Appendix D Expert testimony papers

Section A: NCCSC to complete			
Name:	1. Helen Toker-Lester	2. Doreen Kelly	3. Michelle Beattie
Job title:	1. Joint commissioner of learning disability services, NEW Devon Clinical Commissioning Group	2. Director, Beyond Limits	3. Expert by experience
Address:	1. NHS Northern Eastern and Western Devon Clinical Commissioning Group Newcourt House Newcourt Drive Old Rydon Lane Exeter Devon EX2 7JQ	2. York House, Unit 4, Stoke Damerel Business Centre Church Street, Stoke Plymouth, PL3 4DT United Kingdom	4. Expert by experience. Devon, UK
Guidance title:	Service model for people with learning disabilities and behaviour that challenges		
Committee:	Guideline committee: Service model for people with learning disabilities and behaviour that challenges GC9		
Subject of expert testimony:	You are invited in your capacity as experts in an organisation that supports people with learning disabilities, commissioning of services for people with learning disabilities and experience of using services for children and adults with learning disabilities and behaviour that challenges		
Evidence gaps or uncertainties:	We have searched for evidence in relation to models of service delivery, by models we mean the different types of services, the way they are organised and the way they are delivered. We have found very little high quality evidence in relation to different models of service delivery which meets the criteria for our review questions. We have identified some gaps in the research evidence that the Guidance committee find important to understand how services should be organised and delivered. These were: • Examples of best practice • Personalisation of services We would therefore like you to speak on the basis of your expertise as an organisation that supports people with learning disabilities, commissioning of services for people with learning disabilities and experience of using services for children and adults with learning disabilities and behaviour that challenges,		

R.Q.1. What is the effectiveness of different types of **Community based services** (including residential) for children, young people and adults with learning disabilities and behaviour that challenges?

We have searched for evidence in relation to evaluation of different types of services for people with learning disabilities and behaviour that challenges. The criteria for inclusion to test the effectiveness of different types of services was that the study had to include a control group to compare the service with (usual care or an alternative service).
We found very few evaluations of different types of service for people with learning disabilities and behaviour that challenges in the community. This is because there have been few randomised controlled trials or controlled trials that have been done in this area.

In answering these questions we are very interested in hearing from you about your experience as to what community based services help or do not help and what is it about them that makes this so. If you have comments about what community based services you would have found helpful, but are missing, then we would like to hear about this too.

R.Q.1.2. What is the effectiveness of different types of **in-patient services** (in and out of area) for children, young people and adults with learning disabilities and behaviour that challenges?

We did not find a great deal of evidence meeting our criteria to evaluate all the different types of in-patient services. We were particularly lacking in research evidence on the effectiveness of

- Secure inpatient services and how these link up with health and social care
- Different types of respite care and short breaks, specifically for adults and/ or children with behaviour that challenges.

We would be interested to hear from you about your experiences of in-patient services, what you thought helped and what did not help.

R.Q.3.1. What **models of service** delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers? By models we mean the different types of services, the way they are organised and the way they are delivered.

We did not find any rigorous research evidence meeting our criteria about comparing different ways of organising services for people with learning disabilities and behaviour that challenges compared to usual care/ practice or alternative service model.
We are particularly interested in hearing from you, based on your expert opinion more about:

- Effective services that are personalised and organised around the individual
- Using personal budgets to purchase services, and using personal budgets to personalise the services.

- Assessments and referrals i.e. what sorts of services are best to deliver these assessments and referrals?
- Experiences of using services for children

Section B: Expert to complete

Summary testimony:	

This statement is made by Helen Toker-Lester (NEW Devon CCG) and Doreen Kelly (Beyond Limits)

R.Q.1.

Doreen

For the group of people who challenge services, in my experience, residential or any other group form of care seldom is the solution. I feel this is because if you have your own troubles and need a particular environment then it is difficult to achieve this if there are several people living in the same environment. This is often the case even if two or three people are sharing accommodation. That said if two or three people with learning disabilities state they want to live together then that must be supported, problem being it is usually on offer as an existing service rather than a bespoke service set up around two or three friends.

Helen

The main principle is that the service needs to be built around the person. We know that in the past multiple placement failures occurred for some people because they are squeezed into existing services that are often a very poor fit for a person's needs. For a person who has significant cognitive impairments, and may have experienced very traumatic events in their past this can be intolerable. Particularly if you have a diagnosis of autism the very unpredictable behaviours of those around you can be immensely distressing.

Furthermore staff must understand the complex behaviours of people, they need to have a honed individual focus that can anticipate idiosyncratic triggers, avoid distressing situations and have the energy and interests to engage people in the things they like to do. Therefore it makes sense that staff are chosen to work with someone when they have the right temperament, values and shared interests and hobbies that will help that person develop and grow.

Accommodation is critical- as part of the planning process we identify what housing is needed, we use a home identification form which generates a specification for the property that we then seek and resource- we always aim to split accommodation and support. This way if a service provider ever struggles the person does not lose their home. We use tenancies: -some people have bought their own homes using shared ownership under the government's "help to buy" scheme and HOLD (Home ownership for people with long term disabilities). This means that they can never be served notice on their accommodation because they own it- it provides a wonderfully stable base for community living.

Other key features of this model include the need for systems working- especially with the police and CJS, housing, and primary and acute healthcare. Who we work with largely depends upon the needs of the person, but in most cases multi agency support has been required.

Of course all this takes huge effort; it is not as simple as just placing a person in a residential home. However when we have used this approach readmission is exceptionally rare- just one person in the last 3 years has been readmitted to hospital when we have used this approach. We also see big improvements in the quality of life looking at HEF scores from being in hospital and later in the community- one measure we have used on a number of people is the Health Equalities Framework, there is now also a child version we are piloting in Devon.-This framework has been developed by the National development Team for Inclusion. We also have commissioned a long term study of this work by the Centre for Welfare reform orientated on the Citizenship model.

As people live their life, (and they have real relationships with people not paid to be with them) we are able to safely reduce support creating some savings. This is important as initial bespoke services are often not cheaper than hospital care- (however the improvements in the frequency, duration and intensity of behaviour are usually immediate and stark) The savings take time to show in our system, but they do come- therefore with this model we need a long term view, and we need to be realistic about how long it can take to help people feel fully settled after years, sometimes decades in hospital.

R.Q.3.1.

Doreen and Helen

The best models we have witnessed working well for this group of people as individuals are those models that deliver a bespoke service. Starting with a blank sheet of paper, working with the person and their family to produce an Individual Service Design (ISD), then putting that ISD into practice avoiding too much compromise because of what already exists. This would include the use of a Personal Health Budget (PHB) either in its truest sense or by using the PHB as an Individual Service Fund (ISF). This is where the organisation are paid the money directly but the organisation has internal rules around how the money can be used and how decisions are made in this respect. The person and their family must be at the centre of this. This is a way of people having power and control over their money and life without the overall responsibility of what can sometimes be large sums of money and complicated legal employment responsibilities. It includes people employing their own staff or the organisation employing staff for them using the ISF. Again the person and their family must make final recruitment decisions and each person should have their own dedicated and matched staff team. At Beyond Limits we operate a Third Party Agreement, where the person and their family are mentioned in the staff contract of employment as requiring to agree to the recruitment and on-going employment of that staff member. If Third Party is withdrawn then the member of staff cannot continue to work with that individual. This puts the person and their family fully in the driving seat with regards to who is supporting them.

Helen

The flexibility of response is based in having a mature and trusting relationship with the provider. It focusses on outcomes and we pay a month in advance for services using a payment card. If the core team decides that they want to change the style and shape of direct support that is permissible. We then review outcomes, input and expenditure with the provider and adjust the overall package costs to reflect needs. This flexibility also avoids the need for repeated requests to funding panels from care management staff- it ensures a prompt response when change is needed and reduces the transactional time and effort for administrative and care staff .

Assessments and referrals can be made through various routes in Devon for people who have learning disabilities. We have very good primary care learning disability nursing liaison, additionally throughout our TCP we have good input from intensive assessment

and treatment teams (These six IATT teams have a specific focus on positive behavioural support).

R.Q.1.2.

Doreen

Having qualified as a nurse 37 years ago I have experienced many iterations of in-patient care. In my experience it is difficult for any in-patient service to be effective in treatment plans unless these plans are for a short period of time and very treatment focussed. This would include medication but where there is a range of therapies, including talking therapies, activities that are based on real skills learning and good social and leisure activities, the service is usually more effective. In my experience when in-patient services focus on rehabilitation and are very clear about the route to discharge then they are much more successful. The other main issue that can positively affect in-patient services is the ability of that service to engage with the person first and foremost and not strip them of their power but of importance too is that service's ability to engage with and work in partnership with the person's family and any community supports that person may have.

When people are in a very bad place and are displaying this with their behaviour it can be difficult for in-patient services to see the person under the problems but this is something that is crucial to avoid long term placements becoming the problem rather than the solution.

My experience since working in England and spending a lot of time in a lot of out of area in-patient facilities working to get people out, has been very varied. Some of the places have done some good work even if people are in too long but equally I have experienced some places where it is clear that there is iatrogenic damage being caused.

It is of great concern to me that the person who is a patient in hospital is relying on the (hospital employed) medical staff to agree or not their discharge. I have often felt that there is a conflict of interest when these decisions are being made and on more than one occasion I have experienced the medical staff refusing to release the person unless they were to go to another hospital. On occasions where this has happened the person has left the (second) hospital and moved to the community where they have proceeded to have a good life so on hindsight this was an unnecessary hoop to be jumped through.

A particular issue lies with out of area placements not least because of the isolation this can cause as families cannot always afford the time or money to physically stay in touch with people and I think we have learned from the Winterbourne View experience that people are at greater risk if they are isolated from their families and communities.

Helen

Short term, local focussed intervention can be very helpful, especially where a person has acute MH needs requiring assessment and treatment. However we have identified a high degree of iatrogenic risk with many inpatient services especially those that are focussed on behavioural management, where people seem to stay for years.

Despite this I have noticed that some of our local inpatient MH wards struggle to support people with autism, often they can be challenging environments to manage a wide range of needs in for staff.

Over complicated and hierarchical behaviour reward programmes in some hospitals are unhelpful. In fact what we have seen is that some people respond to their environment, demonstrating their distress through their behaviours. In turn they are more constrained and their behaviours escalate- this is a downward spiral that sees a person rarely perceived as "ready for discharge".

For example one lady I saw as part of a Care and Treatment review, was sleeping in the day and was up at night- she had adopted this pattern of living because she found the behaviours of fellow patients worrying, as she has seen physical violence in the ward and was trying to avoid harm.-It could be argued that this was eminently sensible and not a clinical presentation as such.

Even if interventions are used in inpatient wards to manage behaviours these are often not transferrable to community settings.

The use of Care and Treatment reviews is helpful but invariably there is a reliance on the psychiatrist at the hospital in approving discharge. Additionally, where individuals are under Home Office restrictions this can create added complexity in discharge planning as restrictions need to be factored into the Individual Service Design and also the working policy. We have found that occasionally transfers and transition planning can be extensive and prolonged to the point of creating frustrations for the person and added cost for the commissioner.(With double costs of both the old and new placements)

It could be argued that we work within a system that is very clinically focussed (for those in hospital) interfacing with a social model of disability and citizenship in the community, so achieving agreements about the shape of service delivery and discharge planning can be challenging. An important point to note is that often MOJ discharges rely on having a fixed address in place for the person to go to before discharge can be even considered- this assumes somewhat that the traditional residential model will be used. (This needs to be adjusted in line with the model outlined in Building the Right Support 2015) Over time we have raised this directly with the MOJ and have seen some growing flexibility in this area.

In terms of our population I have noted that we have no consistent way of recording people who have an Autistic Spectrum Condition in primary care. The use of the DES for annual health checks for people who have learning disability makes identification much easier for people with a learning disability now- this helps us track the needs of people in our system and we can easily develop a dynamic register of people in the community who may need additional focus and support with behaviour. Often the first we know of a person with autism is when they are already admitted making focussed and positive prevention very difficult.

R.Q 3.1

Helen

With Beyond Limits we use third party individual service funds, funded through our personal health budget programme. This commissions not only the direct support but also has a contingency amount of funding to be used for “what if” scenarios, and up front recruitment training and induction of staff.

This flexibility is based in having a mature and trusting relationship with the provider. It focusses on outcomes and we pay a month in advance for services using a payment card. If the core team decides that they want to change the style and shape of direct support that is permissible. We then review outcomes, input and expenditure with the provider and adjust the overall package costs to reflect needs. This flexibility also avoids the need for repeated requests to funding panels from care management staff- it ensures a prompt response when change is needed and reduces the transactional time and effort for administrative staff within the CCG.

Assessments and referrals can be made through various routes in Devon for people who have learning disabilities. We have very good primary care learning disability nursing

liaison, additionally throughout our TCP we have good input from intensive assessment and treatment teams (These six IATT teams have a specific focus on positive behavioural support). There is patchy provision of forensic psychology, but we are planning to use funding from Specialist commissioning to increase proactive community support in this area of work as part of our Transforming Care programme.

References (if applicable):

Below are links to some of the approaches/evaluation mentioned above:

Home identification form

https://www.housingandsupport.org.uk/documentdownload.axd?documentresourceid=620

Health Equalities Framework

https://www.ndti.org.uk/resources/useful-tools/the-health-equality-framework-and-commissioning-guide1

Centre for Welfare Reform

First report

http://www.centreforwelfarereform.org/library/by-date/returning-home.html

Second Report

http://www.centreforwelfarereform.org/library/by-date/returning-home.html

Please note: A third and final report is being written now,

Section A: NCCSC to complete	
Name:	Maria Saville
Job title:	Principal Manager, Positive Behaviour Support Service (PBSS), Halton Borough Council
Address:	Runcorn Town Hall, Runcorn, Cheshire, WA7 5TD
Guidance title:	Service model for people with learning disabilities and behaviour that challenges
Committee:	Guideline committee: Service model for people with learning disabilities and behaviour that challenges GC9
Subject of expert testimony:	You are invited in your capacity as an expert in Halton borough council, an example of best practice in the implementation of a service model for people with learning disabilities and behaviour that challenges.
Evidence gaps or uncertainties:	We have searched for evidence in relation to models of service delivery and have found very little evidence in relation to different types of services and different models of service delivery which meets the criteria for our review questions. In particular we have identified as a gap in the research evidence information on • Community based services • In-patient services • Models of service delivery We would therefore like you to speak on the basis of your expertise in Halton Borough Council model of care for adults with learning disabilities and behaviour that challenges. We are aware of three studies that talk about the Positive Behavioural support service in Halton and have included these in our review. Iemmi (2015) Positive behavioural support for adults with intellectual disabilities and behaviour that challenges: an initial exploration of the economic case. Uses the PBS service in the study Iemmi (2016) What is standard care for people with learning disabilities and behaviour that challenges and what does it cost? One of the authors mentioned; could be a contact plus study participant CBF (2015) Paving the way: how to develop effective local services for children with learning disabilities whose behaviours challenge one brief case study of the PBS service Toogood (2015) Providing positive behavioural support services: specialist challenging behaviour support teams.

R.Q.1. What is the effectiveness of different types of **Community based services** (including residential) for children, young people and adults with learning disabilities and behaviour that challenges?

We have searched for evidence in relation to evaluation of different types of services for people with learning disabilities and behaviour that challenges. The criteria for inclusion to test the effectiveness of different types of services was that the study had to include a control group to compare the service with (usual care or an alternative service).
We found very few evaluations of different types of service for people with learning disabilities and behaviour that challenges in the community. This is because there have been few randomised controlled trials or controlled trials that have been done in this area.
In your experience of different types of services in Halton, are you aware of any evaluations of different types of services? What makes services effective and how is this measured, what are their components and how do they work best?

The types of services we would like to know more about would include, but are not limited to:

- CAMHS
- Community learning disability teams
- Specialist behaviour support teams.
- Early intervention

R.Q.1.2. What is the effectiveness of different types of **in-patient services** (in and out of area) for children, young people and adults with learning disabilities and behaviour that challenges?

We did not find any rigorous research evidence meeting our criteria to evaluate the different types of in-patient services. In particular we are interested in

- secure inpatient services and how these link up with health and social care
- different types of respite care and short breaks, specifically for adults and/ or children with behaviour that challenges.

R.Q.3.1. What **models of service** delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

We did not find any rigorous research evidence meeting our criteria about comparing different configurations of services for people with learning disabilities and behaviour that challenges compared to usual care/ practice or alternative service model.
We are particularly interested in hearing more about

- Effective services that are personalised and organised around the individual
- Assessments and referrals i.e. what sorts of services are best to deliver these assessments and referrals?

Section B: Expert to complete

Summary testimony:	

I am the principal manager for the Positive Behaviour Support Service (PBSS), Halton Borough Council. I am a Board Certified Behaviour Analyst (BCBA) and have an MSc in Applied Behaviour Analysis. The service works with children and adults in Halton and surrounding commissioning areas. The service is for individuals who are engaging in behaviour that challenges services. A core eligibility criterion for the service is a moderate to severe learning disability, which may include a diagnosis of Autistic Spectrum condition. The service is staffed and led by behaviour analysts, assistant behaviour analysts and behaviour practitioners. A full

description of the service model can be found in '*Providing positive behavioural support services: specialist challenging behaviour support teams*' Toogood et al (2015).

PBSS has completed a service analysis of referral characteristics, resource allocation, case management and overview of outcomes (Toogood et al, 2015b). Outcomes identified were reduced challenging behaviour, increased functionally alternative skills, increased engagement in meaningful activity and increased community participation. Outcomes were measured in a variety of ways including direct observation, indirect measures and subjective reports. This paper describes how outcomes are measured. In addition PBSS has also published some in depth description of its work in case study format (Saville et al, 2016).

PBSS works alongside other services in the local area e.g. CAMHS team and an Integrated Behaviour Support Team and in adult services the community LD team. PBSS tends to work with those individuals with the most complex needs who require a full functional assessment, PCIP and supported intervention. The other teams will refer to PBSS when they do not feel they can meet their needs. This has advantages and disadvantages. The PBSS is not resourced to treat everyone locally who engages in challenging behaviour and therefore it is appropriate for other services to support. However, sometimes individuals end up going through all services and still coming to PBSS. At this point families/staff can be quite disheartened and unwilling to engage.

In my opinion the aspects that make PBSS a service successful include the following:

- A highly person centred approach
- A clear set of core values
- A detailed functional assessment conducted by skilled clinicians
- A Person Centred Intervention Plan (PCIP) based upon the functional assessment
- Stakeholder participation in the PCIP development. Staff work with the individual and their family/carers/staff to develop interventions that meet the contextual fit of the situation
- Supported intervention (PBSS staff work directly with families/carers/staff to put strategies in place)
- Additional support needs may be identified e.g. a parent may be unable to implement some of the PCIP due to mental health issues, therefore PBSS would work with social care to identify a different support package for a family.
- Working across all setting e.g. home, school, short break, outreach, day services etc.
- Specific training opportunities delivered by PBSS e.g. Active Support
- Intensive input. Workers hold small caseloads to allow an intensive support package. Some service users are visited on a daily basis. The work needs to be intensive to give optimum success and reduce the likelihood of referral back to the service. NB: the number of individuals referred back to the service is very small
- Robust MDT participation (we rarely work in isolation)
- Robust maintenance and discharge procedures, to prevent 'procedural drift'
- Out of hours support e.g. staff in PBSS provide direct support to families at 7am in the morning/over the weekend if that is what is required. A recent referral to us showed challenging behaviour was most likely to occur at 4am; therefore that is when the allocated behaviour analyst conducted his observation assessments

In referencing what works well it is important to acknowledge some of the barriers the service encounters:

- Parent burn out or mental health issues.
- Overzealous risk assessments, which significantly reduce opportunities for individuals.

- Established negative staff culture. PBSS often find staff groups who are focused on the individuals needing to know their behaviour is wrong and over use of sanctions. It can be difficult to change this culture unless there is a strong manager in place
- Recruitment of support staff- frequently support agencies do not maintain their staff. This appears to be related to a number of factors including burn out, pay rates etc. It means we will train a set of staff to implement intervention only for half of that staff team to leave the service a few months later.
- General culture where a lot of professionals still feel that residential placements are 'safer' for people who engage in behaviour that challenges services, rather than a focus on community living
- Available housing

PBSS supported a scoping review completed by Dr Nick Gore (Tizard Centre, University of Kent). The scoping review examined the use of Residential school placements for children and young people with intellectual disabilities. It can be accessed via this web link http://sscr.nihr.ac.uk/PDF/ScopingReviews/SR10.pdf

On rare occasions PBSS has worked alongside inpatient settings with service users allocated to the team. Predominantly with young people and adults. Generally service users have ended up in such settings under the 'mental disorder' aspect of the MHA by diagnosis e.g. Learning Disability, rather than having a mental health issue. Most admissions have been due to levels of challenging behaviour, causing placement breakdown. PBSS have often found that people's behaviour deteriorates in such placements. It is very difficult to implement a Positive Behaviour Support (PBS) plan in a hospital environment. PBS is generally not used in hospital settings. Meaningful activity is greatly limited due to the nature of a ward setting, community participation is controlled and people are amongst others who present with significant challenging behaviour. In addition access to family and friends and usual routine is disrupted. People are subjected to restrictive practices e.g. seclusion and restraint.

Several service users have been seen to get 'stuck' in this system. As behaviour deteriorates the need for detention is reinforced and more than one service user known to the service has ended up having a lengthy stay in hospital. Some accessing private hospitals, contradictory to the transforming care agenda. Developing bespoke services for individuals is a lengthy process and often subject to delay finding suitable housing, staffing etc. Our experience of inpatient settings is generally damaging to the individuals.

PBSS has also worked with individuals in residential settings. There are some significant barriers to successful implementation of PCIPs within residential settings. Predominantly this relates to staff culture, a high amount of staff turnover and a lack of bespoke care. Our experiences tell us it is better to build a bespoke package of care around an individual in their own home, rather than try and fit them in to an existing service model that doesn't meet all aspects of their care. Staff turnover is a major issue and in an analysis of placement breakdown completed for one person we found in a 3 month sample they had been supported by 120 different staff. Most staff had seen the person once. The provider was a well-known 'specialist challenging behaviour' setting with national reputation, with a robust clinical team. However, with that level of staffing it is near impossible to secure appropriate support for an individual with such complex needs.
PBSS experience is bespoke, community based packages (either with family or own tenancy) with PBSS support and a wider MDT are the most effective.

References (if applicable):

Toogood, S, Saville, M, McLennan, K, McWade, P, Morgan, G, Welch, C and Nicholson, M (2015a) 'Providing positive behavioural support services: specialist challenging behaviour support teams', *International Journal of Positive Behavioural Support*, 5(1), 6–15.

Toogood, S, O'Regan, D, Saville, M, McLennan, K, Welch, C, Morgan, G and McWade, P (2015b) 'Providing positive behavioural support services: referral characteristics, resource allocation, case management and overview of outcomes', *International Journal of Positive Behavioural Support*, 5(2), 25–32.

Saville, M, Cooper, P, Coleman, S, O'Regan, D, McWade, P, Toogood, S (2016) 'Providing positive behavioural support services: quality of life and challenging behaviour outcomes for a nine-year-old child with autistic spectrum condition and severe intellectual disability', *International Journal of Positive Behavioural Support*, 6(2), 28–38.

Section A: NCCSC to complete	
Name:	Kevin Elliott
Job title:	Clinical Lead, Transforming Care
Address:	Transforming Care Programme Nursing Directorate NHS England
Guidance title:	Service model for people with learning disabilities and behaviour that challenges
Committee:	Service model for people with learning disabilities and behaviour that challenges
Subject of expert testimony:	You are invited in your capacity as the clinical lead in the Transforming Care programme
Evidence gaps or uncertainties:	See below

R.Q.3.1. What **models of service** delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?
We did not find any evidence meeting our criteria about comparing different configurations of services for people with learning disabilities and behaviour that challenges compared to usual care/ practice or alternative service model. The Winterbourne View Joint Improvement Programme (WVJIP) case studies provide useful information on the components of the models and some barriers and facilitators to implementation currently being trialled under Transforming Care programme. However, they do not tell us whether the proposed models were fully implemented as intended or whether they were effective in terms of health and social care outcomes for the people who were due to be resettled in the community.

Are you aware of any early findings from these case study areas that indicate what aspects of the models were effective in resettling people with learning disabilities and behaviour that challenges into their community?

1. From these ten case studies, are there any that are considered to be a good example of a service model? If so, why?

2. Do you know if there have been any evaluations or are there any planned impact studies on the transforming care program?

3. Do you know of any more recent published case studies to do with transforming care?

Case specific questions

Richmond
Does having the transition development officer role make a difference?

What has been the impact of partnerships across council functions, the CCG and registered social landlords?

Islington
Has Islington been able to increase the supply of local extra care supported housing? [Considering land not easily available in this area]

Does the 'pod' system of housing seem to be working?

Has the transition housing scheme been developed?

How well is the 'circle of protection service working for people out of area?

Surrey
In Surrey there has been a big emphasis on building relationships with and developing the provider market, are there other examples where this is working well?

Bedford
Has the involvement of service users and the use of pre-screening of job applicants (testing values and attitudes) had any impact on the satisfaction of service users?

Gloucestershire
Gloucestershire is also featured in a European Social Network practice example (http://www.esn-eu.org/raw.php?page=files&id=2171), where it talks about using co-production to develop strategy/services. Would you consider Gloucestershire to be one of the best examples of early service development? If not, which other areas are doing particularly well at transforming services?

Leicestershire
Do we know if what was planned has happened?

Nottingham
Has the Care, Support, Enablement framework been abandoned completely in Nottingham?

Is there any other evidence of services using 'pen' pictures of individuals so that service providers and people working with an individual get a better understanding of their needs?

Dudley
Dudley has well developed supported living services. As a consequence, some local authorities are moving people into Dudley services. Then on the basis of 'ordinary residence', Dudley social care is responsible for providing services to people outside its geographic remit. How can this type of service use be better planned for?

Sunderland
Sunderland is one of the few case studies that mentions advocacy and support for carers, particularly for people in hospital. What is Sunderland or other areas doing to ensure appropriate advocacy is available in the community?

Barnsley
How has the CLDT continued to implement the progression model?

R.Q.5.1. What mechanisms enable effective **joined-up working between** education, health and social care **service providers** supporting children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

In your experience of the transforming care programme what are the most effective things that services can do to make sure that they work well with other services?

R.Q.5.2. What mechanisms enable effective **joined-up working** between health and, social care providers of services and **with children, young people and adults** with behaviour that challenges, and their families and carers?

In your experience of the transforming care programme what are the most effective things that services can do to make sure that they work well with the person with learning disabilities and behaviour that challenges, and their families and carers?

R.Q.5.3. What mechanisms **enable effective shared decision making**, empowerment and coproduction of services between education, health and social care service providers of services and children, young people and adults with learning disabilities and behaviour that challenges, their families and carers

In your experience of the transforming care programme what are the most effective things that services can do to make sure that they enable effective shared decision making, empowerment and coproduction of services between education, health and social care service providers of services and children, young people and adults with learning disabilities and behaviour that challenges, their families and carers

Section B: Expert to complete

Summary testimony:	

R.Q.5.1

These notes are supplementary to the slides presented to NICE committee January 2017.

In answering the 3 questions we considered our experience at national and TCP board/commissioner type level

- **Clear vision, shared vision and ambitions –** e.g. Gloucestershire created a concordat signed by representative groups, statutory services (NHS, Police, Fire Service), social care providers, commissioners, specialist support providers community services (leisure centres) that set out their shared values and commitment to people with a learning disability.
- **Clarity on roles and responsibilities –** and checking these are understood. It helps when people and organisations understand what is expected of them and who has responsibility for what.
- **Bring everybody together from the start –** generally it is best to bring people together from the beginning of project however, at times it was found that, particularly when covering a technically heavy issue (e.g. writing clinical guidance), that providing a draft to start from, can help.
- **Co-production at every level -** true co-production brings all together to plan, develop and provide support services. Some areas seem to think it is simply commissioner and provider, not so. When done well it leads to better outcomes and is more empowering for people.
- **Local leadership is key –** having good leadership in place makes a big difference. Typified by individuals who have the **will** to make things happen, bring people together and provide a clear direction of travel.
- **Let them know what you need now and what is coming up -** we found agencies/providers etc keen to work collaboratively but need to know what is the 'Ask' & earlier the better e.g. housing partners supporting person admitted to hospital need to be given information at admission rather that at end of stay.
- **Think broadly re involvement -** think wider than specialist support providers to include organisations such as acute hospitals, GPs, Village agents – system wide & including community assets. Useful in bringing in fresh perspective and skills but also in promoting and ensuring inclusion of people with a learning disability, autism or both in wider community. Helps others see the valued contribution people can make to the community not just as receivers of support.
- **TCPs as a platform –** these partnerships bring together a wide range of stakeholders with a broad field of influence that can be effective in promoting and supporting collaborative working. They have resources and influence that has not been present previously and create a useful platform for delivering system change.
- **Communication** – needs particular attention, challenge assumptions, persevere, and use various mediums. Experience has highlighted that we make assumptions that we have been clear in communicating a message only to discover it has been misunderstood. This is in giving message and receiving.
- **Glossary of terms –** shared language – people interpret words and terms differently so be clear.

- **How to get involved info –** be clear how people can get involved, provide various options and level of involvement.

R.Q.5.2 & R.Q.5.3

Proactive – Do not just wait for problems but be proactive and think ahead

Engage at earliest point with people – as above – at Individual and at population level

Co-production means involving everyone – see also; Co-PRODUCTION: New ECONOMICS FOUNDATION / National Endowment for Science, Technology and the Arts (NESTA): & Centre for Welfare Reform – www.centreforwelfarereform.org

Good Advocacy – is important in giving people a strong voice. (Others have described what good advocacy looks like)

Good information – about options available, should be in straightforward language and no '*one size fits all*' and an '*easy read leaflet doesn't mean you have simply done your job*' so will need to be personalised for the individual The accessible information standards & Mental Capacity Act are helpful. Keeping people informed is not easy and needs to be remembered when planning what resources are needed.

- **Empower people** – as citizens – to understand & be involved in processes – early on – have conversations with children, young people & families about how they want their futures to look – valuing people as citizens – have a voice – when this is done properly then people on the Empowerment group (supported by LGA) said "*Things feel different when done right & lead to better outcomes*" **- different approaches for different people.** See videos on Empowerment on the LGA website or at https://youtu.be/z5RnuOnRaaM

PHBs & EHC plans as helpful levers _ Annual health checks are another one. It is helpful to inform people as to why we want to see things change but also helpful to know what levers (the things people must do if they want to get paid for example) are available to you or for you that help to make change happen

Assurance – locally, regionally, & nationally – *'measure what you value not value what you measure'* – asking people what is important to them – At national level Scott knows nationally picture as co-chair but at local level is not informed as a citizen.

References (if applicable):

Appendix D Expert testimony papers **Section A: NCCSC to complete**	
Name:	Dr Gillian Bell
Job title:	Consultant Forensic Adolescent Learning Disability Psychiatrist
Address:	Email: gill.bell@ntw.nhs.uk Tel: 01912456857
Guidance title:	Service model for people with learning disabilities and behaviour that challenges
Committee:	Guideline committee: Service model for people with learning disabilities and behaviour that challenges
Subject of expert testimony:	You are invited in your capacity as an expert in the Health and Wellbeing of Children and Young People with Intellectual Disabilities and their Families
Evidence gaps or uncertainties:	We have searched for evidence in relation to models of service delivery, by models we mean the different types of services, the way they are organised and the way they are delivered. We have found very little evidence in relation to different models of service delivery which meets the criteria for our review questions. We have identified as a gap in the research evidence information on ➢ Types of in patient service provision and their effectiveness and cost effectiveness ➢ Models of service provision that include different types of in patient service provision and how these work best with service in the community to ensure people stay only for as long as they should and only because there is a clinical need for them to be in In-patient care. We would therefore like you to speak on the basis of your expertise in person centred planning and support

R.Q.1.2. What is the effectiveness of different types of **in-patient services** (in and out of area) for children, young people and adults with learning disabilities and behaviour that challenges?

We did not find any rigorous research evidence meeting our criteria to evaluate the effectiveness and cost effectiveness of different types of in-patient services. In particular we are interested in

- Secure (low, medium and high) inpatient services, their effectiveness and cost effectiveness, what types of service facilitate timely and successful outcomes for children and adults
- If and how “step down” services can facilitate or obstruct discharge and return to communities for people in low and medium secure inpatient facilities

- What different types of respite care and short breaks are there, specifically for adults and/ or children with behaviour that challenges?

R.Q.3.1. What **models of service** delivery are effective for children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers?

We did not find any rigorous research evidence meeting our criteria about comparing different configurations of services for people with learning disabilities and behaviour that challenges compared to usual care/ practice or alternative service model.

We are particularly interested in hearing more about how inpatient services contribute into a model of support that is personalised and organised around the individual

This could include, but is not limited to:

- How can in patient services contribute to a model of support which is personalised and organised around the individual
- How can the arrangements ensure that people are receive a quality assessment in a timely fashion?
- What arrangements need to be in place to ensure that people move effectively between services when they need to?
- What professional arrangements and pathways work well to promote such working (primary, secondary and tertiary care, health, social and third sector agencies)

Section B: Expert to complete

Summary testimony:	

The population served is a very heterogeneous group with multiple pathology. Indeed many services do not admit for the treatment of learning disabilities, the admission is for the purpose for treatment of the comorbid pathology with the reasonable adjustments made to support the fact that an individual has a learning disability.

Confounding Factors will effect a young person's trajectory and the outcomes achieved. Eg response to intervention; number of co-morbidities etc

Purpose of or reason for admission can be considered as a number of themes that run through different types of provision.

- **Risk**: both to self and or others (occasionally property).
- **Safeguarding:** either to an individual or due to an individual's behaviour
- **Engagement:** For individuals or families who find it difficult to engage with services or who are difficult to engage inpatient admission may be the only way to either start that engagement process or engage with a young person or their family sufficiently to produce an assessment and or appropriate intervention.

- **Intensity of support/ intervention/assessment:**
- **Legal framework:** alternative to custody; legal framework for treatment or intervention.

Clinicians consistently identify 3 population groupings, those with challenging behaviour or behaviour that challenges, forensic patients and mixed (or unknown). These patients are often separated by the degree of learning disability and the types of intervention that they can access or benefit from.

Models of service and service design are often changed by external features and I can describe some of the previous models and current models. Some issues currently are around lack of effectiveness come from the concept of secure inpatient services as opposed to forensic inpatient services and physically robust inpatient services with a high level of specialist staffing.

References (if applicable):

College Report CR200