on a number of outcome measures including psychiatric symptoms, overall level of functioning, severity of mental health problems and behavioural problems. Capacity – inpatient services – in this study, 84 admissions were</td>
<td></td>
</tr>
</table>

		accounted for by 54 patients out of an active case load of 320 adults with LD and MHP living in an area serving a total population of 680,000. That means, just under 17% of the patients in contact with the community mental health and LD teams require inpatient care over the approximately 3-year period of the study. **Study limitations** People were not randomly allocated to the groups and the outcomes of people in the generic group were not measured, so we don’t know if people in this group might have experienced the same level of improvement as the specialist treatment group. Due to the small number of beds in the specialist unit and low turnover this meant that some admissions that might have been more appropriate for the specialist unit had to be directed to the generic wards. The study also only assesses the outcomes of people at the time of discharge so we don’t know if the positive outcomes can be sustained over time. Also the outcome measures used in the study are not entirely independent from each other and are not all standard measures used with people with LD and MHP. It is also worth noting that the study took place at only 1 site, with a modest number of participants so we cannot be sure	

		at how far the findings could scale up to be applicable to other areas of the UK.	