Appendix B Critical appraisal and findings tables

Findings table

Abbott D, Busby K, Carpenter J (2009) Transition to adulthood for young men with Duchenne muscular dystrophy and their families: final report to the Department of Health (++/++)

Intervention/aims	Findings
1. To investigate, from their own perspectives, how the health and wellbeing of young men living with DMD, and that of their parents, can be maximised, particularly at the transition to adulthood. 2. To consider the potential contribution of the National Service Framework for Long Term Neurological Conditions for this group of people (p5).	**Multiple services – views and experiences** **Postal survey** - The survey found that the families in the three regions covered had been in contact with a range of services and different types of clinics. - The survey found that despite this contact with services only 1/4 had a key worker or care coordinator or social worker. - Some parents reported that some transition planning took place at school, but over half said that they had no transition planning. - Most commented that their children took an interest in planning for the future. **Interviews** - The interviews revealed information about use of services and health and social care transitions. - Overall contact with services was felt to be problematic and parents said that they struggled to get the children's needs met. Transition was difficult because there was uncertainty about which adult professional they would be meeting and why. - Some people commented that were told about transition ahead of time and that there

	was some flexibility in the process. - In one area (South West) there was no adult services neuromuscular consultants working in the area, which left families concerned about services for their children post transition. - Some families had good relationships with their GPs and planned services through them. Parents commented that they used the muscle centre which was available to all ages and required no transition. They valued this service. - Patients commented that they did not appreciate the focus, in appointments around transition age, on their deteriorating health, they felt it was demotivating. - Families found that they were lost the services of physiotherapy and they received variable support from occupational therapy for adaption etc. - The involvement of social workers varied. If families had a social worker, so found them to be supportive during transition. Some comments said that social work involvement focused on ‘paperwork and meetings rather than any outcomes or support’ (p8). Some families found that after transition they did not have a named social worker, but dealt with the duty social worker instead. Families found that hospice support was no longer available following transition and no alternative was provided. - Half the families said that they were in contact with children’s services, but any lost services following transition. - There was criticism of how services were delivered and some said that contact with social services was sporadic. - The interviews showed that few families were prepared for transition. What support they did receive was described as ‘handover’ and following transition they no longer received support from a single named worker. ‘If you want something, once you’ve turned 18, you have not got a social worker that would come and visit you on a monthly basis. You phone the civic centre and you’re allocated a social worker that’ll deal with the problem at hand and then it’s gone. Then the next time you want one you get another one’ (p108). ‘We had that letter and that’s it! We don’t even know where they’re based now or anything. And this was what, when

	he was 17’ (p109). ‘I found that a bit difficult once he went over to adult. I found that they took less notice of you. It took longer to get things done, where they’re [social workers] falling over themselves when they’re children. Once they’re not children it seems like there’s a stop point, and after that is seems harder’ (p109). - There was no easily identifiable pattern in the nature or age of transition from child to adult social services. In one family, contact with children’s social services stopped at aged 16 and for the next 2 years there was no contact with social services. Then, when the son was aged 18, an adult social worker initiated contact. There was, in effect, no transition: one service stopped and then after a while, another started. His mother found this disconcerting: In terms of both health and social care services there were concerns about a lack of continuity in services around transition. - Many of those interviewed had a lack of knowledge about what would happen following transition. ‘I would just like more information on transition and exactly … how it goes. I mean is it [adult’s services] just as good as the children’s services? I mean why can’t it be? Just because he’s turned into an adult, why should the services change? Or why should they become more difficult to get?’ (p105). ‘Where’s the next step for respite and that, where does he go after this? They only take them to 18 and they don’t tell you what the next step is, which is crazy’ (p105). Families and patients commented on the lack of knowledge about how transition would unfold, some were unconcerned as they knew there were few services for their children or themselves, and some were more anxious. There were comments that families felt unsupported and had a perception that services did not care what happened to them following transition. ‘It does seem to be that before you’re 16 there is a plan – this happens, then that happens, and it’s smooth. Then you get to a certain age and no one’s thought about what happens next. It’s like, “We’ve done our job now, it doesn’t really matter what happens next, just find out for yourself.” Once you’ve done with school it’s like, ‘OK,

	well you've got your benefits you can sit at home and do nothing and that's fine" (p105) '[Son] will be 25 this Christmas and it's as if some people think, "Oh you're still around, you shouldn't be, we don't know what to do with you". And I'm sure there's more and more boys lasting longer' (p105). - There was considerable variation about the quality of services between regions depending upon the availability of specialists. There was a lack of professionals with specialist knowledge in adult services. - 'So, we still carried on seeing [children's consultant]. And then this particular day we was up there and he said, "He's an adult now, so he's got to go to adult services." So we said, "Yeah, fair enough." We see someone and they said "See you in 12 months' time." So we said, "Yeah all right," and we're still waiting for the letter, and that was what, 4, 5 years ago?' (p107). - There was also a lack of trust in the quality of adult's services. 'What is adult services? I don't have a clue. They deal with adults – crappy compared to children. I mean you just hear these stories that when you go into adult services you don't get things as quickly as …' (p107).

Allen D, Channon S, Lowes L, et al. (2011) Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service (+, relevance to this guideline: highly Relevant)

Intervention/aims	**Findings**
To examine the experiences of young people and their primary carers during the transition from children's to adults' services, with a focus on the role of primary carer in this period.	**Views and experiences** While mothers were in general supportive of young people's move to independence, the study found that a long-term condition such as diabetes meant that they were still involved in supporting their sons and daughters in managing it. While the young people might increasingly be making their own decisions, these were not necessarily made on their own (p997): 'I would double-check with my mum say if I had eaten a bowl of pasta or something I would say do I need four units and then she might say oh I'd give five.' The authors found that the clinics used different approaches in regards to parents coming along to clinics. They found that clinics which encouraged lone consultations (young person only) had higher rates of this, whereas those which left the decision to families had lower rates. They suggest this indicates that when families can choose, they more often choose joint consultations where parents continue to come along to appointments. The mothers would like to be more informed after young people transitioned to the adult clinic and started attending consultations on their own. They argued that this was because while they were moving on to independence they were still living at home, and still relying on their mothers for support with their diabetes care. This was supported by some young people (p997): 'I would go by myself but mum likes to keep a check, she likes to know what's going on, I mean that's fair enough, she does help me out quite a lot so she likes to ... keep up to date with it all.' In 1 of 5 five clinics parents were able to access support for their needs during transition, this was where a specialist nurse was a joint adult and paediatric specialist so mothers knew her from before the transition.

Allen D, Cohen D, Hood K, et al. (2012) Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study (+/++)

Intervention/aims	**Findings**

‘To identify the continuity mechanisms central to a smooth transition from child to adult diabetes care, the service components through which these can be achieved and their inter-relations in different contexts’ (p140). The study objectives were to: develop a typology of diabetes transition models, building on previous research on continuity of care; identify users’/carers’/providers’ experiences of, and preferences for, transition services, the processes and organizational challenges involved and assess costs; identify what works best to promote ‘a smooth transition’, for whom and in what circumstances (p141).	**Barriers and facilitators** **Factors that help and hinder** - Relational and longitudinal continuity. Young people were more comfortable being treated by a clinician with whom they had developed a relationship. Some wanted to have a regular worker but did not want a close therapeutic relationship. The study found that young people wanted an approach that felt tailored to their needs and that help was available if their conditions worsened or changed. If there was continuity in their care young people felt more able to navigate changes and crisis. Carers felt the same way. It was found that if continuity of care was established, a lack of information about transition was less problematic, whereas if continuity was not present, gaps in information were more keenly felt by young people and their carers. - Cultural continuity. The study looked at ‘culturally continuous and culturally discontinuous transitions’. When services were considered culturally continuities, transition was found to be much smoother and young people needed less preparation. If services were not culturally continuous, as it was in model 1, it was found that a transition nurse who worked across services was beneficial to help establish continuity between children’s and adults’ services. But it was found that communication between services could not guarantee continuity. Some services had worked together a long time and had not established continuity, It was found that ‘clinical leadership and a commitment to adolescent health’ helped to establish continuity. - Management continuity The study argues for communication systems to help with relational/longitudinal continuity, but only in small teams or co-located teams. In more complicated service configurations, more management continuity measures are needed. This can be in the form of formal written communication, when a young person was changing doctors. But this information was often very clinical and did not acknowledge the importance of the relationship.

	- Nursing teams were more flexible in their working and were consistent. - Other clinical teams were subject to changes of staff and part time members making continuity difficult to achieve. - Carers contribute to continuity and this needs recognition. - Children's services were much better at supporting families and carers and involving them in decision making but only in one model, did this continue into adult services. - Informational continuity. The models were found to have different results around information needs. Those using services which had high levels of relational continuity did not need as much information support. When transition was between two completely different services, much more information was needed. - Flexible and developmental continuity. All the models aimed to improve young people's independence. This meant working with them and not their parents and aiming to have them consult with staff alone. All the services acknowledged that young people who has transitioned needed heightened levels of support. This was delivered through email mentoring, nurses on-call and extra clinics. Young people were not interested in attending peer support groups or additional education sessions. The models had different levels of developmental or flexible continuity. It was found that services with more flexibility about time of transfer helped young people with developmental issues, but young people wanted to maintain autonomy over their own decisions. - Survey findings. - High levels on developmental continuity corresponded to higher parental control scores, lower activity scores and lower satisfaction scores. - High levels of developmental continuity was linked to less satisfaction, lower general health scores and higher vitality and mental health scores. Flexible continuity in services was linked to lower symptom impact and with better life and treatment satisfaction. Self-efficacy was also improved as was carer satisfaction.

	- High relational or longitudinal continuity led to better health and symptom impact and parental control was higher. Life and treatment satisfaction was lower, as were self-efficacy scores. Carers also reported lower general and mental health scores. - Cultural continuity was found to have a lower impact on treatment and symptoms impacts and lower impact in quality of life scores. Life and treatment satisfaction, health care climate and self-efficacy scores were higher in users who consulted in models with high levels of cultural continuity and carers reported higher vitality and mental health scores.

Andemariam B, Owarish-Gross J, Grady J, et al. (2014) Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care (-/+)

Intervention/aims	**Findings**
The study described the intervention as	**Barriers and Facilitators**

a ‘formal combined transition programme’. The transition service was set up between the paediatric medical centre in Connecticut and the sickle cell disease centre at University of Connecticut Health Centre. The intervention used a 3 stage process taken from the former transition process: preparatory, transitional and completion. Both the preparatory and transition stage began at age 16 and the transitional and completion stages were jointly managed by children’s and adults’ services. Monthly combined transition clinics were held and the children’s medical centre. These were attended by parents, patients and staff from both children’s and adult’s services, including nursing, social work and medical staff. Each patient was expected to attend at least 4 of these combined clinics. **Study aim** The study aimed to ‘evaluate the successes and failures of a new transition program’ (p697) for young people with sickle cell disease. The study looked at a transition programme in Connecticut after it had been implemented for five years.	68% of the 47 patients who transitioned between 2007 and 2012 did so successfully. This group all ‘established continual, ongoing, comprehensive care’ (p699). 32% who were thought not to transition successfully did not appear to seek treatment elsewhere. 63% of female patients transitioned successfully and 75% of male. Mean combined transition clinic attendance rate and clinical visits also did not correlate with transition success. Those that transitioned had higher mean combined transition clinic visits attended, but the difference was not statistically significant (2.1 vs 1.5, p ¼ 0.07) (p699). Medical status and condition did affect transition success. ‘SC or Sbþ genotype and a lack of a need for chronic transfusions were significantly higher in the unsuccessfully transitioned group of patients ... 21% of SC/Sbþ patients did not transition successfully compared to only 21% of SS/Sb0 patients (p ¼ 0.04)’ (p699). Of those who did not transition successfully, 93% were not on chronic transfusion therapy. There was no difference in utilisation of hydroxyurea or in frequency in acute chest syndrome between the successful and unsuccessful transitions. Crisis hospitalisation was similar between the 2 groups. Those who started on the combined transition intervention at a later age were found to transition less successfully. Only 25% of those who started the process after 21 or later were successful. 77% of younger participants transitioned successfully. The distance the clinic was from participants home was also significant. Those who lived 20 miles away or more were less likely to transition successfully (33% vs 79%, p ¼ 0.01). (.700).

Barn R, Andrew L, Mantovani N (2006) Review of life after care: the experiences of young people from different ethnic groups (++/++)

Intervention/aims	Findings
This paper describes the perceptions, needs and concerns of minority ethnic care leavers in the UK compared to that of their white peers. Key areas explored were the outcome of young people in education, housing, employment and training. The views of 13 social work professionals (senior managers and practitioners) based in the Leaving Care Teams were also explored, with emphasis on perceived needs and concerns, and support levels.	**Views and experiences** **1. Intro:** a third of the young people reported leaving care at 16, over a fifth at 17 and two-fifths at 18. Almost a fifth had experienced 10 or more placements and a quarter had had between 4 and 9 placements. White and mixed parentage young people suffered most severe placement disruptions compared to the other groups. White young people tended to leave care at an earlier age than other groups (aged 16) and African young people left when older (aged 18). African and Asian young people came into care as adolescents and experienced the least placement disruption. **2. Race ethnicity and experience of care:** the study highlights the complex ways in which young people associate with a particular racial and ethnic identity. For example, most young people of Caribbean, African and Asian valued their cultural heritage – probably reinforced by being brought up in multiracial areas and placed in families of a similar racial and cultural background where the socialisation process was not at conflict with their own identity. However, most of the mixed parentage young people were of Caribbean and white parentage and their identity was shaped by a complex mix of factors. Despite, the availability of local authority stats on ethnic breakdown of looked-after children, ethnic breakdown of care leavers was less accessible. Sometimes ethnic categories (e.g. African and Caribbean) were subsumed under the heading ‘black’, thereby obscuring the different circumstances and needs of specific groups such as African young people who were asylum seekers. Notably, most young people said they had no explicit preference for social workers from their own ethnic background, but were more concerned about the competence of the worker. But, having a minority ethnic after-care worker was important for some young people as far as helping them to prepare for independent living whilst being able to ‘keep it real’. **3. Preparation and after-care support:**

	a) Help and advice before leaving care – many young people reported having a good relationship with their social worker. But there was divergence between the views of social care professionals and young people, where young people said they did not get adequate support in key areas such as budgeting skills, benefits and housing at both the ‘preparation’ and ‘after-care’ stage. Many young people felt they did not get support with other life skills too, such as learning to cook and developing personal relationships. For the majority of young people, this sort of support and preparation for leaving care was not ongoing but started at the age of 16 or a few months before they were due to leave. Consequently, some young people said that with the transition to independent living they had to learn to adapt quickly and were often left feeling lonely and isolated. In comparison, young people said that foster care and semi-independent placements made up for this gap. As well as emotional support, foster carers provided them with ongoing support and confidence in learning basic everyday skills such as cooking and cleaning, being organised and self-disciplined. By the time they become involved with the Leaving Care Team, many young people had already faced a considerable degree of disadvantage such as placement instability, minimal contact with birth family/community, lack of racial/cultural input and poor educational outcomes. This was a challenge for Leaving Care Teams. Several young people said that the quality of preparation, including being well supported and informed, was directly related to the commitment and effectiveness of their personal adviser (p65), who could be a social worker, someone from the youth service, etc. **b) After-care support** – more young people reported receiving support on things like housing and benefits after leaving care than prior to leaving care (p66), probably as the reality of having to manage these issues at this stage of transition became more meaningful and practical. Young people were significantly concerned at the lack of after-care support for budgeting skills. The social services’ assumption, was that securing a placement meant that a young person would be able to live independently. **c) Leaving care planning** – The Leaving Care Teams have a remit to offer care and after-care support to 16–21-year-old care leavers through individual casework, independence groups and developmental work in collaboration with other projects, such as peer mentoring groups. The majority of young people were dissatisfied with the way

	in which pathway Planning for transition – which was coordinated by a personal adviser – was delivered (e.g. they had little involvement or choice). **Barriers and facilitators** **Factors that hinder** - The limitations of social services provision especially where other factors such as unsuitable housing came into play and contributed to homelessness. - Leaving care at an early age was identified as another key factor resulting in difficulties. One practitioner (Petersfield, p34) thought this was about the lack of resources. - Professionals expressed the need for training to ensure for staff working with young people from diverse backgrounds. - The involvement of care leavers was considered to be vital in shaping services and giving young people opportunity to share experiences and ideas about the best way of delivering culturally appropriate services to them. **Factors that help** - Most professionals felt the Children (Leaving Care) Act 2000 had improved the service offered to young people, especially pathway planning and the distinct role of personal adviser. Inconsistencies that had such as very different allocations made through leaving care grants had now been replaced by a more comprehensive needs assessment. - There was evidence of culturally sensitive practice and awareness of the issues of diverse ethnic groups. The importance of ethnic matching of social worker and young person was acknowledged. In one London borough, if a young person requested a black social worker, this would be made available, but competency was always prioritised above ethnicity of the worker.

Bent N, Tennant A, Swift T, et al. (2002) Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study (+/++)

Intervention/aims	**Findings**
Multidisciplinary teams set up to facilitate transition from children's to adults' services, usually including a consultant in rehabilitation medicine, a psychologist, therapists and a social worker.	**Effectiveness** The researchers explored the relationship between measures on pain, energy, health status, independence, self-esteem, self-efficacy, stress, proactive attitude, age, sex, income and service model (young adult team or ad hoc/service as usual), and their primary outcome which was 'participation in society' measured by the London Handicap Scale. After controlling for the most significant variables (pain, stress, energy), the researchers found that reception of the service model 'young adult teams' made young people 2.54 (95% CI 1.30-4.98) more likely to participate in society compared with those received services as usual.

Beresford B, Cavet J (2009) Transitions to adult services by disabled young people leaving out of authority residential schools (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
The aims of this small scoping project were to identify: • Differences in practice with regard to transition planning for disabled young	**Barriers and facilitators** **Factors that hinder** 1. The 'independent' nature of the schools. This affects the transition planning process

people in residential schools compared to young people attending their local special schools • the factors which impact on transition planning and transition outcomes for these young people • key areas for future research and the feasibility of such work.	so that schools do not need to adopt government practice or procedures through policy or guidance documents and were 'working in a bit of a vacuum' despite being responsible for initiating reviews and transition planning processes. Interviewees (practitioners) had no control or influence in this process or in how schools worked with the young person in terms of supporting and preparing them for transition. 2. Schools may have related adult residential provision. This can cause conflict between the business interests of the school and what local authority staff viewed as the best interests of the young person. Parents, especially those with good experiences of residential school placements, were often persuaded by schools (well in advance of statutory transition planning meetings) that it was conducive for their child to graduate to the associated adult provision. This goes against local authority goals of transitioning the young person back into the home authority. 3. The geographical distance between the home authority and the school. All authorities reported that the geographical distance (sometimes hundreds of miles) between the home authority and the schools where they placed young people was a barrier to planning transitions. The logistics of arranging visits by home authority staff meant these were few, making it difficult for them to build relationships with young people and residential school staff. 4. Lower levels of direct involvement by adult services. Geographical distance made it much less likely that staff working for adult social care services or a potential service provider visited a young person. 5. Ambiguity about non-educational outcomes of the placement. Where education departments took the lead role in placing a child in an out authority school and in reviewing processes, this (unintentionally) led to other practitioners believing this to be a primarily educational placement. Therefore, targets such as plans for bringing the child/young person back to the home authority and longer-term outcomes were not properly identified or examined at the time of making the placement or in reviews until transition planning was initiated. Consequently, the opportunity for strategic planning regarding new specialist adult services was missed. 6. The reason for the placement may still be present at transition. As illustrated by

	practitioners below: ‘Most of them who have been placed out of county because we can’t meet their needs “in county” and that doesn’t necessarily change when they reach eighteen’ (adult social care); ‘The reason why these transitions may be problematic is because it is typically young people with complex or challenging needs and they are leaving highly specialised settings which cannot be replicated in the community’ (adult social care). This could mean that provision has to be made, and funding renegotiated, for the young person to remain on at the school until services have been put in place. 7. Healthcare is being transferred between authorities. Participants working in health as well as those working in adult social care noted problems including: • delayed transfer of the young person’s GP from the host authority back to the home authority because of difficulties registering with a local GP • clarifying responsibilities between home and host authorities with regard to funding and carrying out health assessments (e.g. continuing care assessments, leading to delays in such assessments being carried out and consequent delays in funding and/or placement decisions) • health professionals not typically allowed by their job contracts to work outside of their authority • a period without healthcare (where the young person was not returning to the home health authority) due to negotiations between the home health authority and the authority where the young person was going to be moving to. 8. The passing on of health information by schools. Information sharing with schools and the home authority and/or adult services/placements could be problematic and could affect choices about placements and the suitability of the type and level of health services provided in the new placement. 9. Lack of established procedures. This project was carried out at a time of considerable change within transition services. This meant there was a lack of precedents in terms of how these transitions from residential school back to the home authority were managed, especially where the young person had complex needs, which included physical or medical health care needs, compared to just behavioural or mental

	health needs. 10. The young person may not know or be familiar with the home authority. This was especially relevant to transition planning for young people in 52-week placements where real involvement in decision-making was hindered by their lack of knowledge of their home authority. ‘If you’ve spent six years in Manchester, for example, actually are you still a ____ child? What are your aspirations? Where is your community? What should we be looking for in terms of what’s in your best interest? That’s complex’ (disabled children’s service). 11. The young people are transferring from institutions to the community. Where the young person was moving to the community, this in itself could be seen as a new challenge as services would now be delivered from different locations as opposed to where they were delivered on site as in residential provision. And because most young people did not return to the family home, it is was also more likely that more services or agencies would be involved. The study suggests that some of the common problems related with transitions are ‘magnified’ for this particular group of young people. These are: 1. Identification. Other research highlights that disabled children and young people in residential out authority schools are at risk of being ‘forgotten’ by the home authority. In this study however, despite all the local authorities saying this was not an issue, none were completely confident that the infrastructure was in place to ensure transition teams and/or adult social care services would be involved in transition planning for all disabled young people in ‘out authority’ settings. 2. The complexity of need. Accessing the young person’s views It was harder to gauge the views of young people with impairments and needs, especially severe learning difficulties, autism and/or challenging behaviour, and this was exacerbated by geographical distance, as young people were less familiar to staff. 3. The complexity of need. Funding issues Where there was greater complexity of need in young people placed ‘out authority’ there was often more difficulty in regards to agreeing funding responsibility. The issue was not in terms of eligibility for adult social

	care services, but more about the input of health to the care package. The problem was exacerbated for reasons such as adult health services not being allowed to accept referrals or carry out assessments until the young person turned 18. 4. Institutionalisation and difficulties transferring independence skills. The move out of a ‘safe’ institutionalised setting would probably present new challenges for both the parent and young person. 5. Moving back to the family home can require significant readjustments. The period of time the young person has spent away, especially if the placement was at some distance from the family home, can lead to weakening of family bonds and parents having lost touch with their child: ‘They [parents] become estranged from their children. They miss out on the changes and developments that happen during adolescence and so haven’t adapted to having an adult child’ (adult social care). Added to this is the loss of social networks. 6. The amount and extent of change interviewees believed that the range of changes faced by a young person returning from out authority residential school is, typically, considerably greater than those who stayed at home. For some young people everything will be new: where they live, how and where they spend their time, what they do, where they go to learn, the staff who work with them, the topography and physical appearance of the local area and so on. 7. The complexity of need. The great majority of young people placed in out authority residential schools are there because of the complexity of their needs. This, in turn, makes transition planning and the care package more complex and costly. Sometimes there may be a need for very specialist services which are simply not available. 8. Unmet healthcare needs. The increased complexity of needs typically found in young people returning from out authority residential placements compared to those who remained ‘in authority’ is likely to mean they have continuing healthcare needs. Failing to address healthcare needs of the young person once they leave school could negatively affect transition outcomes such as a loss of, or deterioration of, physical abilities, physical health and/or mental health, with associated negative impact on a young person’s wellbeing and their activities and placements.

	Factors that help - The majority of interviewees felt that it was harder to achieve positive transition outcomes for young people in ‘out authority’ placements compared to those young people in local ‘in authority’ special schools. But others felt that poor outcomes of transitions should not be seen as a foregone conclusion given that transition planning for young people in ‘out authority’ placements started earlier and were prioritised over young people who remain in authority (p41). - When services are commissioned from out authority schools, the longer-term outcomes of children should be considered. For instance, schools could be required by a local authority to ensure that person centred planning approaches are in place. These would prepare the young person for transition and involve the young person, family, school and local authority and happen during different periods of schooling (p46). These approaches could include looking at post transition plans and destinations, with options for visiting placements and so on. - Posts that are designed with a specific remit for young people placed out of authority can help deal with issues caused by geographical barriers. - Systems that help prepare for strategic planning by adult social care should be put in place so that authorities are aware of the population of children and young people in out of authority schools and can project need for adult social care services. - Health care transfers need to be supported and more clarity of responsibility for healthcare assessments is needed, including putting systems in place whereby referrals to home health authorities can be made prior to the young person returning home and giving permission to health professionals to visit young people while they are in out authority placements (pviii). - The plans of young people leaving ‘out authority’ schools should fit with their needs, wishes and circumstances. For some, going back to the family home was a clear option (e.g. those young people who were placed only for educational reasons such as people with sensory impairments or autistic spectrum conditions without behavioural problems). For other young people it was better for them to stay on in the authority

	where they had been placed, and usually local authorities acted to enable this. - Where families were unable to support a child who had been placed out authority, residential college placements were seen as a viable option. - A number of authorities were actively working on developing services, especially supported living, which would better meet the needs of young people leaving out authority residential schools and reduce the need for out authority adult residential placements. - Interviewees said that the local authority have a duty to incorporate the longer-term views and aspirations of the child into placement arrangements (e.g. providing a range of opportunities such as work experience to prepare a young person for leaving school and beyond). - Independence skills have to be suited to home authority contexts. The example given being that of equipping young people to travel in urban environments and not only where they are located – often rural locations with simpler public transport infrastructures. - The role of children's services might also be widened to include that of strengthening connections with the family and the home authority, through work with the young person and the family (p48). - Friendship and social needs have to be given more prominence in assessments, planning and placement choice and in the continuing work of staff in adult services.

Beresford B, Harper H, Mukherjee S, et al. (2014) Supporting health transitions for young people with life-limiting conditions: researching positive practice (the STEPP project) (+, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
The STEPP project aimed to gather the experience of transition into adult services for young people with life-limiting conditions, and from the point	**Barriers and facilitators** **Factors that hinder** (problems when admitted as inpatients) - Distress and anxiety caused by the health or confused state of other patients.

of view of young people, their parents and professionals. It conducted interviews with these groups across 6 case studies which all represented condition-specific pathways into adult care.	- Parents excluded from being involved. - Unmet care needs. - Social isolation and lack of occupation. - Staff not recognising the significance of the admission (degeneration or worsening health) Not being made aware in advance of transition of the differences in culture and practice between paediatrics and adult wards. **Factors that help** - Visit to the adult service. - Opportunity to meet adult services staff, including a person who will be present at their first appointments at the adult clinic. - Information, especially in regards to differences in practice and procedures – young person having a choice on whether parents attend with them or not. - Adult clinical staff being aware of their status as having recently transitioned in from paediatrics. **Views and experiences** - Feeling anxious, some felt they had to make the move to adult services before they were ready. - Being a minority group in the adult services, they experienced staff not being willing to adjust their practice to accommodate their needs, e.g. by excluding parents. - Another minority status was for those with rare conditions, especially where medical advancements meant that they were surviving into adulthood – e.g. the lack of experience and knowledge of Duchenne muscular dystrophy in adult respiratory wards. - Being experts on their own situation and healthcare, embedded in paediatric practice,

	which clashed with practice in adult services. ‘The advantage of “knowing the system” in paediatrics actually became a disadvantage on moving to adult services. Interviewees described feeling anxious and disempowered when they encountered procedures and practices in clinics or on the ward that were different from those in children’s services’ (p406 in Beresford and Stuttard 2014). **What works** - Preparation in paediatrics including active involvement in consultations and teenage transition clinics, list provided (p405 in Beresford and Stuttard 2014), in regards to what is useful during transition: - visit to the adult service - opportunity to meet adults’ services staff, including a person who will be present at their first appointments at the adult clinic - information, especially in regard to differences in practice and procedures - young person having a choice on whether parents attend with them or not - all adult clinic staff being aware of their status as having recently transitioned in from paediatrics. **What doesn’t work:** List (p406 in Beresford and Stuttard 2014) in regard to problems when admitted as inpatients: - distress and anxiety caused by the health or confused state of other patients - parents excluded from being involved - unmet care needs - social isolation and lack of occupation - staff not recognising the significance of the admission (degeneration or worsening health) - not being made aware in advance of transition of the differences in culture and practice between paediatrics and adult wards.

Beresford B, Moran N, Sloper T, et al. (2013) Transition to adult services and adulthood for young people with autistic spectrum conditions (working paper no DH 2525) (+/+)

Intervention/aims	**Findings**
Five research sites which had all adopted a multiagency approach to transition into adulthood for young people with autistic spectrum conditions.	**Multiple services** This study had a holistic view on the transition process as encompassing both service, developmental and living/life transitions. Overall, the study concluded that young people with autistic spectrum conditions need low intensity, early intervention to support their transition into adult life. Young people and their parents were highly concerned about education and employment prospects. Some services were engaged in helping young people into work, but these were exceptions and there appeared to be a lack of awareness of autistic spectrum conditions among staff working on employment issues. Some young people used specialist day services and experienced these as ‘normalising’. While the study found good support when moving into adult services for young people with learning disabilities, this was not the case for young people with high functioning autism or Asperger’s syndrome. Knowledge of and access to available transition support from third sector agencies was extremely varied. The study found that young people valued experiential information, for example being introduced to a service by way of a visit, or meeting someone in person. This view was echoed by managers and practitioners. The study highlights the need to improve support and training for practitioners, to prepare young people for independent living, and this was particularly important for young people not eligible for adults’ services. Transition services for young people with autistic spectrum conditions need to take into account the particularities of these conditions, and plan with these. The study found that the period of transition should include mental health support, rather than removing it (as in the cases where young people move out of CAMHS but not into any other form of mental health support or service provision). ‘A number of practice- or service-centred factors were identified which, practitioners believed, supported transition planning. These included: features of the transition team (e.g., ASC-specific skills and knowledge); providing opportunities for experiential

	information; joint-working (including co-location of practitioners from different agencies, and effective information sharing systems) and strategic work' (p72). Managers and practitioners in this study were supportive of person-centred planning, and they thought this enabled a more tailor-made transition, as well as bringing together everyone who knew the person well. They also thought person-centred planning reduced conflict between parents and children. However, risks of person-centred planning were also noted: that it could lead to unrealistic expectations and that it could leave the young people confused due to a large number of practitioners being involved.

Betz C, Lobo M, Nehring, W, et al. (2013) Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition (++/+)

Intervention/aims	**Findings**
To gather evidence related to the views and experience of adolescents and emerging adults with special health	**Views and experiences** Young people described transition as a process that brought about positive change including development of knowledge and skills and a more positive outlook on life. For

care needs (AEA-SHCNs') regarding their health care transition (HCT).	example, kidney transplant patients felt that an interdisciplinary transition clinic helped them to make a smoother transition to adult care (Belair et al. 2011), indicating that a linked service between paediatric and adult services was a good thing. Others (e.g. AEAs with congenital heart disease) saw it as a 'normal' life process and transition from paediatric care was timely as their developmental and medical needs changed, as was the case of young women in need of gynaecologic care (Moons et al. 2009). On the other hand, some young people lacked knowledge to help them make a smooth transition to adults' services due to a lack of information, preparation, and support from paediatric providers. Some participants (e.g. AEAs with Type 1 diabetes) expressed confusion and feelings of 'abandonment' when long-standing relationships with paediatric staff came to an end (Scott et al. 2005). This was also true for a group of AEAs who had received heart or heart/lung transplants (Stabile et al. 2005). Some participants were anxious about taking on more responsibilities for their care because they felt unprepared and furthermore, were worried about maintaining their health (Valenzuela et al. 2011). Compared with pre-transition and younger transition-aged adolescents, older young people were more able to identify the factors that helped or hindered their transition, which can be attributed to experience of using health services and their developmental stage in life.

Betz C, Smith K, Macias K (2010) Testing the transition preparation training program: a randomized controlled trial (+/+)

Intervention/aims	**Findings**
A 3-module training programme consisting of 8 sessions delivered over a 2-day workshop. This workshop included the development of a transition	**Effectiveness** This study found no evidence of positive or negative effects from the intervention.

plan which focused on the young person's own goals for the future in relation to health, education, work, community living, housing, recreation and leisure. The plan was developed over the two workshop sessions.	

Bhaumik S, Watson J, Barrett M, et al. (2011) Transition for teenagers with intellectual disability: carers' perspectives (+/++)

Intervention/aims	**Findings**
Study aim To identify healthcare needs of young people within a local area, their carers' perceptions of the transition process and to make recommendations on how to address unmet needs.	**Views and experiences** There was wide concern amongst carers about the transition process. The authors explore differences between ethnic groups (Caucasians and those of South Asian heritage) and report that those of South Asian heritage had greater unmet needs in all areas of healthcare. - Almost 50% in both groups reported problems with accessing adult disability services. Only 31% of carers were aware that their young people had a transition plan, and only half of these had a copy of it. Of most relevance to the question about how to deliver services effectively to those using a combination of services: drawing on the survey and in-depth interviews with carers, the researchers identified 9 recommendations: 1. Proactive process starting earlier, and in a continuous, relevant fashion that lasts for longer. 2. Coordination of transition planning with annual reviews. 3. Information provided earlier, in a clearer and more comprehensive way, and for both parents and young people. 4. Greater involvement of professionals in the process.

	5. Clearly defined responsibilities for each professional. 6. Increased involvement of parents in transition decisions. 7. Key worker. 8. Long-term social worker. 9. Assessment of carers, especially stressors.

Binks J, Barden W, Burke T, et al. (2007) What do we really know about the transition to adult-centred health care? A focus on cerebral palsy and spina bifida (+/+)

Intervention/aims	Findings
Study aim In relation to the transition from children's to adults' services for young people with spina bifida and cerebral	**Barriers and facilitators** **Factors that hinder** The barriers reported in this review drew from studies with adult and paediatric care

palsy. To identify barriers associated with the transition process, to identify characteristics that should be included in transition programmes and to review evidence on transition process and transition outcomes.	providers, young people and young people's parents. - Paediatric healthcare providers' attitude to adult services, and inability to 'let go' of their patients. - Young people's unwillingness to transition into adult services. - Parents not being ready to take a step back from involvement in their children's care. - Adult services: 'Adult-centred physicians may have limited training and experience with childhood chronic illnesses, and therefore have limited knowledge or interest in caring for these young adults' (p1067). **Factors that help** - Timing of the transfer should be planned with the young person and their parents/carers, and be flexible according to individual needs. - The planning and preparation for transfer needs to be initiated early. This preparation should include training and encouragement for self-care, with involvement of the family/carers. - Coordinated transition: communication between all important parties (young person, family/carers, adult and paediatric providers and primary care). - Up-to-date medical summary by paediatric providers to give to adult providers (including treatment regimens and recommendations). - Clinical transition plan which includes the services needed and who will provide them, financial planning (housing, education, employment) should also begin during transition and before adulthood. - Transition clinics: these should include more than one visit before transfer to adult services and at least one consultation where people from both paediatrics and adult services are present. - Youth-friendly and interested adult services: 'There must be interested adult-centred health care providers on the receiving side of the transition' (p1067).

Bloom R, Kuhlthau K, Van Cleave J, et al. (2012) Health care transition for youth with special health care needs (++/++)

Intervention/aims	Findings
This review did not focus on a specific type of transition strategy, as long as it was about supporting purposeful and planned transition into adult services for young people with special health care needs. The review focused on identifying outcomes for young people whose transition is not supported within this kind of framework. It also focused on the effectiveness of such strategies in supporting successful transitions, in particular in terms of providing access to adult care. **Study aim** To assess the adult outcomes for young people with special healthcare needs who do not receive a special transition intervention. To identify evidence for interventions, models or strategies which improve outcomes, with a focus on access to adult services.	**Barriers and facilitators** - Young people with physical health conditions such as diabetes or cystic fibrosis who do not receive a purposeful and planned transition have comparable social life outcomes to their the general population. They might have lower educational and income levels in adulthood. - Young people with developmental disabilities, mental health problems and severe learning disabilities who do not receive a transition strategy face further challenges in adult life. This review considered the evidence on outcomes for young people with long-term conditions who did not receive a specific transition intervention. They found broad population-based studies which indicated that although there were some differences between the adult outcomes of healthy peers and those with long-term conditions: 'after controlling for the mother's socio-demographic characteristics, young adults with chronic conditions (54% with asthma, 7% spinal anomalies, 6% each diabetes mellitus and rheumatoid arthritis, 5% epilepsy, and others) experienced no difference in educational achievement' (p215). Other studies did find a relationship with long-term conditions and poorer outcomes compared with peers, but no clear pattern emerged. The authors concluded that 'it appears that youth whose special health care needs involve mental health, developmental disabilities, or severe mental retardation face extra challenges in achieving the expected milestones of adult life' (p215). **Effectiveness** Findings from evidence on 'unsupported' transitions, or the absence of a transition strategy, focused on long-term developmental outcomes, all outcomes outside of the scope for this guideline. Overall, it appears that young people with physical health

	conditions such as diabetes or cystic fibrosis who do not receive a purposeful and planned transition have comparable social life outcomes to their the general population, but might have slightly lower educational and income levels in adulthood. Young people with developmental disabilities, mental health problems and severe learning disabilities who do not receive a transition strategy face further challenges in achieving the expected milestones of adult life. Findings on effectiveness of interventions from comparison studies are based on 3 studies, which were very different and so are reported separately. One study found that meeting adult providers in advance of the transition reduced concerns about: leaving paediatrics, fear of infection, admission to the adult hospital floor and care quality. Effect sizes or confidence intervals for these outcomes are not reported, but stated to be statistically significant based on p-values. Findings from a UK study are also reported. This compared young people who used services provided by 'young adult support teams' to those who did not have access to such a team and found that those who used the team were 2.54 times (95% CI: 1.30–4.98) more likely to participate in society (measured by the London Handicap Scale). Their narrative findings do not report on the results of a third study, but their findings table indicate that this found evidence of impact on the quality of care. This review also reports findings from studies which were not categorised as comparison studies. These studies all measured the outcomes from transition support in the form of special transition clinics which included adult providers. One of these studies found impact from this on condition-specific outcomes, and one did not. Two studies found impact from this on young people's satisfaction with the transition. One study found that these clinics which included professionals from adult services reduced readmission to hospital, and another found that it improved clinic attendance in adult services 2 years after the transition. One study found that these kinds of transition clinics did not impact on hospitalisation (admission and length of stay).

Broadhurst S, Yates K, Mullen B (2012) An evaluation of the My Way transition programme (+, relevance to this guideline: highly relevant)

Intervention/aims	Findings
This study is an independent evaluation of the effectiveness of ‘My Way’, approach to transition developed by the MacIntyre Charity. The focus is on the transition of young disabled people into adulthood. The paper also summarises existing research on the outcomes achieved by young disabled and factors that promote best practice for successful transition, as well as cost information, concluding with certain recommendations.	**Views and experiences** The My Way transition programme, involves holistic, person-centred support planning, the use of facilitators in a brokerage role and a focus on outcomes. My Way facilitators work closely with the young person as well as their family, friends, support networks, teachers, support staff and various external agencies to gather information, create a transition plan and then, most significantly, ensure that this plan is put into action. The evaluation of the My Way programme focused on four key questions around outcomes achieved, experiences of transition for young people and their families, costs of care packages and comparison to traditional care management. **Does the My Way transition programme deliver the types of outcomes that previous research states young people and their families want?** Information provided by My Way facilitators at the end of the project showed that out of the 75 young people involved, 57 had experienced positive outcomes, 18 experienced no change and no negative outcomes were reported by any young person. For the 18 individuals who reported no change, they did however say how empowered they felt simply by having received the information on the programme. The My Way project supported the local authority and its partners in transitioning young people, most notably in terms of moving young people on to independent living, building social relationships and employment. **Is the experience of transition for young people and their families improved in comparison to the experiences reported at baseline?** The interviews conducted before the My Way project was introduced highlighted the negative experiences of many families, in terms of poorly planned and chaotic transitions with negative outcomes for the young person. Young people were not always properly supported to explore suitable options, including how they might make their aspirations become a reality. This backdrop was the catalyst for local authority investment in the My Way project. Most young people, their families and professionals said at the end of the project that My Way transitions had been successful and furthermore it had consolidated

relationships between them. But sometimes solutions worked through with the young person and My Way were not sustainable in an unstable care sector, as was the case where the local authority thought it was untenable to continue a residential placement for a young person, when they (the authority) were in the process of decommissioning residential care. This example demonstrates the need to support young people to manage when plans have to change.

What is different about the My Way approach in comparison to the traditional care management approach?

My Way facilitators were able to support young people and their families more intensely than traditional care managers. They were enablers, helping to empower individuals and harness their skills and resources to find solutions for themselves. As well as advocating, facilitating, brokering and supporting people to fill out forms, attend meetings and so on, facilitators were very much seen as the ‘doer’ – the most crucial part of their job, which was about making the person-centred plan a reality. This included: writing service specifications in partnership with the young person; encouraging young people to try activities they were interested in (e.g. cafe, swimming, friendship groups); and gathering information from other organisations. Facilitators were supervised by a project lead, who also made a huge impact in terms of turning the PCPs into reality. Their role included: enabling young people (and their families) in similar situations to meet each other; coordinating socials during college holidays for young people to meet in a relaxed environment; collating and sharing information about positive transitions and outcomes to help raise awareness to young people, families and colleagues of the benefits of properly planned transitions; supporting young people to publicise their experience through different means including an ambassador role.

This study provides evidence that suggests the My Way approach is more effective than traditional care management at enabling people to turn their PCPs into reality and in a way that is cost effective.

Barriers and facilitators

Factors that help

Local authority senior managers said that the My Way transition programme was the

	reason why 3 formal complaints and two crisis placements were avoided, all of which could have been extremely costly to the authority. A manager from adult social services commented that by being able to work in a different way with providers and developing the market, they (the local authority) have developed a positive reputation as a potential partner to work with.

Burgess C. (2007) Staying afloat: effective interventions with young people in South Ayrshire. An evaluation of the impact of social work services and related agencies on outcomes for young people (++/++)

Intervention/aims	**Findings**
The overall aim of the study was to outline the range of services offered by social work and related agencies and identify any particular models of intervention or common features within these which appear to have been successful in engaging and working effectively with young people, thereby helping to produce positive outcomes for them. The 2 main strands of the study were as follows: • identification of particular patterns and models of social work intervention occurring throughout young people's lives, especially those associated with key life events, such as periods of transition • utilisation of a framework of measurable outcome factors in order to	**Effectiveness** Community-based support for young people and families (p15). • The youth support team, run by the local authority, is aimed at 'children in need' and looked-after young people aged between 11 and 17 years; it supports them to remain at home, in the community and in mainstream education and undertakes intensive individual and group work with young people and works with families in crisis. • Target Leisure in Girvan is managed by social work services and offers extra supports for young people to enable them to become involved in activities and sports facilities. • The residential unit for young people at Coylton provides an outreach service for young people and families offering support and guidance, with the aim of preventing young people from becoming accommodated. Health-related services: the Ayrshire and Arran Health Board offers services to the families of young children through the health visitor system. For those who are identified as having particular needs there is the educational psychology service and the child & adolescent mental health service (CAMHS). • There is 1 residential unit run by the local authority at Coylton by Ayr which can accommodate 11 young people up to the age of 16 years. It also has a semi-independent flat for the use of young people who are moving on to independence. The

ascertain how effective social work provision has been for young people, taking into account their individual circumstances.	unit aims to meet young people’s physical, emotional and social care needs and works with the young person’s wider family through its outreach work. • There are 26 foster care families supervised by the local authority and foster placements provided by independent and voluntary agencies. • The Quarriers Supported Accommodation Project offers individual flats for 6 young people aged 16–21 years; it provides full-time staff support and its aim is to equip young people with the practical, social and emotional skills to move on to more independent accommodation. • The South Ayrshire Befriending Scheme has been running since 1996 and works with a range of children in need. Interviews with key staff members from social services and partner agencies. Main opinions expressed: 1. Good communication between the main agencies helped strengthen joint developmental and planning work. 2. Shared aim of working in an integrated way with an agenda for improving services. 3. Shared ethos in the approach to work with young people, who are considered to be ‘children in need but some room for improvement. “There are good pieces of partnership working being developed but they need to be thought through. Sometimes workers are doing the same things and it’s hard for staff, and also young people, to see how it all fits together and who will do what. We need to start with the young person and maybe work on changing one thing at a time; assess, implement and evaluate” (professional staff member). 4. Most of the staff interviewed, from both social work services and partnership agencies, said main strength of the work with young people was in the positive relationships they developed with them; staff were seen as caring and committed and prepared to ‘go the extra mile’. Young people were given opportunities to participate fully in planning meetings. 5. Staff felt valued by the authority and this made for a generally positive working

	environment. 6. Interventions with young people were creative and ways of solving problems were inventive and made use of local community resources. 7. Some concern expressed about the frequency with which residential schools were used for young people and the difficulties which ensued in equipping young people for their move back to the community. 8. Main gaps in services which were identified by staff were in the area of mental health. The suggestion was made that there needed to be a team of community-based mental health nurses, with a similar role to the one based at the Throughcare Support Team, but for younger children (p20). Interviews with young people aged between 13 and 22: the semi-structured interview schedule comprised 4 main areas: young people's experience of the social work service itself; their experience of other services; their involvement with Throughcare services, if appropriate; and other supports in their lives, their achievements and aspirations. Their general experience of social work was mixed – more young people considered it a good support or influence over their lives than those who considered it a negative one (p25): 'They got me a better education, definitely. They got me back to school when I wasn't going. And they did help my relationship with my mum and dad. But it just didn't feel good to have one [a social worker]; going to panels made you feel anxious. It was like they ran your life and made decisions you didn't like' (young man aged 17 years). Positive aspects: • they gave you opportunities to do things like the Venture Trust • they helped sort out problems with school • you could tell your social worker something you couldn't tell your mum and your social worker could pass it on to your mum and act as a mediator • they tried to get you on the right path; • they did their best with you and it wasn't their fault that sometimes nothing could make

	a difference • they wrote positive things about you for panel reports and were on your side. Negative aspects: • they were not there when you needed them but they were when you didn’t; • they were often late and unreliable • they came to get information for reports but didn’t really listen • their theories about why people do things are not always right • they had pre-set plans for you and you couldn’t influence decisions • they bribed you with going to McDonald’s but it didn’t work. - Most of the young people had a fairly clear idea of why social workers became involved in their lives; even if this was hard to understand when they were very young, it was explained to them as they became older. - Young people had clear views about whether social workers listened to them and this was very important to them. ‘My social worker didn’t really listen to me. It wasn’t a time thing, she had the time; it was just that she didn’t know how to get on with me, to speak to me and get me to speak to her’ (young woman, aged 17 years). The key messages were that the social workers who were seen as effective were good listeners, non-judgemental and able to understand, whilst being honest and open with young people about what was going on and what might happen to them. - Community-based support: some of the young people interviewed who used the Family Centre had praised it as well as some of the staff who were described as ‘fantastic’ and ‘helping you big time’. - Residential care and post-care accommodation: there were mixed views about this and some felt the experience of living in it depended very much on the other residents (p28). - Health and well-being services: young people did highly value psychological and

	psychiatric services, as they felt they were being labelled as ‘mad’ and were not clear about the approach as far as questions posed to them by staff. But the service offered by the Throughcare Support team-based nurse was very highly regarded. Young people’s experience of Throughcare Support: the young people were very positive about this service and described the practical help provided including that doing practical tasks together helped build strong bonds with staff.

Cadario F, Prodam F, Bellone S, et al. (2009) Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach (-/++)

Intervention/aims	**Findings**
A transition coordinator worked with the young people during their last year in paediatrics, and continued this work as they moved onto adult services. An	**Effectiveness** The researchers present differences in the 2 groups on all measured values but did not calculate effect sizes. The young people transferred prior to the introduction of a transition coordinator experienced less support from specialist services during the

adult endocrinologist were involved in the transition planning. The coordination included a letter to the young people describing the transfer process, and young people were given the option of moving back to paediatrics if they didn't want to continue in adult services after the transfer. The last clinic at paediatrics was conducted jointly with the adult endocrinologist, and without parents present. At the last clinic the paediatrician also gave a conclusive letter and a programmed file to both the adult endocrinologist and the young person. The paediatrician was then present at the first adult clinic visit. Comparison intervention At the last paediatric visit young people were given a letter summarising their clinical history, and a date for an appointment in the adult clinic.	transition period, and they also experienced a break in examinations compared with the transition support group. The groups differed on mean HbA1c measured in adults' services, with the transition support group having an improved measure while it did not change for the non-transition group. The mean HbA1c remained better in the transition group after 1 year in adult services. However, 3 years after transition similar levels were observed in both groups. Attendance at adult clinics was statistically significantly higher in the transition support group than in the pre-transition group. There was no difference in satisfaction between the groups in terms of the paediatric services they had received, but 29 of the 30 young people receiving transition support rated their transition experience 'good', compared with 4 out of 27 young people in the comparison group. The options on this questionnaire were 'good', 'poor', 'bad'.

Care Quality Commission (2014) From the pond into the sea: children's transition to adult health services (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
The aims are not explicit but the report states that the CQC began a process of 'themed' work to look at the transitions	**Barriers and facilitators** **Factors that hinder**

arrangements for young people with complex health needs, through various consultation methods that highlight the challenges faced by young people, their families and carers.	- The process of transition was often not understood by young people and families or professionals. MDTs, young people and carers spoke about a lack of clarity over roles and expectations. - Local authority or educational providers who were the lead players in preparing the young person for transition (p19). - Inconsistent and poor information and lack of preparation from children’s services (for young people and parents) about what to expect after transition. - Commissioning staff said that there were gaps in the processes and guidance for transition was not adhered to (e.g. attendance by health professionals at transition planning meetings was sporadic). - Half of the young people and families spoken to said that there was no lead professional to support them; 70% of health and care staff agreed. This was due to a lack of resources and capacity in children’s services. Adult health services are not funded to deal with transition planning for under 18s. Additionally, GPs are not regularly involved in the care of young people with complex needs. - Young people, families and health and social care professionals said that adult health settings were not appropriate for young people. - No clear procedures existed to record assessments of family members regarding their ability to manage the care of young people with complex needs. There was a culture of over-reliance on partner organisations to undertake these assessments and put supporting provision in place. Families said that health professionals lacked concern about these roles, and provided inadequate support or information. Some parents felt abandoned by health and social care staff. - Some young people and their families were left without equipment, services or respite because of disagreement about who should fund them. **Factors that help** - Adherence to good practice guidance, which includes having objectives such as access to a key accountable person, a documented and sound transition plan, a health

	passport, and respite and access to short break provision. - GP involvement is key and they should be involved early so they can contribute to transition planning. - Appropriately tailored and flexible services that are delivered by staff trained in the specific needs of young people and knowledgeable about how services should collaborate effectively. - Individual health budgets and, sometimes, direct payments can provide more flexible packages of tailored support for young people. - Staff should be knowledgeable about the health condition of the young person because of their long-term involvement with them. - Provision of adolescent clinics. - Good communication with young people, their parents and each other.

Certo N, Mautz D, Smalley K, et al. (2003) Review and discussion of a model for seamless transition to adulthood (-/+)

Intervention/aims	**Findings**
Transition service integration model.	**Multiple services**

The premise of this model is to integrate the 3 main services which are important to disabled young people with support needs: education, rehabilitation and developmental disabilities. The study was conducted in the US, and the equivalent agencies in the UK would presumably be education, occupational therapy and physiotherapy, and health services. Integration was sought through a) joint funding, and b) transition service provision starting in the last year of school and thereby all adult services referrals and transitions having happened by the end of a young person's last school year. The aim was to secure employment so that young people would go straight from school to work. Similarly, during the last year of school, workers aimed to link young people into community activities which would continue beyond graduation.	A high number (>80%) of students transitioned seamlessly, that is, they continued services initiated during their last year in school in the first semester after existing school. This stability continued up to 3 years after graduation, when 90% of young people were still with the services they were referred to during their last year of school. Competitive employment was also high in the cohorts receiving the programme (>48% up to 97%) across the 4 years. An average 71% were still in paid employment up to 3 years after graduation. It is worth noting that employment became harder to secure as more students graduated. The authors conclude that the success of the model is mainly due to joint funding arrangements which improved service collaboration and integration.

Cheak-Zamora N, Xuejing Y, Farmer J, et al. (2013) Disparities in transition planning for youth with autism spectrum disorder (+/+)

Intervention/aims	**Findings**
'This study expands our understanding	**Effectiveness, barriers and facilitators**

by examining the receipt of HCT [heathcare transition service] services in youth with ASD compared with youth with other special health care needs (OSHCN)' (p447). 'This study investigated the following: (1) the prevalence of receiving HCT services among youth with ASD, (2) the difference in prevalence for youth with ASD compared with youth with other special health care needs (OSHCN), (3) how individual, family and health system characteristics influence the acquisition of HCT services' (p448).	Logic regression findings: this analysis found that individual and health system factors were related to receipt of HCT services. The study states that one demographic factor impacted services. Hispanic participants were less likely to receive HCT services (by 71%). Health status also related to access to services. Individuals with autism and other health conditions decreased the odds of getting an HCT by 81%; there was also a decrease of 22% for young people with autism and another developmental disorder. Young people who said that they were 'partners in decision-making' and were happy with their own care were 3 times more likely to receive HCT. Under 25% of the sample with autism were receiving a HCT. Less than half the group were 'usually or always encouraged to take on appropriate responsibility for his/her health care needs' (p450). 40% 'discussed adult health care needs with their provider, but less than a quarter of participants had a similar discussion about health insurance retention (22%) or transitioning to an adult provider (14%)' (p450). The study found that fewer young people with autism received transition interventions and services than those with other special health needs. 'Youth with ASD were half as likely to receive HCT services (21% vs 43%, P, .05) and a third as likely to be encouraged by a provider to take on appropriate responsibility for his/her health care needs (45% vs 74%, P, .05)' (p450). Physicians did not discuss the issue of transition with young people with autism.

Children's Workforce Development Council (2010) Do young people experiencing the transition from children's services to adult services understand the process and what their choices are? (-, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
This study aims to identify progress	**Views and experiences**

made locally over the first 2 years of Aiming High for Disabled Children (AHDC), government guidance for disabled children's services in England launched in May 2007. The study looks at the transition experiences of young people and their carers. A particular focus is to explore how planning for transition between North Yorkshire Children's Social Care Disabled Children's teams and adult and community services could be improved for disabled teenagers.	The report highlights that most young people had no relationship with their transitions worker and that parents were also often unable to identify a person to support them in their anxieties about their dependants' move to adult and community services. Furthermore, both adult and community services and children's social care services fail to develop a meaningful relationship with young people so that they can participate in the planning process. The majority of the young people interviewed did not know who their adult and community services transitions worker was, nor did they have any clear idea of any choices they might have. Other agencies (such as education) seem better able to engage with young people. Of the 9 young people interviewed, 2 reported that they could not name any worker they came into contact with. Of the remaining 7, teachers were the most prominent person in an individual's life, followed by social workers who 3 people were aware of. Roles such as transitions worker, Connexions worker and Mencap worker were mainly unknown, with the exception of 1 person from the sample. Less than half the group knew what transitions meant, let alone a transitions plan, and only 3 people got involved in developing this collaboratively. There was a lot of disillusion with the transitions service, especially from parents. As far as future options were concerned, information often went directly to parents, totally bypassing young people – a fact that a parent pointed out was not appropriate. In terms of promoting independent living, young people spoke of needing help with general day-to-day activities, including help to take any medication, continuing to stay at their independence group and sharing experiences with each other.

Clarke S, Sloper P, Moran N, et al. (2011) Multi-agency transition services: greater collaboration needed to meet the priorities of young disabled people with complex needs as they move into adulthood (+/++)

Intervention/aims	**Findings**
This is not an evaluation of a particular intervention, but it did focus on	**Multiple services** The authors organised the findings around areas of need, which have been identified as

providers and service users of transition teams in the UK.	important by young people through research: 1. Information and advice about the transition process: About 3/4 of the pre-transition parents and 1/2 of the post-transition parents identified unmet needs in relation to information about future options. Staff in all services provided verbal information, but only 2 services provided written up-to-date information packs about the transition process. Other forms of information were transition days in special schools, and DVDs/websites. 2. Leisure and social life: high levels of unmet needs were identified in the parents' and young people's questionnaires (>69%). While staff said they would provide information about opportunities, it was acknowledged that there were structural restrictions to young people's engagement in these: accessibility, cost, transport and lack of support, attitudes of staff and the general public. Staff did also report several examples of initiatives in their area aimed at enhancing disabled young people's engagement in social life and leisure. 3. Benefits and finances: more than 3/4 of parents and young people reported that they needed more help with finance-related issues pre-transition. Transition service staff said they did sometimes help with this, but that in general they referred people on to other specialist organisations. 4. Future housing options: housing was recognised as an unmet need by 76% of parents pre-transition; this dropped slightly to 61% post-transition. There was a difference in how much emphasis the transition workers placed on housing, with those placed in adults' services being more engaged in organising housing than those based in children's services. 5. Further education and employment: more help with planning for further education and employment was highlighted as an unmet need by a large proportion of both pre-transition and post-transition parents and young people (>64%). 6. Independent living skills: a high proportion of young people (10 out of 16) and parents (75%) reported unmet needs in terms of training for independent living skills, both pre- and post-transition. The training that was available in this area was provided through special schools and colleges of further education.

	7. Adult relationships and sexuality: support with adult sexuality and relationships was reported as an unmet need by both pre- and post-transition young people and their parents. Information about this was expected to be covered by schools in PSHE lessons and by nurses. 8. Identifying/planning future goals or aspirations: a large proportion of pre- and post-transition young people and their parents reported an unmet need to plan for the future (>73%). While most staff saw this as one of the tasks of the transition team, person-centred planning was not universal apart from in one team.

Cobb R, Alwell M (2009) Transition planning/coordinating interventions for youth with disabilities: a systematic review (+/+)

Intervention/aims	**Findings**
Transition planning and coordinating interventions	**Effectiveness** Due to heterogeneity, results from quantitative evaluations were analysed by intervention construct and study design. Reported here is the analysis of studies which

	are relevant to our scope and PICO (albeit borderline). Three comparison studies of student-focused planning: no significant heterogeneity, and a statistically significant large effect size of g=1.47 (z=5.1, p=<.001). The outcome this refers to is not entirely clear but seems to be ‘participation in planning meetings’. Note that since these interventions were about student-focused planning this outcome seems to be more about the implementation of the interventions’ aim of involvement, rather than what effect such involvement has on the transition. The use of proxy measures rather than direct outcomes is noted as a problem by the authors. Also worth noting are the small sample sizes (n=22, 43 and 21). The z is a measure of how this would look if replicated and it is indicating that this is not a very precise estimate. The authors conclude that the 3 studies on student-focused planning were of high quality and produced statistically significant effect sizes. The qualitative studies echoed this in that having no transition planning was perceived as very negative, but effective transition planning had to include person-centred planning This meant: ‘efforts to make students feel heard and valued at IEP meetings’ (IEP = individual education programme). Such involvement appears to be enhanced when programmes include peer advocates, mentors and friends as active participants. Also, transition planning needed to be implemented across the year and over time, not at one annual IEP meeting. Overall, the review found a positive impact from student-focused transition planning interventions, and also from comprehensive transition planning and coordination packages, and the authors call for a scaling up of evaluations of such programmes and for them to be tested by randomised controlled designs. Finally, the authors state that these studies support individualised planning rather than set transition options.

Commission for Social Care Inspection (2007) Growing up matters: better transition planning for young people with complex needs (-, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
‘This study examines in detail the	**Views and experiences**

experiences of young-people aged 14–19 and their families of transition into adult life. It also examines the perspectives of those who provide and organise care and considers the impact of current organisational and policy changes' (p3).	Multiagency working, key points - That councils need to look at, and learn from the experiences of those who have passed through transition. - Young people and carers are currently not involved in strategic planning to an acceptable level. Councils should involve young people and carers in transition stage planning. - Multiagency groups need to consider what happens post-transition. Feedback from young people should be a source of key learning. - Multiagency approaches need to be supported at a senior and political level for them to be effective. - Staff and management 'value specialist transition workers and teams. Individual casework approaches risk overwhelming lone transition workers' (p44). - Some local authorities assess and ensure the quality of their transition services, but there is room for more of this. - The Every Child Matters agenda is still important. The experiences of 14–19-year-olds and their carers. - Young people and carers need information about the options open to them. Information needs to be in accessible format and inclusive to all communities. - Services for young people are not engaging at the right time. - To ensure young people access services they should be identified in school year 9 and contacted by a specialist transitions worker. - Funding barriers need to be solved in order to develop joint services. - The needs of patients should be central. Attention to parents and parents from diverse communities should be given. - Continuity of support is important: person-centred planning is important.

Cowen A, Duffy S, Murray P (2010) Personalised transition: innovations in health, education and support (-, relevance to this guideline: highly relevant)

Intervention/aims	Findings
Personalised transition – a model to help young people with complex needs to take an active part in organising their care and support during transition from school to community. This model was developed at Talbot Specialist School in Sheffield in 2006 in collaboration with families, schools, Sheffield City Council, NHS Sheffield and the Learning and Skills Council and brought funding into a single pot. **Study aim** The aim of this report is to describe personalised transition, which is a new way (at time of publication) of organising support for young disabled people and their families. It enables young people with complex needs to leave school and achieve active citizenship within their communities.	**Implementation** No methodology regarding collection of views, despite the report being based on interviews with parents and professionals and workshops with young people (p57). One detailed case study on a parent called Katrina (p20) who explained that individual budgets has been a life-changing experience for her son. She described the positive impact on his health as a result of opportunities he has to do activities of his choice from leisure, outings, etc., supported by a team of PAs and her organising all the admin work. She believed that transition planning should be initiated at school as education professionals know the children and parents well and are in the best position to organise appropriately tailored care and support.

Craston M, Thom G, Spivak R (2013) Impact evaluation of the SEND Pathfinder Programme research report (++/+)

Intervention/aims	Findings
This study, part of a bigger project evaluating the SEND Pathfinder Programme is the impact evaluation of	**Barriers and facilitators** - The study shows that the Pathfinder approach can help with transition as well as

the programme. It aims to describe and analyse ‘Experiences, outcomes and distance travelled by the initial cohort of participating families’.	other milestones. - Families accessed Pathfinder when they wanted help to plan support for their child – including long-term planning such as for a transition from children’s to adults’ services. (p31). - The planning element of the SEND was felt to help with planning a smooth transition supported by a holistic and joined up package of care. - Professionals felt that SEND could help them to work with staff from adults’ services in a cross-working style. - The focus on outcomes in the Pathfinder approach enabled ‘a clear focus on outcomes, and a pathway into adulthood was useful to planning transitions and beyond’.

Crowley R, Wolfe I, Lock K, et al. (2011) Improving the transition between paediatric and adult healthcare: a systematic review (-/++)

Intervention/aims	**Findings**
‘Approaches to improving the processes and structure of transitional care’, this	**Effectiveness** The study concluded that existing evidence supports the use of educational

was defined as ‘a health service intervention during the period of transition from paediatric to adult care’ (both quotes from p549). **Study aim** To identify and review studies on the effectiveness of transitional care programmes for young people with a long-term condition or disability who are moving into adults’ services. To identify the essential components of effective programmes.	programmes, joint paediatric/adult clinics and specific young adult clinics, but the authors state that this is derived from studies on young people with diabetes and so it is unclear as to how generalisable the findings are to other populations. The authors did not perform a meta-analysis due to the heterogeneity in their sample studies. The authors found 10 studies but only present findings from 6 studies which found statistically significant improvement from the transition interventions. This creates bias in the findings, because it is unclear as to whether the remaining 4 studies found evidence of harm or no effect, and the quality of this evidence. This review found no RCTs and included studies were characterised by poor methodological quality. The 6 studies for which findings are presented did find important effects from transition interventions. The interventions were a combination of various approaches: education programmes, transition coordinator, joint paediatric/adult clinic, separate young adult clinic, out of hours phone support and enhanced follow-up. Statistically significant effects were found on the following outcomes (all these relate to young people with diabetes). **Condition-specific outcomes**: 5 studies found improvements for the disease-specific biochemical marker HbA1c, 2 of these studies did not have a comparison group. Three studies found improvements for acute complications (diabetic ketoacidosis, hypoglycaemia), however 2 of these 3 did not have a comparison group and 1 additional study found no effect on this. Two studies found improvements in terms of chronic complications (hypertension, nephropathy, and retinopathy). One study measured, but did not find improvements on, diabetes-related quality of life scores. This study did not have a comparison group. **Continuity of care**: 1 study found improvement in follow-up and attendance rate, another study found no effect on this. Two studies found improvements in rates of screening for complications. **Self-efficacy**: 1 study found improvements in self-management skills and disease-specific knowledge, however this study did not have a comparison group. The overall conclusion by the authors (from the abstract) is: ‘With most commonly used strategies

	in successful programmes were patient education and specific transition clinics (either jointly staffed by paediatric and adult physicians or dedicated young adult clinics within adult services). It is not clear how generalizable these successful studies in diabetes mellitus will be to other conditions.’

Day P, Turner J, Hollows A (2007) Bridging the gap: transition from children’s to adults’ palliative care, final report (internal validity +, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
‘The aims of the study were to examine, in detail, transition arrangements for adolescents with acute mental health problems. This would encompass the points of view of clients, families, mental health workers and GPs’ (p2).	**Views and experiences** **The vulnerability of teenagers** The young people spoken to criticised services for children and young people on the grounds that they felt patronised: ‘I felt that he was used to talking to children and I didn’t have the same problem as them’ (p149). The young people said that they found some of the therapeutic options open to them were not age appropriate: ‘they were asking me to draw pictures and what my favourite colour is. They treat you like you don’t know how to express yourself in words’ (p149). Members of the focus groups also said that they felt daunted by entering adults’ services. ‘I just feel slighted intimidated because I don’t really understand it and also because there’s some really unwell people in the CMHT day service and I feel a bit frightened’ (p149). Others were pleased with more independence. ‘I was relieved to go to the adult service because I was fed up of them treating you on [a] child basis ... I was relieved to go to the adult one because they treated you more on an adult basis, that you know more about the condition you were in and things like that’ (p150). **The need for support**

	Young people said that they wanted services that instil hope and provide support. Adults' services were seen as: 'more on the ball if you know what I mean, more helpful ... like they would sort things out straight away' (p151). The focus groups revealed that adults' services allowed young adults more autonomy with less focus on parents. 'It would be good idea to send progress reports to parents through the post ... or have separate meetings' (p151). **The timing of transition** The groups found that people wanted transition to be 'planned, gradual and flexible'. Young people also felt that they needed to trust adults' services. 'For a lot of people there's trust issues, for me it was' (p151). The flexible approach was thought to make transition happen between the ages of 15 and 18, and it should be the patients who decides when they are ready: 'Different people are ready at different times' (p151). Some patients felt their children had transferred too young, at 16, and in fact they would have been more capable if it has been delayed until they were 18. **Multiagency working** GPs who were supportive of transition were shown to be highly valued by the young people who participated. The GP could 'bridge' the gap between CAMHS and adults' services. 'It was my GP who actually got it for us because my GP's great, she'll do anything for us and first they couldn't accept me because I was the child one and she said "well that's stupid" so she sent about 3 or 4 letters and eventually they accepted me' (p151). Having an advocate to act in this way was shown to be important to young people.

Donkoh C, Underhill K, Montgomery P (2006) Independent living programmes for improving outcomes for young people leaving the care system (++/+)

Intervention/aims	Findings
This review looks at the effectiveness of independent living programmes. Independent living programmes (ILPs) are intended to equip young people who are exiting the care system with the skills they need to transition into independent living and adulthood. These schemes can offer a wide range of training and assistance including education and employment support and help with personal development and the skills needed to live independently.	**Effectiveness** The review did not find any studies which meet the criteria for inclusion. All the evidence found was in narrative reviews, non-systematic searches and non-experimental studies. The review briefly mentions the studies it found which were not randomised but used control groups. These studies generally reported better outcomes for those who used ILP interventions than those who did not. The review deems that findings from studies without comparison groups are not reliable. The review concludes that there is a need for more robust research around interventions like ILPs. Randomised studies would offer a much clearer picture of how ILPs affect outcomes and also test the theory that better ‘independent living skills’ can compensate for a relative lack of family support.

Doug M, Adi Y, Williams J, et al. (2011) Transition to adult services for children and young people with palliative care needs: a systematic review (+/++)

Intervention/aims	Findings
Transition from paediatric to adult palliative care. However, studies were sampled primarily on population. **Study aim**	**Barriers and facilitators** Three principles which underline successful transition: Information, communication, and planning or coordination.

To evaluate the evidence on transition from children’s to adults’ services for children with palliative care needs, especially focusing on the continuity of care, young people and their families’ experiences, and to identify examples of good practice.	**Factors that hinder** - Fragmentation of care between primary and speciality care providers and across paediatric and adult providers. - Lack of available or appropriate adult care, including lack of adult expertise in long-term condition originating in childhood, and lack of understanding of adolescent health care needs. - Paediatric providers reluctant to transition young people into adults’ services. - Geographical issues related to location of providers. - Provider time constraints (no time to address transition). - Poor communication between children’s and adults’ services. - Lack of effective and evaluated transition models. - Young people and/or family reluctant to move from children’s to adults’ services. - Expectations in the adult system of patients’ independence ‘becoming burned out on healthcare’ (p82, table 3, and citing one paper only). **Factors that help** The review found three factors that impede successful transitions: service-based demands, restrictions in relation to service provision and personal preferences. - Transition/adolescent clinic where young person is seen by paediatrician and a general physician. - Adult professionals trained and certified healthcare passports. - Joint transition plan between children’s and adults’ services, combined with joint transition clinic. - Communication and shared responsibility for transition between teams and with young people. - A medical summary transfer (transition note) and/or information pack about adults’ services.

	- Assessment of young people’s readiness to transfer to adults’ services. - Continue the successful aspects of the paediatric plan after transfer. Start transition years before the transfer to adults’ services. - Transfer date flexible and according to individual needs. - Transition keyworker for point of contact throughout transition Encourage self-management and confidence in own care. Involvement of parents and carers. - Online support and information Visit to adult clinic in advance of transfer - Mentor programmes where young people are paired with young adults with the same condition. This review drew on a wide range of evidence, including qualitative and quantitative research findings. Drawing from findings across all papers the authors identified 3 principles which underline successful transition. These were: information, communication and planning or coordination. There was some evidence to suggest that the family plays an essential role in transition. The authors recommend that young people have an allocated keyworker, and that young people are provided with life (not illness) plans. Transitional clinics are a promising intervention. The authors also considered barriers and facilitators to good transitions, and delays caused by clinicians reluctant to refer people on was a barrier. This was underpinned by a concern that their adult colleagues would not understand the young person’s needs. Another challenge was that there might not be adequate adult services since, in the past, some young people with certain conditions did not survive into adulthood There is a lack of evidence where palliative care is the main focus, and a lack of robust evidence on transition. The overall conclusions of the authors are: there is no evidence of transition services that address ‘palliative care’ as an overall concept. Transition programmes that exist are mainly condition-specific. No long-term outcome data exist to compare the effectiveness/cost effectiveness of condition-specific or generic transition models. Some consensus exists on what may facilitate or impede successful transition programmes. This suggests transition programs should be multidisciplinary in nature, individualised in terms of addressing need and navigated with the help of a designated key worker (p78).

	Effectiveness The main finding in this review was the lack of evidence of transition services that include ‘palliative care’ as the originating concept. The evidence base is mainly drawn from the area of life-threatening or life-limiting conditions rather than palliative care itself. Within this context, it was also very hard to locate any material on young people’s views and experiences. Below is an indication of what little reference there was to this subject. Fragmentation was mentioned as a problem that existed between child and adult providers, with evidence of poor continuity of care. This complicated the transition period for many young people. Some studies noted the significant differences between child and adult providers, while the family was seen as an important resource in facilitating transition. Lack of access to, and availability of, suitable equivalent adults’ services for young people approaching transition was a major concern expressed by many young adults, families, carers and child health providers/organisations. The reviewers acknowledge that services need to be flexible and tailored to chronological age and developmental stage.

Downing J, Gleeson H, Clayton P, et al. (2013) Transition in endocrinology: the challenge of maintaining continuity (+/+)

Intervention/aims	**Findings**
No distinct intervention but the study looks at young people in transition from children’s services to the young person’s transition clinic, not adults’ services. **Study aim** ‘This study examined indicators of	**Barriers and facilitators** The study looked at the affect appointment attendance on patient loss post-transition. - The study found no major difference between the numbers of appointments attended pre- and post-transition. - The study did find that cancelled appointments decreased post-transition significantly

patient loss to follow-up at initial transfer from paediatric care to identify implications for transitional care practice and research' (p29).	(p<0001). - There were less appointments made in the year after transition than the year before transition (p<0–001). 'Overall, 85 had been attending paediatric clinics, of which 68 were seen in the YPC within 12 months, but 17 failed to attend within the first year. 18, who had been defaulting from paediatric clinics, were contacted to arrange an YPC visit; 7 then attended the clinic within 12 months but 11 did not' (p68). - 28 young people did not use the YPC in the first year after transfer, for 8 of this number no appointments were ever made, the rest did not attend appointments or cancelled them. On average those that did use the YPC had an appointment with 6 months. - The study analysed the nonattendance at the YPC: gender and age had no impact, neither did condition or diagnosis. - Patients were more likely to fail to attend the YPC if their first appointment was over 6 months away (9-fold increase), and if they had one or more failed attendances (14-fold increase) and/or one or more clinic cancellations in the first year in the YPC (14-fold increase). - Non-attendance in paediatric clinics was associated with nonattendance at the YPC.

Everson-Hock E, Jones R, Guillaume L, at al. (2011) Supporting the transition of looked-after young people to independent living: a systematic review of interventions and adult outcomes (++/-)

Intervention/aims	Findings
This systematic review looks at a range of interventions that are designed to support young people as they transition out of care. The interventions presented in the studies included in the reviews were	**Effectiveness** Despite the seeming relevancy of this review and its good methodology, most of the outcomes are outside the scope of this guideline. The only outcome that is within the scope is mental health – 3 of the included studies gathered information on the effect of transition support services on mental health

aimed at securing positive outcomes in a range of areas. The majority of the outcomes are not relevant to this guideline, such as education, employment, crime/offending, parenting skills and housing. The outcome which is relevant to this guideline is mental health.	outcomes for participants. Only 1 of the papers found a positive effect on the intervention group as opposed to the control group. This paper evaluated an ILP and it found that those who received the intervention felt more hopeful about the future, but the other 2 papers found no favourable effects on the mental wellbeing of the young people who took part.

Fair C, Albright J, Lawrence A, et al. (2012) 'The pediatric social worker really shepherds them through the process': care team members' roles in transitioning adolescents and young adults with HIV to adult care (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
No intervention as such; participants were asked to identify the different roles of HIV care providers during the transition process. **Study aim** The study aims to analyse interview	**Adults' services** The interviews found that the paediatric care team takes the lead in determining when the transition should take place and how. The study also found that social workers played a key role in the transition process. The majority of interviewees felt that paediatric social workers had a key position in the process. - '[We are] involved every step of the way [and] help the patient really understand the

material gathered from 19 HIV care providers. The professionals were specifically asked about the different roles of providers during transition from paediatric to adult care.	transition' (paediatric social worker) (p341). - 'I think they have a huge role because they ... have the most ongoing contact with the patient ... the paediatric social worker, really shepherds them through the process' (adult medical provider) (p342). The interviews show that social workers carry out a number of tasks during the transition process including, making assessments and referrals to other, community-based services. - The social worker coordinates the transition with other professionals: the social worker works closely with the family to explain complex information and facilitate introductions to new service providers. Paediatric social workers also communicate with adult social workers and adult social works take up a similar coordinating role with transitioning individuals, helping them access services and also working with parents. - Medical providers' roles: the interviews suggested that paediatric services played 2 roles in the transition process. This involved supporting young people medically for the transition to adults' services and also emotionally. They were also responsible for communicating with the family and adult services. One pediatric provider stated, '[we] make sure we've optimized their medical regimen and conveyed the information to the adult clinic ... we have those discussions so that the kids are comfortable in their transition' (p344). - The interviews found that the paediatric care team took the lead in determining when the transition should take place and how it should be organised. The paediatric social worker liaised with adult staff to coordinate the transition. The role of adult social workers and medical staff is also discussed. • The interviews showed that adult social work teams had responsibility for communicating with paediatric social workers who were the primary drivers of the transition. • Adult social workers were also responsible for assessing needs and making referrals to community services. • Adult social workers helped young people get used to their new clinic and support

	parents and careers to adjust to a reduced role in an adult medical setting. • Adult medical staff were responsible gathering relevant medical records and also for helping patients feel comfortable throughout transition; relationship-building was found to be important, especially when gathering sensitive information from patients. ‘[I] make sure that patients understand what role the parents are going to play and what role they’re not going to play’ (p343). ‘The most important thing is to synthesize all that information from the paediatric provider and to make a corny sounding warm and welcoming environment that’s supportive and facilitates what this person’s needs are’ (p343). ‘Well, I would like to think that an effort would be made to understand that this is a new experience for this teenager, and so to be welcoming and accessible’ (p343).

Fegran L, Hall E, Uhrenfeldt L, et al. (2014) Adolescents’ and young adults’ transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis (++/++)

Intervention/aims	**Findings**
To synthesise qualitative studies of how adolescents and young adults with chronic disease experience the transition process from paediatric to adult hospital services.	**Views and experiences** Four themes encapsulating young people’s experiences of loss of familiar environments and relationships together with insecurity and a sense of being unprepared for transition were identified. These were: 1. Experiencing changes in significant relationships such as that between paediatric staff who were hands-on and less time conscious to relationships with healthcare professionals in adult wards, which were more constrained and impersonal, with a

	focus on disease management. 2. Moving from a familiar to an unknown ward culture, which was cold and sterile in comparison to a paediatric ward was challenging. 3. Being prepared for transfer – young people felt that transition readiness and maturity were more important prerequisites to achieving a successful transition in comparison to biological age. Despite the transition period being a time when some young people felt unprepared and reluctant to take on responsibility, they generally valued the opportunity to take on responsibility and become more independent. However, they expressed a need for guidance and support. 4. Achieving responsibility – with transition, young people had to take on increased responsibility for managing their health condition, whereas in paediatric settings parental support would have been a greater feature. This forced detachment was often welcomed by young people, but some parents could find this aspect difficult to deal with.

Garvey K, Wolpert H, Laffel L, et al. (2013) Health care transition in young adults with type 1 diabetes: barriers to timely establishment of adult diabetes care (++/+)

Intervention/aims	**Findings**
'To examine barriers to health care transition reported by young adults with type 1 diabetes and associations between barriers and prolonged gaps between paediatric and adult diabetes care' (p946).	**Barriers and facilitators** **Factors that hinder (self-reported)** - 78% said that they had experienced some form of barrier to transition. The study categorised these in terms of small, moderate or major. '48% reported ≥1 moderate/major barrier; of these patients, 52% reported 1 moderate/major barrier. 27% reported 2 moderate/major barriers, 14% reported 3 moderate/major barriers 7% reported 4 moderate/major barriers' (p948).

	- The most common complaints/barriers to the establishment of adult care: ‘Lack of adult diabetes provider name (47%), competing life priorities (43%), and difficulty getting an appointment (41%)’ (p948). In each case more than half of the respondents rated it as a moderate or major barrier. - Lack of contact from their adult clinician was one of the key concerns from respondents. The study found that the participants who complained of moderate to major barriers also had a gap of care of >6 months. So they were more likely to experience barriers. Lack of an adult provider name (39% vs 12%; p<.0001); lack of adult provider contact information (23% vs 5%; p<.0001); competing life priorities (41% vs 14%; p<.0001); insurance problems (14% vs 4% (p948) (p=.003).

Gilmer T. Ojeda V. Fawley-King K, et al. (2012) Change in mental health service use after offering youth-specific versus adult programs to transition-age youths (+/+)

Intervention/aims	**Findings**
The study looked at the effects of outpatient programmes designed for transitioning young people using mental health services. The study was set in San Diego. The programme was designed for 18–24-year-olds and staffed by workers who had a level of experience working with young people. The transitions team	**Effectiveness** The study looks at the use of mental health services 12 months before enrolment in the youth-specific programme and 12 months after joining the youth programme, and similarly with the comparison group who joined the standard adult outpatient programme. In the intervention group outpatient visits increased by 21.4%. In the control group outpatient visits increased by 9.2%. This difference was statistically significant. There were no statistically significant differences between the groups in terms of inpatient admissions, use of emergency services or incarceration (jail service days).

worked with other professionals involved in the young people’s care. The programme focused on independent living skills, educational and vocational services and age-appropriate social skills. This included peer support provided with young people with mental health services experience. **Study aim** • To assess the impact on service use when providing young people-focused services, in comparison to providing adult services, for young people aged 18–24.	

Hagner D, Kurtz A, Cloutier H, et al. (2012) Outcomes of a family-centred transition process for students with autism spectrum disorders (-/+)

Intervention/aims	**Findings**
Three components: A: Group training sessions for families teaching them about person-centred planning, networking, using adults’ services and how to plan a future beyond high school. B: Person-centred planning: facilitators worked with the student	**Effectiveness** Effect sizes are not presented, although enough detail is provided for these to be calculated. The authors did a very basic analysis by considering the pre- and post-means for each group, on each outcome measurement, and considered the statistical significance of the difference between the mean scores for each group. They did not combine these into effect sizes for each outcome. Self-determination, measured on the Arc Self-determination Scale: intervention: n=15, Pre-mean 59.73, post-mean 73.93, t=-5.583, p=.001, waiting list control: n=17, pre-mean 62.36, post-mean 67.07, t=-1.646, p=.062. The authors argue that the differences between pre- and post- measures were statistically

and their family to select and invite extended family and community people to 2–5 meetings. Once this group had agreed ideas for transition, staff from their school and adult services were invited to provide input to the final plan. It was the role of the facilitator to ensure transparent and full participation in the group, especially for the young person. This included further support to the student outside of the planning meetings. C: Follow-up assistance: facilitators who were involved in the planning provided 4–6 months follow-up on the implementation of the plan.	significant for the intervention group but not for the waiting list control group, and therefore conclude that the changes observed cannot be contributed to maturity over time but to the intervention. They note the following limitations of this study: the findings are based on self-reports and some participants were not able to fill in the survey. The study had a small sample size and was lacking in diversity. The period for measuring outcomes was short, due to the waiting list control design.

Hamdani Y, Proulx M, Kingsnorth S, et al. (2014) The LIFEspan model of transitional rehabilitative care for youth with disabilities: healthcare professionals' perspectives on service delivery (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
The LIFEspan model means that transition preparation starts at the age of 16, so that young people have 2 years of preparation before they go through a coordinated transfer to adult services. LIFEspan is implemented in both	**Multiple services** Professionals found that preparation for transfer needed to include parents or carers, but at various levels according to the young person's needs: 'So it is nice to see the comfort level of people as they go through the system going from really, really overwhelmed and "oh my god, what am I doing here?" to "you know, I can do this"' (HCP 14) (p83). Because of this individual focus, the professionals found that there was a lack of tools to

paediatric and adult services. In both paediatric and adult services teams of professionals work with the young person. Preparation in paediatrics includes explaining about the reduced service provision in adults' services, so as to manage expectations.	provide appropriate care, and that they had to create these themselves, and work with parents and young people when tools were felt to be inappropriate. For example, some parents of young people with severe disabilities felt that questions about certain learning objectives were inappropriate. In conclusion: transition readiness preparation had to be tailor-made for individuals and their families, and professionals had to be creative in their approaches so that individual needs could be met. While the LIFEspan model emphasises that both parents and young people should be involved, the preparation for transfer also included encouragement to self-management of condition, so that responsibility would be shifting from parents or carers to the young people. Again, this would be within individual needs, and parents of young people with multiple or severe disabilities would be much more involved and perhaps the main participant in the transition planning. These interviews were carried out 3 years after the implementation of the LIFEspan model. During this time, an expert transition team had been established. The professionals contributed the successful development of this team to committed mid-level management and transition champions. Teams made up of largely part-time staff were seen to hamper individual and tailor-made service delivery, due to lack of flexibility for appointments. 'I think, for the clients, it's the amount of time that they're in the clinic appointment. I think it's the amount they can absorb, sometimes there are cognitive challenges. Every single situation is unique, so you never know what information you're providing they may follow up on or not' (HCP 9) (p85). 'I'm going to guess that there may be some sort of need ... to be an increase in maybe some of the existing resources from a ... maybe from an FTE perspective, I don't know, but ... I just know when our clinic has grown and grown over the years, that with that, we've had to grow the resources to go with it too' (HCP 2) (p85). Three years after the implementation of the transition model, professionals felt the burden of increased referrals and users of the service, without a corresponding increase in time and resources. They therefore had to change their provision as a result, from intervention-focused practice to more consultative.

	The lack of a computer-based shared information system meant that extra time was spent on asking young people and their carers' questions which might have been on a share records system. While the professionals did feel that the LIFEspan model had helped improve collaboration between children's and adults' services due to the appointment of cross-service staff, they still recognised two particular problems: a) The need for an expanded circle of care for young adults with childhood-onset conditions: 'I think that the adult side isn't used to the blatant sharing of information, whereas, in the paediatric side, the circle of care is understood to be anything that can ... any team member that's working with a client is considered to be part of that circle of care (e.g. education, community and social services), even if they're not physically in this building' (HCP 10) (p85). b) Concerns about sharing of individual patient information: 'There's been some meetings with the privacy officer ... There is still a bit of a divide in the team in terms of their comfort level with that' (HCP 6) (p86). The professionals felt that it was important to link in with other services such as education or housing, and worked hard to establish such links. This was also the case for links to primary care. Overall, it was found that services were run in silos and there were challenges in collaborating across. The authors conclude that the LIFEspan service delivery model focused on individual and tailor-made approaches to preparing for transition, and for managing it. System restrictions to successful implementation of transition planning were lack of time and resources to meet increased demand, and lack of shared information systems. As a result, the services on offer and links to other services were weak. Recommendations for transition service planning (from table 2, p88): Establish partnerships with community resources (from rehabilitation, health care, education and employment sectors) to support coordinated care, Establish partnerships with primary care resources to support model sustainability. Develop clear guidelines of professional responsibilities and privacy policies Increase staff

	working hours, full-time and cross-appointed positions where finances allow. Clarify service delivery expectations for staff and create clear guidelines to assist staff in managing growing caseloads. Review service delivery and supporting processes with a focus on increasing efficiency and maximizing client-provider interactions. Create a cross-hospital shared information network client specific activities. Promote youth self-advocacy through knowledge and skill building opportunities as appropriate. Encourage family support of youth self-management of health care through early introduction of transition information and opportunities to practice skills. Develop and adapt care to meet individualized needs and goals of youth and their families

Heslop P, Abbott D (2007) School's out: pathways for young people with intellectual disabilities from out-of-area residential schools or colleges (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
Though not explicitly stated in an aim, the study explores the views of parents of young people with intellectual disabilities (IDs) regarding what factors contributes to a good pathway and outcome from an out-of area residential school or college on to the next phase of their son's or daughter's life. Professionals' views are used to supplement this or where they provide	**Barriers and facilitators** **Factors that help** - Being well-connected with other parents or with key professionals. Parents felt that good transition was linked to good relationships and connections with other parents and professionals. This was found as a way to gather information, suggestions and signposting and also emotional support. Some parents said that it would be beneficial to have mechanisms to connect them to other parents and key professionals, or events to link people together. Some parents had found a single key professional. One parent mentioned a Connexions adviser: 'I know that if I did need to know anything I could just give him a ring and he would help me if he could. And if not, he'd put me onto the right people to get the information I needed' (p491).

background.	- Parents wanted continuity of workers, a single named worker or social worker. If a worker changed, parents wanted warning and an overlapped period to get to know the new worker. A named social worker was recommended by parents and professionals. - A proactive approach from parents was found to be beneficial in satisfactory transition. Parents said that they had to be advocates for their children and push for what they wanted throughout the transition process. Professionals also said that they appreciated proactive parents in the transition process. Some parents said that they felt that they shouldn't necessarily have to take such a key role and they found the process stressful and worrying. Some parents said that they felt they should be supported by transition professionals or 'transition champions' (p492). Professionals agreed that this kind of role was necessary for a positive transition. - Parents wanted sufficient information to help them navigate the transition process. Parents wanted school or residential facilities to help them visit possible placements and discuss options. - Quality of the information also a key factor in parents' decision-making about service after transition. Parents favoured information in paper form, like newsletters, information detailing different options, a database of local services and options, videos, visits to places and an information offer to consult. - Good forward planning between all the parties involved (parents, the current and future residential school/college and the transition lead) and allowing adequate time to prepare. This could include things like ensuring appropriate aids or equipment are in place and staff knowing how to operate them and planning ahead to provide for the social, leisure and communication needs of young people. One young man at college valued having short breaks at a potential future placement so as to familiarise himself with the place and other residents, and therefore transition immediately after finishing college. In another example a residential college set up work experience placements with national companies so that college-leavers moving back to their home area would find it easier to transfer within that company, having had the benefit of being placed there before. **Views and experiences** Four main themes emerged from talking to parents about the process of transition. These

	were: 1. Being well connected with other parents or with key professionals, who were usually the source of information, suggestions or could signpost. 2. Taking an active part in negotiating with professionals and advocating on their child's behalf to get the best possible outcome. 3. Appropriate information to help young people and families make informed choices. 4. Good forward planning between all the parties involved (parents, the current and future residential school/college and the transition lead) and allowing adequate time to prepare. This could include things like ensuring appropriate aids or equipment are in place and staff knowing how to operate them, and planning ahead to provide for the social, leisure and communication needs of young people.

Hiles D, Moss D, Thorne L, et al. (2014) 'So what am I?' multiple perspectives on young people's experience of leaving care (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
The study aims to highlight the experiences of care leavers in transition, and the support available, within the context of a highly pressured leaving care system. Implications for policy, practice and future research are also considered.	**Barriers and facilitators** **Factors that hinder** 1. The 'train wreck' at 18. Participants described uncertainty in support and accommodation available, alongside an arguably unsuitable push for independence. Young people on turning 18 were aware that they would no longer be 'in care', yet uncertain whether they could 'stay put' with their foster carers or 'move on' to new accommodation. Funding to stay put was unlikely unless the young person attracted labels such as 'risky' or 'vulnerable'. Moving on was also challenging where continued financial support was not guaranteed and often only offered to those who complied with the wishes of 'the system' by staying in education. Participants talked about the paradoxical push to independence where the experiences that care leavers have had may result in them needing additional support. This seemed at odds with an active push towards independence at a far earlier age than most of their peers. Participants described having insufficient time to prepare some young people

	for transition, and noted that it could be particularly difficult for those with a history of placement instability. There was acknowledgement of the potential costs to things like physical and mental health of providing inadequate support. 2. Service design and development. The system was described as chaotic and complex, forced to react to crises and predictably those young people not in crisis received less support or none at all. Poor staff retention and the use of temporary staff increased the problem of lack of consistency or continuity of relationships. These problems were reinforced by a lack of integration and joint working between CAMHS and other children's services. Short-term planning was more common, despite the potential for long-term cost-savings of maintaining placement stability or providing adequate care leaving support. 3. Working as a professional. Participants recognised that connecting with young people and building trust were fundamental to providing effective support, but this engagement usually needed a proactive approach and investment in time. Participants said they had no say regarding budgets and described having to 'beg' for money on behalf of their young people. They also described specific challenges in relation to managing the way in which time was distributed across significant caseloads. **Views and experiences** Four main themes emerged from talking to parents about the process of transition. These were: 1. Being well-connected with other parents or with key professionals, who were usually the source of information, suggestions or could signpost. 2. Taking an active part in negotiating with professionals and advocating on their child's behalf to get the best possible outcome. 3. Appropriate information to help young people and families make informed choices. 4. Good forward planning between all the parties involved (parents, the current and future residential school/college and the transition lead) and allowing adequate time to prepare. This could include things like ensuring appropriate aids or equipment are in place and staff knowing how to operate them; and planning ahead to provide for the social, leisure and communication needs of young people.

	Within the care leavers' group, three core themes relevant to the study aims were identified. 1. leaving the system, 2. the constantly changing social network and 3. lived experiences of support, along with seven sub-themes. **1. 'Leaving the system' 'So what am I?'** Young people said there was confusion over their identity, on the one hand being told that they're leaving care (not least via the 'care leaver' label), but at the same time remaining in care for up to 8 years after the label is given. **2. The constantly changing social network** Participants talked about an active social network that changed to reflect their changing needs and situations. This included multiple friendship groups, neighbours, family, professionals and work colleagues. Groups were usually seen as independent of each other, and performing different roles. Whilst relationships with professionals were seen as indispensable, their status prevented some young people from developing trust with them. The role of digital social networks such as Facebook was an expected thing. The researcher journal alluded to the individual nature of care leavers' social networks, '... and to me reinforces the need for this to be mapped out and taken account of when supporting young people in transition'. **3. Lived experiences of support** Participants spoke of great efforts in getting the support they needed both from professionals and people of their social network. This was contrasted with 'forced' or 'pointless' support where they had often had experiences of being offered the wrong type of support ('pointless') at best, or having support 'forced' upon them at worst. Support often seemed to be something that was given, without the involvement of young people, often meaning that their wishes or knowledge of their own needs went unheard. Researcher commentary: 'I was drawn to the experiences of "forced" support, wondering what it must feel like for a young person to have a clear understanding of their needs, yet to have these ignored and different needs forced upon them. It seemed to me that this could be experienced as abusive, and if nothing else, must surely engender a sense of powerlessness.'

Hiles D, Moss D, Wright J, et al. (2013) Young people's experience of social support during the process of leaving care: a review of the literature (+/++)

Intervention/aims	Findings
The aim of this review is to collate and synthesise research relating to young people's experiences of social support during their transition from care. Key themes were identified, and briefly considered using relevant psychological theory and implications for policy, practice and future research.	**Views and experiences** The studies in the review highlight the vital role of social support for young people during their transition from care. The researchers themed these into five groups as summarised below. **1. The influence of past experiences on social support in the present** Young people were wary of building new relationships and wanted to protect themselves from the pain of ending relationships, so often avoided them in the first place (Johnson et al. 2010; Quest et al. 2012). Daly (2012) noted that the high numbers of moves while in care jeopardises the chances for young people to develop an established support network to help that they could benefit from in their transition from care. Some young people said they found it hard to develop peer relationships as they were seen as 'different' from their peers (Dima and Skehill 2011; Ibrahim and Howe 2011; Morgan 2012). Trust was seen as a vital element of a supportive relationship, yet was difficult for young people who had been betrayed in the past. Some suggest that young people may feel it is safest to trust only themselves (Munson

	et al. 2010). However, there was also evidence of the positive impact of past experiences to care leavers’ current transition, e.g. those who had a history of stable placement(s) while in care, (as well as a later and more gradual transition to leaving), often managed transition well (Cashmore and Paxman 2007; Daly 2012; Dixon et al. 2006; Johnson et al. 2010). Equally, foster carers often played a vital role in preparing young people for the leaving care process (Barn et al. 2005; Geenen and Powers 2007; Mendes and Meade, 2010; Munro et al. 2012). **2. Supportive relationships during the transition from care** Some care leavers were supported by their extended families, but many were not (Geenen and Powers 2007; Mulkerns and Owen 2008; Samuels and Pryce, 2008). Some care leavers said they had nobody to talk to at all, but most individuals were able to potentially approach a wide selection of different people for support (Munro et al. 2011). However, this latter scenario could be confusing to young people who were having to deal with so many professionals and were not clear about different roles. In the UK context, 2/3 of study participants ranked the support from their social worker as ‘good’ or ‘very good’ (Munro et al. 2011). Trust (together with openness and honesty) was a fundamental aspect of all these relationships. Care leavers saw relationships with some professionals (e.g. personal adviser or leaving care worker) as absolutely key in making sure that practical needs, especially in the areas of housing, education and employment, were addressed. Mentoring relationships were also valued by care leavers, especially because of the emotional and appraisal function. Peer relationships were also valued, as expressed in many studies (Broad 2005; Dima and Skehill 2011; Dixon and Stein 2005; Morgan 2012; Morgan and Lindsay 2006; Parker 2010; Perez and Romo 2009). **3. Relationships with birth families** Most care leavers try to make contact with at least some members of their birth family upon leaving care, most frequently their mother or siblings (Dixon and Stein, 2005; Dixon et al. 2006; Munro et al. 2011). While many found that changed circumstances over the years led to improved relationships upon leaving care, others found the opposite to be true (e.g. Dixon et al. 2006), As well as the emotional bonds of family and the potential provision of practical help such as accommodation, these links provided connections with the young person’s culture of origin and family ‘rituals’, which supported identity formation (Barn et al. 2005).

4. The crucial role of practical support

During the period of leaving care, there is an overwhelming need for practical support (such as getting furniture, and sorting out bills). Two studies in the UK suggest that around a third of care leavers will experience a period of homelessness in their first year after leaving (Barn et al. 2005; Dixon et al. 2006). In the UK there is mixed evidence regarding which housing option is favoured by young people (e.g. young people in Morgan 2012 identified a need for more supported accommodation, though only around half of those offered it took it up (Munro et al. 2011), probably due to considerable variations in the quality of the options offered (Dixon et al. 2006; Munro et al. 2011). Dixon et al. (2006) note that those who might be considered amongst the most vulnerable (i.e. those with mental health, emotional or behavioural difficulties) were more likely to experience both homelessness and multiple moves. This also reflects data from Munro et al. (2011), who noted that the high cost of foster placements for this vulnerable group seemed to influence the decision to offer them to young people beyond the age of 16, potentially resulting in them leaving care prematurely. Many care leavers said money was the most significant day-to-day issue (Broad 2005; Harris, 2009; Munro et al. 2011) and budgeting skills were a problem (Dixon et al. 2006; Morgan 2012; Munro et al. 2011). In the UK context, care leavers mentioned large regional differences in the levels of financial support given to them by the local authority. For example, Morgan (2012) found that the discrepancy in the leaving care grant varied between £800 and £2000 depending on the region, and sometimes even within the same service.

5. The lived experience of leaving care

Young people thought that attending meetings to develop leaving care plans was stressful (e.g. Daly 2012; Munro et al. 2011), and in the UK context the majority of young people also thought they were not being listened to in the meeting (Munro et al. 2011) and around a third that the resulting ‘pathway plan’ was completely ignored (Morgan 2012). Young people want more control over the timing and staging of leaving care, though for many this did not happen (e.g. Morgan 2012; Morgan and Lindsay 2006). Care leavers often spoke of the burden of having to adjust to an overwhelming amount of responsibility, without some sort of safety. In 1 UK project designed to address this by allowing 16–18-year-olds to leave and return (Munro et al. 2011), there was very positive feedback, but in reality the scarcity of foster placements meant it was unlikely for someone to return to the same placement.

HMI Probation, HMI Prisons, Care Quality Commission, et al. (2012) Transitions: an inspection of the transition arrangements from youth to adult services in the criminal justice system (Internal validity ++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
This inspection was agreed by the Criminal Justice Chief Inspectors' Group, as part of the Joint Inspection Business Plan 2010–12. Its terms of reference were to assess the quality of work undertaken to promote an effective transition for young people subject to community and custodial sentences, at the age of 18, from youth-based to adult-based provision.	**Barriers and facilitators** **Factors that help** Transition in the community before transition from Youth Offending Teams: - YOTs were set up from the start as teams of staff from partner agencies providing services in an integrated manner, with a clear emphasis on the needs of children and young people. - Before transfer there was a need for more information sharing and discussion between the YOT case manager and the designated probation offender manager to enable smoother transition. Practitioners benefited (in some areas) where there was a single point of contact for initial dialogue and a locally produced case transfer form. - Local policies promoting greater attention to the transition of young people were starting to have a positive impact on practice. - Some adult substance misuse services knew of young people's additional vulnerabilities in an adult service and tailored their service accordingly. Transition in the community after transfer (from YOTs to supervision by the probation trust and other adult services). - Health services went out of their way to continue to provide services for young people beyond the age of 18 if there was a lack of services available. - Good links existed between the YOT mental health worker and the early intervention worker.

	Supporting arrangements (e.g. written arrangements and protocols). - Protocols – the majority of YOT staff knew if there was a local protocol. Health services staff knew of local probation-YOT case transfer protocols, and which service supervised which age group, but most had been marginally involved in transfers. - Information – many staff in both young people’s and adult health services felt that they received appropriate information from each other during transfer. - Higher thresholds for adults’ services – where a clear mental health diagnosis existed (i.e. one which was accepted in the adult field) a reasonable transition was more likely between child and adult mental health services compared to where a young person had a lower level substance misuse problem. - Monitoring – e.g. the effectiveness of transition arrangements for young person’s substance misuse services in Hertfordshire. **Factors that hinder** 1. Transition in the community before transition from YOTs. - There was inadequate timely sharing of information between youth-based and adult-based services to enable sentence plans to be delivered without interruption. - Case transfer meetings did not happening regularly but, when they did, young people, YOT case managers and probation offender managers had found them useful. - When cases were transferred from YOT to probation, the other agencies involved with the young person were not always informed. - Youth-based health (and education, training and employment) services did not always liaise with the corresponding adult-based service, and vice versa. - Case managers adapted their style of supervision to prepare young people for transfer to probation but few young adults felt this was the case or were clear about arrangements after they turned 18. - Substance misuse services for young people were more likely to continue working with young people after the age of 18, with long lead-ins to adult services, but mental health services were more likely to have a fixed transfer point. But health practitioners were often

	unaware of these thresholds when they referred (p31). Transition in the community after transfer (from YOT to supervision by the probation trust and other adult services). - YOT managers and practitioners were unaware about interventions in probation, while probation staff reported that neither the work of YOTs nor child and adolescent development was given prominence in their in-service training. - New intervention providers did not always try to establish if there had been a former provider and take advantage of information from them (although mental health providers were more likely to do so) which meant duplication of assessments and gaps in knowledge. - There could be difficulties in ensuring that physical health issues, which were being addressed in the YOT, were considered in probation and properly supported by adult health services. - Despite examples of local written arrangements for liaison between education, training and employment agencies and between health agencies, there was little understanding in health services of their roles, criteria and thresholds. Transition in custody (i.e. in terms of being prepared for transfer from the young person’s secure estate to over-18 YOI/prison). - There was insufficient forward planning and communication, which led to a break in sentence planning and delivery of services after young people had transferred to an over-18 YOI/prison. - All young adults who had previously been in contact with young people’s substance misuse services had seen substance misuse workers at their new establishment. But there was no sharing of information about young people prior to transfer when it involved a move from one establishment to another. - In custody, HM Inspectorate of Probation’s inspection of youth offending work programme highlights less regular involvement of other professionals in work with young adults after transfer to an over-18 YOI.

Huang J, Terrones L, Tompane T, et al. (2014) Preparing adolescents with chronic disease for transition to adult care: a technology program (++/+)

Intervention/aims	Findings
MD2Me: this is a transition support intervention delivered over a 2-month period via the web and by texting, to support condition management and skills development, followed by a 6-month review period. So this is a total of 8 months transition support. In addition, those in the intervention group had access to 'a texting algorithm for disease assessment and health care team contact' (p e1639). Young people who did not have a mobile phone were provided with one by the study. This was compared with monthly emails or postal materials on general health topics. 'Usual health care communication portals were available to controls' (p1641).	**Effectiveness** Transition readiness disease self-management (TRAQ): MD2Me baseline: 3.4 (0.9), 2 months: 3.5 (0.7), 8 months: 4.0 (0.8) Controls baseline: 3.6 (0.7), 2 months: 3.8 (0.9), 8 months: 3.8 (0.8), self-efficacy health-related self-efficacy: MD2Me baseline: 72 (17), 2 months: 79 (16), 8 months: 81 (17). Controls baseline: 69 (17), 2 months: 69 (16), 8 months: 71 (14). Health outcomes: disease status, functional performance, quality of life: no statistically significant change over the study period in the intervention group. Results for the control group not reported. Effect from the intervention was found in terms of transition readiness (scores on the TRAQ questionnaire) and self-efficacy (scores on the Patient Activation Measure). Note that the mean score for both groups was above 68.5 at baseline which the normalised score is indicating that they are ready for transition. Patient-initiated communications also increased in the intervention group, and not in the control group. The authors argue that this web- and text-based intervention proved successful in improving contact between young people with long-term conditions and their healthcare professionals. It appears that young people in the intervention group with low health literacy did not gain from the intervention. The authors argue that this indicates the need for booster interventions for this particular sub-group. The authors did not find any statistical significant relationship between transition readiness (measured as disease management, health-related self-efficacy and patient-initiated communication) and age. They argue that this indicates that transition is less related to age and more to giving young people the opportunity to develop independence, arguing for earlier interventions than late adolescence.

Jordan L, Swerdlow P, Coates T, et al. (2013) Systematic review of transition from adolescent to adult care in patients with sickle cell disease (+/+)

Intervention/aims	Findings
This review aimed 'to examine the barriers to and approaches for successful transition of patients with SCD [sickle cell disease] from adolescent to adult care' (from the study abstract).	**Barriers and facilitators** **Factors that hinder** - Poorly prepared transfer in terms of informing the young people. - Differing management approaches in paediatrics compared with adult care. Lack of involvement in the transition process from healthcare providers. - Adult care providers not knowing how to be the main healthcare provider for young adults with SCD, and not being prepared for the transitioning in from paediatrics. - Lack of information about the transition process and about new providers. - Lack of multidisciplinary approach in adult services. Lack of patient registers to monitor outcomes from patient-centred protocols. **Factors that help** - Better self-management is associated with higher education and also with higher age. - Independence was associated with poor family relationships and poor knowledge of condition. - Meeting adult providers and visiting adult facilities in advance of transitioning. The review makes two recommendations, graded B ('on the basis of inconsistent or limited-quality patient-oriented evidence', p167): 1. Young people should be provided with a patient-centred and flexible transition plan. Primary caregivers (parents or others) should be actively involved in this. Both paediatric and adult care givers should be involved in the transition programme and

	planning. 2. Healthcare providers should be educated about transition This review, being conducted in the US, identified some important impediments to purposeful and planned transitions which are specific to the US context of privatised healthcare. These are not reported here.

Kaehne A (2011) Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
The study aim is to investigate how mental health professionals organise transition for young people with IDs, what they consider to be the key gaps in services at that critical time for young people, and what they think the main barriers to smooth transitions are.	**Barriers and facilitators** **Factors that hinder** - Mental health services for people with IDs were non-specialist in all 3 local authorities and not integrated into the health or social care team in any of these authorities, creating a rift between the following services: CAMHS and AMHS, mental health services and secondary and primary health services in the children's and adults' sectors, and between mental health services and local social care provision. - None of the local authorities had developed a shared transition protocol between social care and health services that included mental health services. Where contact was made with mental health services during protocol development, this was often tokenistic. - Mental health services had drafted their own transition paths and protocols for transfer from CAMHS to AMHS without integrating them into the wider transition partnerships in social care, and primary and secondary healthcare providers. Three barriers: 1. Coordination of services - Data and information highlighted as very poor between CAMHS and AMHS, as well as between primary and secondary healthcare professionals and social care workers.

	This impacted negatively on the development of transition partnerships. - Lack of knowledge about eligibility criteria in other services led to inappropriate referrals with potential for a knock-on effect on service quality. - Poor multiagency working, especially social care and mental health services. Data not passed on between the two sides, and there was little joint working that included the mental health services. - CAMHS marginalised – CAMHS staff were unaware about the services offered by adult social care, CAMHS staff lacked knowledge about the role of the transition planning groups (led by social care and education). - Potential risk groups – young people with mild IDs and high-functioning autism or Asperger’s syndrome and young people who had no statement of additional education need. 2. Service gaps - Eligibility criteria between CAMHS and AMHS. Where a person stops education at 16 years, CAMHS provision ceases and the expectation is that adult services might plug this gap. Negotiation between services becomes necessary to establish responsibility and reinstate services. - Cooperation with social services. Mental health professionals working with children and young people emphasised the need for close cooperation with social services. - Different service models between CAMHS and AMHS. Those young people who were transferred to AMHS at the age of 16 were getting a different service from those who were not and this could cause anxiety for the young person and family. - Strict eligibility criteria in adult social services. Young people left with no access to mental health support through AMHS, some young people fell through the net. - Vulnerable groups. Certain groups who received mental health services had no access to social care support or an education/social care transition plan: young people with mild IDs, learning difficulties and high-functioning autism or Asperger’s syndrome. 3. Different service models and approaches between CAMHS and AHMS

	- CAMHS worked within a developmental model of psychiatry, while AMHS would determine eligibility according to a medical model, affecting continuity of care for those who do not meet eligibility criteria.

Kelly B (2013) Don't box me in: disability and transitions to young adult life (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
This study aimed to explore the transitional and early adult life experiences of young adults with learning disabilities through qualitative methods including: semi-structured interviews with young people, families and carers and professionals; case file reading; and biographical narrative techniques (Denzin and Lincoln 2000). The study is based on a follow-up study of 10 young adults who were involved in research examining the family support needs of disabled children and their families 10 years earlier when these participants were all aged under 18 and receiving services from their local children's disability social work team.	**Barriers and facilitators** **Factors that hinder** - Social workers expressed frustration about the demands of administrative tasks, ever-growing caseloads and their evolving professional role. Most social workers said that they would like to have more time to spend with families and opportunities to undertake more face-to-face work within the context of the traditional models of social work. - Staff in adults' services expressed concern that person-centred planning was too time consuming and costly. The introduction of new, protracted assessment models was not welcomed as they were aware of the impact of resource constraints on access to services to meet identified needs. - Person-centred planning was more regularly used in children's services as staff in adults' services were concerned that it was too time consuming and costly. There was a general opinion that person-centeredness should be the guiding philosophy of adult learning disability services. - Social workers who valued the carer assessment process viewed it as an opportunity to improve working relationships with families and develop an appreciation of the experiences and needs of carers. - Agreement among professionals that many disabled young people had little knowledge of disability rights or social model ideas. - Professionals acknowledged that managing situations where anxious parents of

	young people with learning disabilities wanted control over their personal relationships was a challenge. Staff do their best to try and ‘educate and advise’. In cases where there was genuine concern for wellbeing and safety of a young adult, professional turned to vulnerable adult policies and procedures to guide practice. 1. Different approaches to transition planning and support: the fact that some trust areas had designated transition coordinators and others had embedded the transition support function within the context of the keyworker role led to some confusion about roles. Young adults and their families reported varied experiences of keyworker support during their transitional years. Good practice included: keyworkers investing in building trusting relationships with young people and sustaining prompt and regular contact with them, prioritising the views of young people; signposting them to other sources of support; and advocating on their behalf. Negative experiences included: lack of follow-up after a crisis in the family and breaks in access to a social worker at key transitional times. 2. Key barriers to involvement in service planning: young adults were often presented with limited choices or only involved when decisions were already made by parents or professionals acting on their behalf. Despite overall consensus that disabled young people should participate in decisions affecting them during the transition years, there were barriers. The researcher acknowledges that there is a need to develop more innovative ways to engage with young people. Capacity-building and giving young people support to challenge services and parents where complex family dynamics exist is also suggested. 3. Parental role: parents sometimes found it hard to adjust their parenting role because of the significant changes and challenges their disabled son or daughter would be facing. Parents expressed concern about the vulnerability of their child but acknowledged that this required balancing against the recognition of their rights as young adults. 4. Day opportunities: several respondents said they needed a ‘base’ for these young adults to ensure they were supported to engage in day opportunities rather than becoming stuck in inappropriate services or remaining at home with no social outlets. There is also a gap in day opportunities for young people who have personal-, health-

	or mobility-related care needs. There is concern that these young people are being incorrectly placed in day centres for those with more complex needs. 5. Construction of self-identity: young disabled people going through transition to young adult life had different views about deficiency and disability, which affected the way they perceived and constructed their self-identity. When young adults accessed life opportunities that met their hopes or reflected that of their peers or siblings (e.g. attending college) disability was often not a major issue. Others expressed annoyance for being treated differently or as less able because of their disability. 6. Social exclusion: young disabled people can be excluded for a variety of reasons including the loss of social networks as service settings change and parental fear about risks. Most young adults looked forward to engaging in personal relationships, however, parents and professionals were concerned about their vulnerability to abuse or exploitation, finding it a challenge to address issues of sexuality and personal relationships and being torn between balancing the rights of young adults with their duty to protect. 7. Supported living: young adults and parents lacked knowledge of supported living options for young people with learning disabilities. The scarcity of supported living accommodation means that young people have less chances to live independently or with support in the community. This is a vital part of capacity building to help them prepare for further transitions later on when parents cannot manage the caring role any further. 8. Direct payments: parents had no knowledge of direct payments or were concerned that they could not identify a service provider or cope with the demands of managing these.

Kime N, Bagnall AM, Day R, et al. (2013) Systematic review of transition models for young people with long-term conditions: a report for NHS Diabetes (+/++)

Intervention/aims	Findings
Models, or components of models, of transition from paediatric to adults' services. **Study aim** The review aimed to answer the following questions: 1. What models or components of models are effective in ensuring a successful transition process for young people with long-term conditions? 2. What are the main barriers and facilitating factors in implementing a successful transition programme? 3. What are the key issues for young people with long-term conditions and professionals involved during the transition process? (p1)	**Barriers and facilitators** **Factors that hinder** - Service/provider issues: non-existent structured transition programme, lack of adequate resources/time/guidelines in relation to transition planning, insufficient transition information and unfamiliarity with transition resources, organisations failing to prioritise/support the process. - Poor inter- and intra-agency coordination from the perspective of professionals, gaps in levels of integration between sectors in the healthcare system, lack of communication between paediatric and adult physicians and other adult care services in the community. - Rigid policies and protocols that create inconsistencies; a single transfer event to an unfamiliar clinic with completely new professionals, whose views on the management of the condition are different from their previous practitioners' views. - Significant differences in care between paediatric services (supportive, family-centred approach; paediatric staff have more time and flexibility) and adult-oriented services (independence expected; adult staff have less time and flexibility because of bigger caseloads). - Sudden transfer to adults' services with little or no prior preparation/planning, poor preparation on the part of adult-orientated services, fragmentation and poor continuity of care, delay in booking appointments at adult clinic after transfer from paediatric service. - Unacceptable provider care (time constraints, lack of transition training and experience with childhood chronic illnesses), difficulty accessing resources and difficulty communicating with adult providers. - Resistance from paediatric care providers; providers' attachment to the family and reluctance to 'let go' and distrust of adult-centred health services. - Parental issues: parents' and young peoples' difficulty 'letting go' of the paediatric

	providers., Resistance of more marginal role they are expected to play in adult consultations, Parents not allowing young people to take an active role. - Young person issues: age, maturity and emotional/cognitive ability at transition, knowledge of condition and care/treatment, reluctance to leave family-centred care, lack of support from paediatric and adult sub-specialists, lack of professionals' knowledge, uncertainty and lack of information about transition, lack of access to HCPs and specialist and allied health professionals due to age limit. Young people showed lack of adherence with f their transition plan. For those young people with HIV, perceived increase in stigma on transitioning to adult care and difficulty with adherence to medication regimen. **Factors that help** - Information: developmentally appropriate education for young people should begin early and ongoing guidance given about what to expect. - Successful transition programmes should include orientation tours and information in several formats. - Referral should be accompanied by a written summary of the paediatric experience and medical situation and adult team to meet jointly with the patient and paediatric team before transition; services to overlap until the patient is transferred. - Patients wanted a continuation of individualised care that they received as paediatric patients and a rapport with the doctor or healthcare team. - Improved communication between all parties involved in transition: aspects of good communication include: key worker role within adult services; a full multiagency assessment that provides a structure for future communication, as well as establishing systems for joint working and communication; a system that ensures all young people's notes are transferred. - Professionals need to acquire additional skills (e.g. communication skills and understanding the physiology of adolescence). - Post-transfer planning and monitoring should be included, with strategies to make the paediatric team's withdrawal of support more gradual for patients. Support needs

	to be provided to youths for 6–12 months after they make the transition to adult care with a policy in place for those youths who fail to make a successful transition (Michaels 2009). - There needs to be a transportation system and stable housing, counselling and psychosocial support; family support; advocacy; and peer/local support. - Almost 10% of the total cohort reporting having had a psychiatric hospitalisation over the past 3 years, so mental healthcare may be a critical component for a successful transition. - Services should be flexible and focus on young people’s needs, including the developmental level of the patient, assessment of vocational needs, educational plans, encouragement of work experiences and a vision for future employment, along with life skills training; recognition of adolescents’ increasing need for autonomy; recognition of the need for psychological support; the continuing battle for control; inclusion and support of the patient’s family and developmentally appropriate care. - Gilliam (2009) reported that transition plans needs to be tailored to the individual, incorporating a holistic approach that takes into account the medical and psychosocial needs of the individual. It is important to establish a transition policy and programme that is explicit and formalised, and which utilises timelines that are tied to individual patients’ developmental stages rather than a rigid schedule (Michaelis 2009). - Education about the chronic condition, self-management and building self-confidence is needed. Improving youths’ emotional readiness and skills for adult medical care, e.g. life skills workshops provided in clinics, is also needed (Michaelis 2009). - Independence should be fostered through appropriate consulting patterns that respect the adolescents’ need for confidentiality and privacy. - Closer links are needed between paediatric and adult clinic staff and strategies for maintaining mutually beneficial clinic-patient relationships even after youths leave paediatric care (Michaelis 2009). - Comprehensive services need to be provided including primary care, pharmacy and dental services and psychosocial services such as case management, mental health,

	and sexual health support groups. - Adult providers need to learn skills specific to the treatment of youth with HIV. Adult-orientated care providers need to be aware of the protected healthcare environment from which these children come from and may have to tailor their language and approach to interacting with patients who have been followed in a paediatric HIV clinic. They should be aware of the specific challenges regarding adolescents with HIV. In particular, stigma played a prominent role in both the challenges to care and the barriers to transition. This is an aspect of the disease that may significantly impede access to healthcare. - Inclusion of primary caregivers in decision-making and treatment planning critical, especially directly following transition from paediatric care and particularly with youth with special developmental needs. - Care should be delivered by culturally competent and lesbian/gay/bisexual/transgender (LGBT) friendly staff. - A multidisciplinary approach to transition encourages continuity and coordination between services. Professionals felt it was very important to involve general practice, community paediatricians and community therapists in transition care planning. - A transition coordinator or ‘champion’ or one person each from the paediatric and adult-oriented teams should be in charge of managing the transition. **Effectiveness** This review identified 16 relevant systematic reviews and 142 primary studies. They decided to update the existing reviews, leaving 16 reviews and 13 individual studies. The overall methodology of the included reviews and studies was poor. **Key findings** There are various transition models, and no single model was identified as the most effective, but components of individual models that facilitate successful transition were evident. Almost a quarter of youth interviewed in (Wiener 2011) said adult providers seemed to

	lack understanding of their psychosocial issues. They need to address common concerns of young people, including sexuality, substance use and other health-promoting and harming behaviours (Wiener 2011). Adolescents expressed desire for a well-known professional (e.g. a case manager from paediatric clinic; paediatric nurse practitioner) to help them through the transition period (Coyne 2012; Jalkut 2009; Jones 2008). Anxiety and specific worries during transition indicated by young people included being overwhelmed, concerns about privacy and health status during transition (Valenzuela 2011). - Patients reported not liking the environment and fears for their future seeing older and sicker patients (Lugasi 2010). Post-transition, young people expressed concerns about access to care, and the type of care available (Young 2009). - Participants also experienced adult care as marking a change in provider expectations and interactions (Young 2009). Many felt the expectation to take on more responsibility with managing their care, such as making their appointments, being punctual and making medical decisions, compared to when in adolescent care (Valenzuela 2011). - With the advent of highly active anti-retroviral therapy (HAART), survival is now expected. The need to help these youths catch up academically and emotionally by reducing dependence on their families has become necessary for day-to-day living as well as transitioning care. This was expressed by participants who reported difficulty with relaying their own medical history, their expressed desire to keep their primary caregivers involved in their care and reluctance by either primary caregivers or paediatricians to give up control of their healthcare. - Clarizia (2009) found that the majority of patients had a basic knowledge of their heart condition; only a third had a clear understanding of the implications and changes associated with their future transition to adult care. Nearly half expressed a desire for more information about their heart condition. Most parents were aware that their child would transition to adult care; nearly half had some concerns about transition and half felt their child was ready. Parents’ involvement was extensive, with nearly all

	accompanying their child to medical appointments, 2/3 staying with them for the entire visit and nearly half administering their medication. **Implementation** • Nine reviews and studies highlighted problems around a lack of structured transition programmes, adequate guidelines and information resources and a lack of commitment within organisations to prioritise transition as a service. • Six reviews and studies highlighted barriers in the form of poor communication between professionals and organisations (particularly communication between adult and paediatric services) and a lack of collaborative and integrated working. • One review highlighted ‘rigid processes and protocols that create inconsistencies’ (p23) as an issue which meant that transition arrangements were not responding to young people’s needs. It found that young people may find that professionals in adult care may take a different approach to their care than those in children’s services. • A strong recommendation from the review was the ‘significant’ differences between paediatric care and adult care. The review found that paediatric services were more holistic, supportive and flexible and adults’ services expected more independence from patients and professionals carried bigger caseloads and had less time for patients. • Three studies and reviews found that transition planning was often poorly implemented, making transition abrupt and leaving patients poorly prepared. This led to services becoming fragmented and badly organised. • There was evidence of a reluctance from some paediatric providers to ‘let go’ of long-standing and close relationships with parents and patients. Three studies found that paediatric professionals exhibited a ‘distrust of adult-centred health services’ (p24). The review goes on to look at issues with parents and patients which might hamper their transition plan. These issues are more to do with parental anxiety, emotional attachment to children’s services and young people feeling unprepared to access

	adults' services. But these findings do not have as much relevance to policy and practice as those above. The review also lays out some key facilitators and recommendations, however these are broad and do not specifically relate to the implementation of guidelines or interventions and so serve more as guiding principles, familiar to other literature around transitions. **Effectiveness** This review identified 16 relevant systematic reviews and 142 primary studies. The authors decided to update the existing reviews, leaving 16 reviews and 13 individual studies. Key findings: there are various transition models, and no single model was identified as the most effective but components of individual models that facilitate successful transition were evident. Transition needs to be: - centred on young people and placed in the context of young people's lives and their changing circumstances - age-appropriate and take into account young people's maturity, cognitive ability, and needs in respect of long-term conditions, social/personal circumstances and psychological status, as well as inclusion of the whole family - a streamlined progression from paediatric to adults' services as part of a planned and structured process embedded in service delivery - a multidisciplinary approach with involvement from professionals in general practice, community paediatricians/nurses. The following are needed: - Self-management education as part of a specified education programme. Incorporating an assessment of young people's self-management competencies, self-

	confidence and readiness to transition. - Close collaboration between paediatric and adult services with designated transition clinics attended by paediatric and adult health care professionals. A transition coordinator to maintain a link with young people and liaise with various health, education and social sectors. - Participation of young people and their families with written and verbal communication between paediatric healthcare professionals, adult health care professionals, and young people and their families. - Consideration of young people's concerns regarding the transition process (feelings of abandonment on leaving the paediatric team and anxieties around acquiring a new adult provider), lack of access to health care professionals in adult care and differences in care between paediatric and adult services. - The joint preparation of a young person's portfolio that moves with the young person, to alleviate young people's fears and provide reassurance their new provider will have all the required information about their medical history. Training of healthcare professionals to treat young people with long-term conditions and to utilise effective interpersonal and communication skills. - Resources to develop, maintain and evaluate transition programmes.

Kingsnorth S, Lindsay S, Maxwell J, et al. (2010) Implementation of the LIFEspan model of transition care for youth with childhood onset disabilities (overall validity ++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
'Two health centres in Toronto, Canada partnered to develop a linked model of care to support transition	**Implementation** The study identified the following factors which contributed to the successful

from paediatric to adult rehabilitation services' (p547). The LIFEspan model draws together 3 stages of care provision to help introduce more continuity into the care process: paediatric services, transfer services and adult services.	implementation of the LIFEspan model. - 'leadership, effective communication, parity, and compatibility between the two organisations' (p547). And also some barriers to the implementation of the LIFEspan model: - 'service delivery ... organisational policies and procedures, information transfer, and the creation and/or delineation of role within an expert team' (p547). The study discovered that there were 4 enabling factors which supported the implementation of the LIFEspan model. 1. Leadership. The study found that the implementation of the project needed to be facilitated by key individuals and groups. Key people needed to advocate for the partnership model, there needed to be a general awareness of the need to change how transition is run and the programme, crucially, needed support from the heads of both organisations involved. Implementation needed to be driven by people with 'commitment, zeal and drive' (p553). On top of strong leadership within the partnership, this study also found that the creation of a business case and securing grants from local authorities were other factors which helped the partnership off the ground. 2. Effective communication. The study identified communication, on 3 levels, as a part of the effective implementation of the project: pre-existing relationships among stakeholders, shared responsibilities in meetings and working together in the same space regularly. These 3 things led to good communication and a high level of commitment to the partnership. Another feature was 'cross appointed' staff who held positions at both sites, connecting the two parts of the LIFEspan partnership. 3. Organisational parity and equity between organisations in the partnership. Interviews revealed that both organisations were thought to be contributing to the partnership with equity. This was measured in terms of hosting meeting at each site, co-branding and shared accountability. Stakeholders felt that the partnership was equally 'owned' by both organisations and was overseen by the cross-appointed coordinator. Stakeholders commented on 'the integration of both our environments'

	(p554). 4. Compatibility. A key part of the success of the implementation of the LIFEspan project was compatibility of the 2 organisations to work with one another. Both organisations shared mission statements, values and mandates. They also shared the same funding sources and were located near one another and shared catchment areas. The centres shared holistic working styles and had ‘strategic compatibility’ (p554). Barriers to implementation are presented under 4 headings: policies and procedures, information transfer, building an expert team, delineation of roles. 1. Policies and procedures. There were some challenges associated with different policies and procedures in the organisations. ‘Doing business in two fairly bureaucratic, fairly large environments ... there was some policies to navigate’ (p555). The linked model of care involved cross-appointing some staff, and working with different workforces some of whom were unionised, some of whom were not. 2. Information transfer. The transfer of patient health information was another challenge. The information management systems at the joined organisations were not linked. Sharing patient information was described as a ‘considerable challenge’. Staff were using different email systems and different access systems. These gaps in information exchange seemed to be a constant issue for staff. 3. Building an expert team. There were problems with filling some of the roles needed in the partnership, notably the nurse PR actioner role. This role needed extra training and so was not properly embedded in the service for some time. Turnover in the team also affected team working: ‘every time there is that change, we go back to square one’ (p555). 4. Delineation of roles. In implementing the new service there were issues with establishing roles. ‘Because it’s a new service, establishing roles is a challenge’ (p555). There was a need to delineate between multidisciplinary working and interdisciplinary working. The programme focused on the latter, which was ‘joint problem solving and collaborative communication among disciplines’ (p556). ‘I think some of the hindrances have been thinking from a much siloed professional

	perspective rather than a transdisciplinary perspective.' Poor role definition was thought to impact the efficiency of the clinic, the team dynamic and the client experience.

Kipps S, Bahu T, Ong K et al. (2002) Current methods of transfer of young people with Type 1 diabetes to adult services (-/++)

Intervention/aims	**Findings**
Study compared 4 different types of transition. 1. Transfer from a paediatric clinic to an adult clinic. 2. Transfer from a paediatric clinic to a young adult clinic held in a diabetes centre at a different hospital. 3. Transfer from a paediatric clinic to a young adult clinic held in the same hospital; patients were introduced to the adult physician in the paediatric clinic prior to transfer. 4. Initial move from a paediatric clinic to an adolescent clinic held in the same diabetes centre (run jointly by the paediatrician and adult physician) before transfer to the adult clinic.	**Barriers and facilitators** - Attendance rates (at least 6 monthly) fell in all 4 areas, but markedly more in 'transfer only' areas: Those who were transferred from a paediatric clinic to an adult clinic: pre-transfer rate 83%, at 2 years after transfer 57%. - Those transferred from a paediatric clinic to a young adult clinic held in a diabetes centre at a different hospital: pre-transfer rate 72%, at 2 years after transfer 29%. - Transfer from a paediatric clinic to a young adult clinic held in the same hospital: patients were introduced to the adult physician in the paediatric clinic prior to transfer: pre-transfer rate 84%, at 2 years after transfer 71%. - Initial move from a paediatric clinic to an adolescent clinic held in the same diabetes centre (run jointly by the paediatrician and adult physician) before transfer to the adult clinic: pre-transfer rate 78%, at 2 years after transfer 63%; post-transfer (at 2 years) HbA1C measures were only available in those attending clinics, and these did not differ by area. - Pre-transfer HbA1C levels were higher in those who subsequently did not attend clinics after transfer.

Kirk S, Fraser C (2013) Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: a qualitative study (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
Study has three aims. 1. To examine how young people with	**Views and experiences** Transition to adult health and social care. Parents and young people reported that

life-limiting conditions and their parents experience transition. 2. To identify families’ and hospice staff’s perceptions of family support needs during transition. 3. To identify the implications for children’s hospices (p342).	they lacked information about the transition and what they could expect from services once they moved across. ‘Nobody seems to take ownership of transition, they just pass the buck and nobody does, they don’t know what or who to pass him on to, so they just don’t do anything’ (p344). ‘They seem to have no information. They’ve got no knowledge … It’s hard, the transition from child to adult, with disability, in this country. Because under 18, you tend to get a lot of support from everywhere. Help with getting you a wheelchair, help getting the house adapted … you just seem to get a lot of help with the things you need … whereas when you start getting over 18, it’s not quite so clear cut …’ (p345). The study reports that some young people and parents felt like the services they were using were not taking ‘responsibility for transition’ (p345) and that they felt a sense of abandonment. Some parents felt that, because their child’s life expectancy was short, adults’ services were unwilling to invest much in their cases. ‘There’s no support whatsoever. In adult care they don’t seem to bother, there’s no care because they don’t care’ (p345). Families described experiencing a significant amount of uncertainty and anxiety around transition. ‘I think transition is a stressful time but it’s been much worse than it probably needed to be … Nobody knows what’s meant to be happening’ (p345). ‘I found it really stressful and frustrating and that was due to the lack of transition into, supposedly, adult services’ (p345). Interviewees found that as they entered adult service there was less support available and fewer services, particularly if the young person had very specialised needs. ‘All services have stopped, we’ve no adult budget for her, we’ve no care plan, we’ve no support package, there’s just nothing … at the minute we’re just in the black hole

	of nowhere … everybody seems to be discharging her' (p345). Families reported getting much less support than they did with children's services. Some of those interviewed reported finding that there were no services to support their child's complex conditions. The study looks at hospices as a possible base during transition and could be seen as a place of stability and continuity. In hospice transition, young people were moved from the children's hospice to the adult building. Some of the young people spoken to about this transition said that they appreciated having more autonomy and independence as they could take a lead role in their visits and care. 'It's really good, they give you a lot of respect and privacy. It's more about what you want than just getting it done' (p346). 'As they're doing it [providing care] they'll ask you if they're doing it right and stuff. Like they're always, they always go the extra way to make sure that you feel comfortable of how they're doing it …' (p346). Young people appreciated the 'parent-free' nature of the adult hospice. They felt that they could be in charge of their own care planning which was good for self-esteem. 'They always go do you want to do your care plan or does your mum or do you both? … It's good how they do that though like you get the choice … I think it makes you feel, don't know, it makes you feel good about yourself I suppose. Because they're just treating you how they treat everyone … with respect' (p346). Parent interviewees were also happy about the way their children were being treated in adults' service and the way their children were given more control over their care and treated like adults. Some parents were anxious about the 'parent-free' nature of the adult hospice, worrying about their children being alone. Some parents said that they had access to less support for themselves than in children's services and were worried that they would have less access to respite services and family breaks, etc.

	There were also concerned about access when the child was coming to the end of their life. One parents said that they did not know what the plans were for end of life care and had not been informed. Changing needs. The study looked at young people changing needs as they entered adults' services. These included emotional support and promoting independence and autonomy. Emotional support. Some of the young people interviewed said that they needed to discuss things like issues with their families and relationships. Specifically for this group, they wanted to discuss death and the life-limiting nature of their conditions. Things that they struggled to discuss with their families. Young people felt that the support they received at the hospice was very important for emotional support. Promoting independence and autonomy. Young people wanted to gain information about the services available to them. 'I didn't know who to talk to or where to get the information' (p347).

Lee Y, Wehmeyer ML, Palmer S, et al. (2011) The effect of student-directed transition planning with a computer-based reading support program on the self-determination of students with disabilities (+/+)

Intervention/aims	**Findings**
Whose Future is it Anyway? This is an organised and planned transition approach which aims to teach students about participating in their own	**Effectiveness** Self-determination: measured on the Arc Self-determination Scale and AIR Self-determination Scale. The authors state that when combining all measures of self-determination, the Rocket Reader impacted positively on self-determination. The

transition. The scheme contains 6 areas, which are covered across 36 sessions: 1) self-awareness and disability awareness, 2) decision-making about transition-related outcomes, 3) identifying and securing community resources to support transition services, 4) writing and evaluating goals and objectives, 5) communicating effectively in small groups, 6) developing skills to become an effective team member, leader or self-advocate. This study only implemented 10 sessions which covered self-awareness and disability awareness, communication, decision-making and team membership. Both groups in this study received this short version of Whose Future is it Anyway? In addition, the intervention group received Rocket Reader, a computer software program for students with disabilities. The Rocket Reader changes text into audio format.	authors did analyse the effect on individual variables (specific components of the overall outcome: autonomy, self-regulation, psychological empowerment, self-realisation) and they only present findings on 'self-regulation' for which they adjusted by covariates (reading level, IQ group and previous experience of technology are mentioned), and they found a statistically significant (p<0.1) effect in favour of the intervention group (person-centred planning with computer-based reading programme), F(1,163)=12.47. Self-efficacy: measured on a 20-item questionnaire by Wehmeyer and Lawrence (1995). No statistically significant differences were found between the 2 groups, both of which improved over time on the outcome 'Understanding the transition planning meeting'. The authors state that the improvement on this was statistically significantly more for the computer-based reading program group than the comparison group, but they did not adjust for between group differences and no overall effect size is given. The authors conclude, based on pre- and post-tests that all students benefited from the intervention. They further argue that the study shows enhanced improvement on self-determination, specifically self-regulation, from the computer-based reading programme.

Lewis S, Noyes J (2013) Effective process or dangerous precipice: qualitative comparative embedded case study with young people with epilepsy and their parents during transition from children's to adults' (+, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**

‘The aim of this qualitative comparative embedded case study was to explore the views of young people with epilepsy (and their parents) about their experience of communication, information and knowledge exchange in two epilepsy services’ (p3).	**Views and experiences** The reporting of which results were taken from a document audit and which were from interviews is unclear. It appears that findings are arranged into the following 7 themes: clarity, communication barriers, continuity of information, disengaging from healthcare, ongoing engagement with healthcare professionals and services, shutting down communication with parents, negative impact of stigma enacted by peers. The study isolates what ‘works’, for whom and in what context for its population. Clarity. Young people in both case 1 and 2 wanted clarity from professionals. They did not appreciate medical jargon and wanted to have all the information about their condition. Some felt that information was being kept from them. This lack of clarity caused anxiety and confusion. ‘They just didn’t want to scare me, but I got more scared because I kept thinking why; and I would have just rather know so I could have dealt with it … because none of my family knew anything at the time so I had no one then that I could talk to’ (p11). Young people appreciated having all the information as they became agents of their own care in adults’ services. Some young people though that they would grow out of their epilepsy and were not always well informed when this was not going to be the case. ‘They said that I could stop taking my tablet in 2 years, or if I wanted to stop them, but if I had a fit then I’d need to take them for another 2 years, I had come to terms with that’ (p12). Families felt that they needed to understand the changed in the young person’s epilepsy as they moved into adult care. They felt that they were often excluded from taking part in clinical visits or did not understand the language used by the professionals. ‘I have never had it explained to me, just that she has epilepsy. I don’t even know

	what type she has now. I didn't realise that there were so many types' (p14). Communication barriers. This theme related to issues around young people working with professionals in adult care. Some young people did not know what questions to ask and find out what they needed to know to manage their epilepsy. Some young people still relied on their parents to communicate. 'When they [parents] come out with the stuff you think of it and they [healthcare professionals], when they tell you, you just understand it a bit more' (p15). Other young people did not ask questions because they were afraid of their symptoms. It [epilepsy] just made me feel depressed really, it was all I could ever think about' (p15). Parents were also afraid to ask some questions about the severity of their child's condition and the possibly life-threatening symptoms. Continuity of information. Some young people were given different information at different stages in their transition and this was found to be detrimental. Having the same information repeated was found to help young people remember details about their conditions. 'I need something told to me three times before I take it in … perhaps be told something and then read it, go through it, you know' (p16). Young people appreciated person-centred communication style with healthcare professionals. Some of those in Case 2 felt that they had learned more about their conditions and were more motivated to self-manage. Some young people learned about seizure triggers and made links between their lifestyle choices and their condition. Some young people wanted verbal and written information in different formats; this allowed them to learn about their condition without having to have repeated discussions.

	It was found that poorly communicated information led to young people leading restricted lives as they did not know how to self-manage. Parents who were ill informed tended to be over-protective. ‘I think my mum keeps me at home more … I am only allowed to go to college, and that’s only if I get a lift off my friend. She wouldn’t say you’re not going but she would be worried to death … she texts me every hour, she won’t let me go to the shop or anywhere on my own’ (p17). Disengaging from healthcare. Some young people disengaged from healthcare services. This was linked to their first impressions of adults’ services and professionals. This disengagement was felt to be due to poor communication with young people by professionals; the use of medical jargon was particularly problematic. Another issue was the change in culture from children’s services. Appointments were not as frequent and clinicians had less time to invest in individual cases. This led to young people feeling abandoned. ‘I’ve only seen him the once when I was transferred to him, but our opinion of him is so low because he has gone so long without contacting us. That doctor I had before, he was really good and now I’ve been handed over to this one and he seems like he is doing it because it is a job, but the other doctor cared about the patient … He wouldn’t just tell you what you wanted to hear to get you out of the room’ (p17). Ongoing engagement with healthcare professionals and services. Young people who remained engaged did so because of continuity of care and a good rapport with staff and services. Those in Case 2 were supported by a multidisciplinary team. These young people were more confident in communicating with professionals about their condition. But most were apprehensive about the move across. ‘I felt a bit shy at first moving … because I have been with that doctor for years

	and I was used to him, moving on was a bit scary' (p18). It was found to be beneficial for young people to meet with the same professional at regular stages and to have a discussion with them. They developed a good rapport with staff. Parents also appreciated developing a relationship with one doctor. Some of the young people liked to have their parents accompany them to help clarify things. '… I was able to ask questions and get answers to them, was able to bring my mum because I felt she needed to be there so she can understand exactly what needed to be known as well' (p18). Shutting down communication with parents. This occurred when young people took ownership of their condition and did not want parents to remain involved. Some young people took control of their medication and did not discuss their epilepsy with the parents at all. For some they only discussed it after a seizure or at the transition clinic. This was not always negative, but some young people felt that they could not discuss their epilepsy for personal reasons. 'They talk to me about it [epilepsy] but I don't talk to them' (p19). Negative impact of stigma enacted by peers. Some young people felt stigmatised by other people because of their epilepsy. This happened at school and at work. The study found that positive engagement with services and efforts to manage their conditions helped people to take control of their condition and that they were being seen as young people not just young people with epilepsy.

Mackie AS, Islam S, Magill Evans J et al. (2014) Healthcare transition for youth with heart disease: a clinical trial (+/+)

Intervention/aims	Findings
An hour-long nurse-led intervention. The intervention was one on one and designed to inform patients about their condition and treatment. **Study aim** To evaluate an educational intervention to improve transition behaviours and knowledge for young people with cardiac disease.	**Effectiveness** At 6 months after the intervention: the mean self-management TRAQ score was 0.47 in the intervention group than in the comparison group (95% CI 0.00 - 0.93, p=0.048). This indicates a borderline statistical significance in favour of the intervention. The mean self-advocacy TRAQ score was 0.21 higher in the intervention group than in the comparison group (95% CI -0.09 - 0.51, p=0.18). This result was not statistically significant. The mean MyHeart score (knowledge of condition) was 10% higher in the intervention than in the comparison group (95% CI 1.6 - 18.0, p=0.019). While this is a statistically significant finding, it is worth noting that the confidence interval was very wide.

Marriott A, Townsley R, Ward L, et al. (20029) Access to independent advocacy: an evidence review (+/++)

Intervention/aims	Findings
Independent advocacy, defined as a partnership between a person who is feeling vulnerable or isolated and a member of the community, where this member of the community provides support, information and representation to this person. This	**Effectiveness** This review did not find strong evaluations to support independent advocacy as an intervention. The evidence they found was largely descriptive or small scale, which meant it could address questions on how independent advocacy can work, and how people view it. This review found some evidence which indicated that independent advocacy might

means that if the person wants, the advocate can act on their behalf in certain situations. The overall aim of the partnership is to encourage the person to express their needs and wishes. **Study aim** This is a review which aimed to look at the extent and nature of the evidence on independent advocacy for disabled people who are at risk of losing their choice and control in 4 situations, 1 of which included transition from children's to adults' services.	help with young disabled people's self-development in terms of self-esteem and confidence, for example. The review found evidence from 1 study that available options for adulthood can be more important than adequate planning. This meant that poor planning did not necessarily lead to poor outcomes if there were good options for young people to move on to, in terms of employment, housing and education. Similarly, good planning could lead to poor outcomes if options were not available. Some studies indicated that advocacy can lead to more involvement of young people in the transition planning process. The review found 2 studies which found an impact from independent advocacy on employment outcomes for young people with disabilities, an outcome which young people themselves have emphasised as being important from transition. Factors that appear to be important in an effective advocacy partnership are: a good relationship built over time; the advocate having credibility and seen as trustworthy by other agencies; a clearly defined advocacy role, related to a set of competencies.

Mills J, Cutajar P, Jones J, et al. (2013) Ensuring the successful transition of adolescents to adult services (+, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
This article discusses the outcomes of transition to adults' services of children and young people with chronic illnesses or disabilities referred to the Department of Learning Disabilities at Nottinghamshire Healthcare NHS	**Barriers and facilitators** **Factors that help** • When young people are referred to adults' services, mental health agencies already involved with their care are more likely to follow the agreed protocol, complete referral letters and face less problems during transitions.

Trust, which covers a population of about 578,000. It aims to collect information on: the age of each client at referral; the age of each client at transition; the specialty of each referring organisation; information communicated in the referral; whether each of the service users had a named care coordinator; any problems that arose during referral.	• Most referrals were supported by adequate referral information. Incomplete referrals also tended to give insufficient information about the reasons young people should be referred, and included goals for support with specific problems, such as deteriorating behaviour. • The level of services received by young people was communicated to carers in 16 of the 20 cases audited. The introduction of standard transition forms that include relevant medical histories in the records of young people approaching their 16th birthdays to ensure well-timed preparation for transition could improve this situation. • The department had issued clearly written care plans to the caregivers of 17 of the 20 adolescents who had been referred. • Care coordinators were named in the records of 7 of the 20 clients referred. The auditors found that 3 community learning disability teams (CLDTs) had been involved in the 17 successful transfers. **Factors that hinder** • Community paediatricians were inclined to hold cases for longer, referring only those young people who were about to leave, or had left, education. GPs also tended to refer later – perhaps reflecting a lack of familiarity with referral guidelines – and often referred to general adult mental health services instead of the adult learning disabilities service. • Referral practices within organisations may have been inconsistent because of different working practices and levels of understanding of referrers about the process involved during transitions. • When young people were referred to adult learning disability services, it was unclear which health professional was the lead person for their care.

Milner C (2008) Experiences of health transition for young people with learning difficulties and complex health needs in Northumberland (+, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
‘The objective of this audit was to investigate and collate experiences of the transition from children’s to adults’ health services, for young people in Northumberland who have both learning difficulties and complex health needs and for their families and/or carers’ (p5).	**Views and experiences** The study points out that most of the views found here are reported by parents and carers and less from young people themselves. Findings are arranged under the following headings: general experiences of health services, four key findings: 1. There was positive feedback about health services. 2. Personal relationships between professionals and patients was very important. ‘The good ones talked to our daughter and allowed her to express her opinions; built up a relationship with her’ (p21). 3. The study found that keeping services turning over and keeping things moving was valued. ‘We have just got a new occupational therapist who is brilliant and is getting a dual purpose sling and a new bed for my son, which he’s needed for a long time. She’s suggested one or two things that will be a big help’ (p22). 4. Leaving the area created complications and gaps in service provision. Key points: 1. There is not enough information about transition: ‘There was no real information provided about the transition. It was just a case of that’s it, this is your last appointment, and you’re being transferred. We were transferred to a consultant at the Freeman and had to go along not knowing what to expect – so felt a little bit in the dark’ (p50). ‘Personally I think it’s really badly done. You have all these people who are involved before he’s 18 and when he turns 18, you’re told that he’ll be going into adult services and that such and such will be getting in touch with you; and now my son’s turned 19 and I’m still waiting. Not that we’ve needed them yet; but if I’d had to, I’d have had to ring around to find out where to get in touch with people’ (p50). 2. Transition can be abrupt: ‘The service just switched off’ (p51). ‘There was really no preparation for any of the changes’ (p51). ‘Before you turn 18, there’s help in abundance – I had doctors coming out of my ears!

You turn 18 and you drop off the face of the earth and there’s nothing there for you’ (p51).

3. Professionals do not conduct a handover: ‘There’s no automatic transition – I have to get the referral. I wasn’t advised of that. I vaguely assumed that the information would be transferred’ (p52).
   ‘For example for her orthopaedic shoes, I phoned her old school to talk to the physiotherapists there to ask what happened as regards getting shoes for my daughter now. They came back and explained that I needed to get a referral from the local GP to access the orthotics department at Hexham’ (p52).
   ‘I’m surprised that there was apparently no contact between the physiotherapy services before and after she left school’ (p52).
4. For those in residential college, transition is part of moving on: ‘The transition was all part of the wider change happening at 18 – and any anxiety was really all around the change of care, rather than the change of health services’ (p53).
   ‘It isn’t clear if she’s still getting physiotherapy or not. The school physiotherapist wanted to know who to pass my daughter’s file on to – and indicated that she still needed physiotherapy. But I don’t know if she’s getting it or not, because she’s not based at home’ (p53).

Improving the transition process: the audit supported the formulation of 7 possible ways to improve the transition process.

1. A period of overlapping services can help prepare for transition. ‘From our son’s point of view, what’s always most important is his relationship with the people involved: so that, for him, what’s important is a that there’s a transfer between the personnel, that’s gradual or overlapping, so that he’s familiar with who he’s going to see and, from their point of view, they build up some sort of an idea of his health needs and what he can say and what’s left unsaid’ (p55).
   ‘I like the idea of some joint appointments with both children’s and adult specialists, where our daughter could see she was being handed over – with some explanation of where things are’ (p58).
2. Specialised workers to support people with learning difficulties may be established: ‘There could be someone in a GP practice whose speciality was learning disability –

	like we have a moles and skin specialist and an eyesight specialist in our practice' (p55). 'Set up learning disability "special interest" roles in GP practices, so that one member of the practice can be trained to deal with the specific difficulties presented by learning disabled patients' (p59). 'The best thing is to get a GP (and a dentist) who can cope with someone with special needs' (p59). 3. A regular health check. Especially for learning difficulties patients to monitor long-term conditions and emerging issues: 'If there had been massive progress in the treatment of, for example, his vision, we would never know about it because his GP wouldn't know about it and he never sees a specialist and there's no health check' (p56). 'The 6 monthly check-up would be a good idea – particularly for people not living at home where a parent is keeping an eye on them' (p60). 4. Improved information around transitions. 'The ideal would be to be told which services are no longer available but which are replacements have been arranged – and here's your next appointment time. Or at least to be told we are no longer responsible and you will have to do such and such' (p56). 'Information provided a few years before the transition would be more reassuring for parents, to see what was coming ahead. It would be brilliant for people to automatically be on mailing lists to get such information' (p61). 5. Improved information transfer between services: 'I would want to be told who was going to be responsible and that the information would be transferred to the relevant department' (p56). 'Information provided a few years before the transition would be more reassuring for parents, to see what was coming ahead. It would be brilliant for people to automatically be on mailing lists to get such information' (p63). 6. Flexibility about when the transition takes places: 'It would be better to transfer some vulnerable people into adult services at a later date. Anyone with learning disabilities can be vulnerable. It's very much down to the individual concerned (p57). 'Introducing some flexibility would be sensible because, for example, if someone was going through a long period of treatment, it would be crazy if the transition were

	forced through in the middle of that period of treatment. It’s a question of looking at the individual circumstances’ (p64). 7. A planning meeting to introduce the transition plan and bring together key individuals: ‘I would have felt more comfortable if there had been such a planning meeting before my daughter had moved on – things would have been clearer’ (p56). ‘I don’t think that having a transition planning meeting would have benefited us because we were just transferring from one consultant to another of the same type’ (p64).

Mitchell F (2012) Self-directed support and disabled young people in transition (part 2) (+, relevance to this guideline: somewhat relevant)

Intervention/aims	**Findings**
A pilot project in a Scottish local authority which used a programme of self-directed support for disabled young people in transition. **Study aim** ‘This paper aims to describe the implementation of self-directed	**Barriers and facilitators** The study uses a realistic evaluation approach to try and isolate the ‘contexts and mechanisms that are most likely to lead to positive outcomes from the local implementation of a national policy within the complex organisational dynamics characterised by multi-agency initiatives’ (p229). The consensus from the focus group was that self-directed support had the potential to

support (SDS) in transitions for disabled children and young people moving from children's to adults' services; it also seeks to describe the use of realistic evaluation as an approach to evaluation of this particular policy implementation' (p223).	increase outcomes, choice and control for children with disabilities. The study reports concerns from adults and practitioners about the quality of care and possible misuse of funds. SDS could allow some service users to misuse public funds. 'There is also an issue about reduced quality of care being provided by unregulated personal assistants' (social worker) (p226). 'We could be expected to jump through even more hoops than now to justify what we need' (parent) (p226). In-depth interviews with senior managers suggested that the pilot might improve outcomes, choice and flexibility. But there were also concerns that staff might be unaware about what services were available and as a result staff may just fall back on offered traditional services. Another concern was that parents would have to bear the burden of managing the personalised budget and also of becoming the manager of the care package. Managers worried that packages might become more expensive and the quality of services would not be guaranteed. Managers also suggested that conflicts could develop between the young person receiving services and their parents. 'There could be possible tensions between service users and their family's expectations. Time might not be filled up but there could be a more appropriate use of time. This could disrupt the family routine' (p226). The managers were more positive about the potential for SDS to encourage integrated working and to build networks between professionals involved in transition. The study isolates the following factors from the study as contextual factors which might improve outcomes from SDS. These factors are specific to Ayrshire, the pilot site: – an organisational focus on process and procedures – robust partnership working arrangements around transitions

	– senior manager’s control funding for care packages – professionals regard themselves as ‘experts’ in assessing needs – professionals hold the knowledge of available social care services – professionals’ concerns around potential misuse of public funds – professionals’ concerns about the quality of care provided by unregistered personal assistants. – Professionals were concerned about SDS and they regard themselves as “experts” in assessing needs and they hold the knowledge of available social care services. – Professionals were concerned about potential misuse of public funds and the quality of care provided by unregistered personal assistants. – SDS could encourage integrated working and to build networks between professionals involved in transition. Parents’ concerns regarding the possibility of increased bureaucracy: – parents’ concerns about increased rationing of resources – parents are regarded as legitimate voices for the views of young people – parents were concerned regarding the possibility of increased bureaucracy.

Montano C, Young J (2012) Discontinuity in the transition from paediatric to adult health care for patients with attention-deficit/hyperactivity disorder (-/-)

Intervention/aims	**Findings**
Study aim To evaluate, from the perspective of healthcare providers, the barriers to continuity of care for young people with attention-deficit/hyperactivity disorder (ADHD) when they transition from children’s to adults’ services.	**Barriers and facilitators** **Factors that hinder** Barriers to continuity of care during the transition into adult services. - Clinician’s knowledge and ability to prescribe medication: many adult mental health clinicians do not know how to treat ADHD. The responsibility of care for adults with ADHD will be transferred to primary care providers, and here too is a lack of expertise on how to

	treat the condition. - A lack of adequate planning and preparation for transition. - A lack of resources: this refers mainly to physicians' lack of knowledge of how to identify and treat ADHD. - Lack of awareness in other institutions serving young adults, e.g. offending institutions. - Lack of transition planning: planning not happening at all, or happening very close to the transfer. - Patient/family resistance: young people not transitioning because of desire to discontinue medication. **Factors that help** - The use of expert nurses might help with this.

Munro E, Lushey C, National Care Advisory Service, et al. (2012) Evaluation of the Staying Put: 18 + Family Placement Programme: final report (++/++)

Intervention/aims	Findings
Study aim The aim of the evaluation was to assess the effectiveness and impact of the Staying Put pilots in meeting the objectives below and promoting positive outcomes for young people making the transition from care to independence. The key objectives of	**Effectiveness** Staying Put models of delivery. 1. Eight authorities adopted a 'pure familial' model for staying put, where young people stay with their former foster carer, with whom they have an established relationship, post-18. This model aims to replicate the experiences of young people in the general population. 2. Three authorities adopted a 'hybrid' model. This maximises the chance for young people

the pilot are to: a) enable young people to build on and nurture their attachments to their foster carers, so that they can move to independence at their own pace and be supported to make the transition to adulthood in a more gradual way, just like other young people who can rely on their own families for this support; b) provide the stability and support necessary for young people to achieve in education, training and employment; and c) give weight to young people's views about the timing of moves to greater independence from their final care placement.	to stay put by removing the precondition that young people must have an established relationship with their carer prior to the age of 18 to be entitled to stay put. 3. Pilot authorities opted not to include young people with disabilities who were eligible for adults' services within the pilot to avoid duplicating existing provision. However, the majority offered staying put placements to young people with disabilities who were below the threshold for adults' services. This was identified as being important to address a perceived gap in existing provision for this group. 4. Most of the in-depth (phase 2) authorities (4 out of 6) required young people to be in (or actively demonstrating a commitment to being in) employment, education and training (EET) to be permitted to stay put. Some young people saw this as discriminatory as it excluded some of the most vulnerable young people from benefiting from an ongoing placement. **Staying put or leaving care? Factors influencing the decision-making process** 1. The majority of foster carers were willing to offer staying put placements, primarily because they viewed young people as 'part of the family'. This was also a key factor influencing young people's decisions to stay put. 2. Thirty-one out of 36 foster carers were willing to extend placements for the young people in their care; 23 of these young people took up this offer. 3. The most common reason young people gave for not wanting to stay put was poor quality relationships with their carers or others in the placement. Those who did not stay put tended to experience multiple accommodation changes. 4. Five foster carers made the decision not to offer young people the opportunity to stay put, for reasons including young people's behaviour and concerns about the young people's ability to develop independent living skills if they stayed put. **Staying put: contributing to providing young people with a secure base and nurturing attachments** 1. Many foster families offer a secure and nurturing home environment. 2. The majority of young people (15 out of 18; 83%) judged to have a strong and secure

	base within their current foster placement opted to stay put. 3. The majority (16 out of 19; 84%1) of young people who stayed put were close to their foster carers and would seek advice and support from them. Ten young people said that they were not close to their foster carers and only 3 of these stayed put. 4. Most young people were positive about their leaving care, personal advisers and the support they received (27 out of 32; 84%), but those who stayed put were slightly more positive (19 out of 21; 90%) than those who did not (8 out of 11; 73%). 5. After young people made the transition to independent living arrangements their support networks diminished; over half (10 out of 18; 56%2) of care leavers revealed that they had a network of just 3 people who they could turn to for support and advice. **Experiences and impact of staying put** Benefits of the programme included: 1. Empowering young people and giving them greater control over the timing of their transition from care to independence. 2. Young people not being judged because of their care status, with choice to experience transitions more like the experiences of their peers in the general population. 3. Allowing young people to remain in a nurturing family situation where they can grow and develop, prepare for independence and receive ongoing support;. 4. Providing continuity and stability to facilitate engagement in EET. **Pathways to independence** 1. Most young people (24; 75%) did not feel that the pathway planning process had helped them with preparation and planning for independence. Individuals said the bureaucratic hurdles were seen to benefit the organisation rather than the young people concerned (Edwards 2011; Munro et al. 2011).

Munro E, Lushey C, Ward H, et al. (2011) Evaluation of the Right2BCared4 pilots: final report (-/+)

Intervention/aims	**Findings**

Right2BCared4 was an intervention piloted at local authorities to improve outcomes for young people preparing to exit the care system. The interventions varied from one authority to the next they were based on the following principles: young people should not be expected to leave care until they reach 18 years old; they should have a greater say in the decision-making process preceding their exit from care; and they should be properly prepared for living independently (p11). **Study aim** The evaluation aims to ‘assess the extent to which the Right2BCared4 pilots help care leaver achieve better outcomes’ (p11).	**Barriers and facilitators** **Factors that hinder** - If young people struggle to live by themselves, in practice it is logistically difficult to place people back in foster care due to a shortage of places. - Pathway plans not including a comprehensive assessment of all transition needs, and lack of updating of plans when circumstances change. - The interview data suggests that the service offered by independent reviewing officers (IROs) differed between authorities and sometimes young people were unsure of their role. **Factors that help** - Young people felt that the option to remain in care until they were 18 and the option to return was a safety net for them. ‘Four fifths of survey respondents said that they thought young people should be permitted to return to care if living independently did not work out’ (p16). - Many young people said they want additional review meetings when their circumstances change (62% of the sample). - IROs – high satisfaction with the support offered by IROs, 52 out of 82 young people in pilot authorities rated the support offered as ‘very good’ or ‘good’; 17 said it was ‘OK’. - Some young people said it was beneficial to meet their IRO before their review. The majority of young people who received support from an advocate rated this highly. **Views and experiences** The outcomes discussed in the evaluation of relevance to this study are around transition readiness, in terms of being allowed to remain in care longer before living independently, experience of care, how involved they were in planning and how good they felt the process was, and quality of life – how highly young people rated their wellbeing shortly after the intervention. Transition readiness. Young people felt that the option to remain in care until they were 18

	and the option to return were a safety net for them. But it was also found that in practice it is logistically difficult to place people back in foster care due to a shortage of places. 'Four fifths of survey respondents said that they thought young people should be permitted to return to care if living independently did not work out' (p16). 'Thirty one percent of care leavers in the pilot authorities stated that they had considered returning to care after they had left compared to one from the control groups' (p16). Experience of Care. The study analysed case records and pathway plans for young people in transition. It was found that these records had limited information on the young people's needs in relation to identity, environmental factors and their relationship with family and the support they were receiving from different places. There was limited information on clients' health needs. Only 22% of plans (6) provided comprehensive data on young people's health needs. Young people's involvement. Many respondents said that they were only 'a little involved' in the development of their pathway plan in the comparator authorities (15% (16) in pilot authorities and 5% (2) in comparator authorities). Young people valued having a plan that detailed approached to changes in circumstance, goal-setting and which service was available. The study found that some plans were not updated promptly or regularly and so they risked becoming irrelevant; 71% of young people reported that they were encouraged to express their wishes and feelings at review meetings and 53% felt they were always listened to. Some 62% of the sample said that they wanted additional review meetings when things changed in their lives. IROs. There was high satisfaction with the support offered by IROs. Fifty-two out of 82 young people in pilot authorities rated the support offered as 'very good' or 'good'. Seventeen said it was 'OK'. The interview data suggests that the service offered by IROs differed between authorities and sometimes young people were unsure of their role. Young people commented that the IRO gave them an opportunity to discuss their foster care with an independent person. The majority of young people who received support from an advocate rated this highly. Quality of life. On the whole young people rated their health, emotional wellbeing and confidence highly. Among those that had health complaints, the most common issue,

	affecting a quarter (25%, 6 out of 24), was depression.

Nakhla M, Daneman D, To T, et al. (2009) Transition to adult care for youths with diabetes mellitus: findings from a universal health care system (-/++)

Intervention/aims	**Findings**
The researchers surveyed the type of transfer coordination provided within 34 diabetes centres. They categorised the types of transfer arrangement by whether the young people would continue contact with either allied healthcare team or physician after transfer, theorising that continued contact with at least 1 of these or both would promote continuity of care. Three centres provided a combination of transfer arrangements that the	**Effectiveness** The researchers found an increase by nearly two cases (7.6–9.5) per 100 patient years after transition. This was found after the omission of outliers, which mainly consisted of young people in the lowest income quintiles (39% vs 4% from the highest quintile). The outliers did not differ from the main sample on any other baseline characteristics. However, increased diabetes mellitus-related hospitalisations were associated with female gender, previous diabetes mellitus-related hospitalisations, and living in areas with low supply of physicians. When controlling for these factors, having no change of physician was found to associate with lower rates of hospitalisations: ‘... individuals who were transferred to a new physician were 4 times (RR: 4.39 95%CI 1.62-14.4) … more likely to be hospitalized after transition

researchers theorised would be conducive to continuity of care during transition: a) change of physician only, so staying with the paediatric healthcare team; b) no change of team; c) staying with the paediatric physician but changing the allied healthcare team. **Comparison intervention** The comparisons consisted of young people who experienced transfer to adult care as a) a change in physician and allied healthcare team, or b) a change in physician and with no follow-up care from an allied healthcare team.	than were those who remained with the same physician' p e1138). Eye care examinations did not seem to be negatively impacted upon by the transition.

Nesmith A, Christophersen K (2014) Smoothing the transition to adulthood: creating ongoing supportive relationships among foster youth (+/+)

Intervention/aims	**Findings**
The CORE intervention was developed to focus on young people's own resources in the transition into adulthood. It provides training to young people, foster carers and social workers in order to enhance young people's ability to establish relationships with other people and drawing on them for support. The	**Effectiveness** Young people receiving the CORE intervention appeared slightly more satisfied with their care than those receiving foster care as usual (independent living skills training). This appeared to also be the case in terms of the changed review meetings. Young people's relationship competencies decreased in the comparison group while remaining the same in the intervention group. There was little difference between the groups in terms of their motivation for developing relationships with supportive adults, neither changing much from pre- to post-test.

emphasis in this training was that adulthood is interdependence rather than independence. In addition, the intervention involves young people in the running of the programme: as educators, coaches and as chairs of their own planning meetings. In addition, foster carers and young people received training on trauma, and how this impacts on behaviour and mental health. Again, young people were invited to be involved as trainers on further trauma workshops for new young people coming through. **Study aim** To assess the effectiveness of the CORE foster care model, designed to support young people in foster care into adulthood.	The groups did not differ much at pre- and post-test in terms of relationship-building skills. In terms of current support at pre- and post-test, there appeared to be some difference over time in favour of the intervention group. So young people in the intervention group were more likely to feel loved by at least 1 person, and also more likely to feel accepted by an adult. When identifying supportive adults, the CORE intervention group identified more relationships as more important than those in the intervention group. Overall there were no differences between the groups in terms of the identification of their most important supportive adult, although some marginal differences in favour of the intervention group on the future and long-term aspect of this relationship. Young people in the CORE intervention group were more likely to feel prepared for moving out of care than those in the comparison group.

Newman G, Collyer S, Foulis M, et al. (2009) A multi-agency consultation project with young people with support needs at the transition between children's and adults' services (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
This study explored the transition experiences of 49 young people with various support needs as they moved from	**Views and experiences** The findings are grouped as follows: Outcomes. The young person's confidence and ability to express needs and make decisions, as well as understand additional support needs, has a bearing on how successful he or she is in attaining them. For some young people, additional support needs (especially those with complex needs) severely

secondary school to adults' services.	restricted choices in terms of training, employment or social opportunities after children's services. Young people who left school without a plan in place were left housebound for a period, despite being well known to services. Young people felt work experience was very significant for confidence-building but opportunities were few. They also expressed a lack of practice and experience in learning life skills, especially managing money. Social opportunities can drop off after children's services for those with more complex needs, exacerbated by lack of transport and access to funding. Young people had experience of involvement in different types of planning meetings and usually preferred to be in control of their own planning. Person-centred planning meetings were preferred by those with previous experience of these meetings. Information. Information or support through the transitions process was lacking for some young people, including that available in higher and further education to those with particular needs (such as signing for someone with hearing impairment). Some young people had no access at home to the phone or a computer. Parents were sometimes unaware of changes in benefits at transition or other changes such as the need to return medical equipment or apply for legal guardianship. Some young people felt they would benefit from guidance to navigate whatever information was available. Getting the right support. Some young people felt they had no control over decisions about their future. For those with more profound disability, choices seemed lacking. Some young people with a complex care package were unable to access appropriate services because of a lack of funding, hampered further by the failure of adult social workers to attend future needs meetings early enough. Appropriate respite was also lacking for some young people and their families. One young person on direct payments and independent living fund seemed to have the best package of support, but only with intensive support from his parents. Transition through health services. Anxiety for young people and families was caused where medical equipment (e.g. made to measure gait trainer, ear thermometer) had to be returned to children's services after a transition and reapplied for in adults' services. Similar anxiety was caused for 1 young person with

	a physical disability whose regular physio, equipment and support were stopped as he transitioned to adults' services.

Noyes D, et al. (2004) Changing systems for transition: students, families, and professionals working together (-, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
The Point of Transition Service Integration Project (POTSIP), providing early intervention, shared funding and regular interagency committee meetings to increase service integration during transition.	**Multiple services** The collated case studies represented different problems in relation to transition. One young person (Frank) had a smooth transition to adult life, according to Frank himself and all other stakeholders. One young person's transition (Victor) was deemed successful by agency workers due to him holding down a job and being paid above the minimum wage. However, Frank's long-term goals of further education, an enjoyable job and learning to drive were not addressed, and were dropped by agencies failing to collaborate. This case study illustrated how a general goal of success does not always reflect real achievement and quality of life. It also showed how expectations did not fit the individual's characteristics and potentials. One young person (Sally) exceeded expectations for transition and was happy with her outcomes, as were the service personnel. Her family felt that she could have achieved more. The final young person (Emily) and her carers were happy with the outcomes of transition, but the service personnel were not. The service personnel felt that more

	could have been done to support Emily to achieve her long-term goals and further vocational training. The researchers identified themes across all interviews and observations. Positive themes about the programme included the following. The transition programme started at the beginning of the students' last year in school. This meant that when school finished, the new programme was in place and there was no gap in service provision. So in effect, the students had two overlapping programmes in the last year of school. This also prevented inappropriate referral of one student who was at risk of moving out of the community. Shared funding helped the students to participate in more activities, and early funding for employment support during the last year of school also enabled more non-work activities. Regular meetings every 3 months improved interagency collaboration. Negative themes emerging from the interviews included a lack of long-term planning and consideration of the quality of daily activities in which the young person was engaged. There was also a lack of collaboration and continuity, in spite of the regular meetings. There was a lack of wider community support and integration, such as friendships as well as education centres and community colleges for young adults with developmental disabilities. There had been logistical problems, with the portability of assistive technology and with transportation due to city boundaries. Ultimately, there was still a gap between theory of best practice and person-centred planning and practice, and no one document holding all information in regard to a young person's long-term goals and aspirations.

Paul M, Street C, Wheeler N, et al. (2014) Transition to adult services for young people with mental health needs: a systematic review (++/++)

Intervention/aims	Findings
The review aimed to look at the effectiveness of different models of transitional care. The interventions found in the included studies are various. The kind of models which emerged in the search were protocol or reciprocal agreement approach and transition programme models. **Study aim** The study aimed to 'systematically review evidence on the effectiveness of different models of CAMHS to AMHS transitional care, service user and staff perspectives and facilitators of/barriers to effective CAMHS-AMHS transition' (p1).	**Barriers and facilitators** **Factors that hinder** - Stigma associated with using mental health services. - Adult services not being young adult-friendly. - Lack of community resources to meet their health and social care needs. - Transition planning starting too close to actual transfer into adults' services: 'difficulties caused by restrictive eligibility criteria and the loss of services when a young person turned 18 years' (p11). - Lack of formal transition arrangements and agreements between CAMHS and AMHS and lack of clarity on transition procedures and different cultures and different eligibility criteria. - Service fragmentation, lack of leadership and prioritisation for the young adult group. **Factors that help** - 'helpful, responsive, wrap-around services' (p.11) **Effectiveness**

	The search did not find any papers which were RCTs, so the studies which were used for the review were of mixed quality. The findings are divided into the follow sections; 1) effectiveness of different modes of transitional care; 2) service user perspectives of the experience of transition; 3) staff perspectives; 4) facilitators and barriers to effective transition. Three US studies were found in the search which evaluated interventions (Gilmer et al. 2012; Haber et al. 2008; Styron et al. 2006). Styron et al. (2006) (no control group) evaluated a young adult service, an intervention which used a variety of elements, including clinical, residential, case management and planned movement between services. Relevant outcomes include fewer mental health problems, greater satisfaction with services, building social support systems and quality of life. The study found positive outcomes, particularly the elements of the intervention which included treatment planning. Young people experienced 'fewer symptoms, less loneliness, fewer mental health problems, higher functioning and greater satisfaction with services'. Haber et al. (2008) used a sample of 193/562 young people aged between 14–21 using 1 of 5 partnerships for youth transition services. These services were designed to offer transition support for youth with severe mental illness. It found that mental health symptoms did change positively following the intervention. Gilmer et al. (2012) evaluated an outpatient programme within AMHS which was designed for young people aged 18–24 who were going through transitions. This was compared to usage of a standard AMHS outpatient unit. It was found that young people used this service more; mean visits were 12.2% which was much higher than use of the AMHS for the other group. Inpatient admissions did not change

Pilnick A, Clegg J, Murphy E, et al. (2011) 'Just being selfish for my own sake ...': balancing the views of young adults with intellectual disabilities and their carers in transition planning (Validity +, relevance to this guideline: a bit relevant)

Intervention/aim	**Findings**

The aim is to examine how the process of transition from child to adult services in ID is managed. Using data from 8 tape-recorded meetings in which transitions were planned and discussed, the authors examine what happens when the views of the parent/carer and the young adult are in apparent conflict. Conversation analysis is used to examine how professionals manage and negotiate this conflict and how some points of view or courses of action ultimately prevail over others.	**Views and experiences** The study highlights a significant practical problem for staff. The discourse of self-determination is embedded within transitions policy in England and increasingly so in everyday practice. Strategy documents including Valuing People (2001) and the update Valuing People Now (2009) still have not recognised the fact that impaired capacity should affect this right. On a practical basis, parents/carers ultimately are central in terms of providing support and helping the young person explore options, but they also have a role in facilitating decision-making. However, the research shows that where the young person's views are in conflict with the parent, transitions staff face a huge dilemma in terms of being caught between the policy ideal of self-determination and the practical task to put in place a workable transitions package which will receive the necessary support from both parent and young person.

Pole JD, Alibhai SM, Ethier MC, et al. (2013) Adolescents with acute lymphoblastic leukaemia treated at paediatric versus adult hospitals (-/+)

Intervention/aims	**Findings**
Treatment of acute lymphoblastic leukaemia at a paediatric hospital. Comparison intervention: treatment of acute lymphoblastic leukaemia at an adult hospital.	**Effectiveness** The findings relate to 4 time periods, each of 5 years, looking at trends across these but primarily comparing those treated in an adult versus a paediatric unit. Comparing treatment across the time periods, there was a shift towards treatment of young people/young adults in a paediatric setting. Also, over time, there was an increase in survival rates across both groups. A survey of protocols found that since 2000 there had been a practice change in adult settings, where they had been implementing paediatric protocols for young people/young adults, meaning that most recently treated patients in adult settings were treated using paediatric protocols. When adjusting for co-variants (time period treated, gender and income based on neighbourhood of residence) there was no difference in

	predicted survival proportions in the paediatric group (0.65, 95%CI 0.56–0.75) compared with those treated in the adult units (0.62, 95%CI 0.52–0.74).

Por J, Goldberg B, Lennox V, et al. (2004) Transition of care: health care professionals' view. Journal of Nursing Management (+/++)

Intervention/aims	**Findings**
The purpose of this study was to explore the views and needs of healthcare professionals from one National Health Service trust regarding the transition of care for adolescents with a chronic condition from children's to adults' services and to identify possible ways to improve the current services for this particular group of young adults.	**Barriers and facilitators** **Factors that hinder** - Preparing the young person for transition – 38% of respondents said they had been involved in preparing young people for adult care services during the transition period. But some of the adult nurses felt unprepared to take over and some felt that the parents were intrusive. - Dialogue with managers – Only 17 of the 40 healthcare professionals in the sample had discussed any issues with their manager and from this group, 11 were satisfied with their discussion. - Transition readiness – only 10% of the sample believed that adolescents with chronic conditions are satisfactorily prepared for transfer to adult services. - Adolescent needs – healthcare professionals thought the needs of the adolescents on transfer to adults' services included: extra support and reassurance (n=10); confidence-building to enable them to manage their conditions more independently (n=6); information about services (n=6); trust (n=4); having their needs, fears and anxiety recognised (n=3); special facilities (e.g. relaxed environment in which to feel 'at home', n=3).

	- Carer support – healthcare professionals felt that families/carers needed extensive support (n=10) and information about adult services, including knowing who the person responsible for the care of their child will be (n=8). - Health are professional needs during transition – ongoing communication and documentation (n=8) was mentioned; education and professional development (n=5); nurses identified clinical supervision; to be supported (n=4); good handover and pathway of care (n=4); and time and patience (n=3). **Factors that help** - For adolescents – meeting with new staff (n=8) was important, followed by having a clear written plan for transfer (n=5), own specialist unit (n=4); information pack about adults' services (n=3); education (n=2); and access to a nurse specialist (n=2). - For family carers, professionals said that they needed: 'Good information as to how the transition will take place and time to ask questions' (children's nurse); 'Gradual introduction to adult services; planned visits to adults ward and specially developed information' (children's nurse); 'Family/carers should get involved in the planning right from the beginning' (adult nurse). - Healthcare professionals said they would benefit from processes and systems including a transfer plan; better communication; a set protocol; and more staff. Of note, the majority (97%) of the sample said both paediatric and adult doctors should be involved in the management of transition of care followed by children's nurses.

Powers L, Geenen S, Powers J, et al. (2012) My life: effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education (+/+)

Intervention/aims	**Findings**
The study evaluated the Take Charge intervention which is designed to enhance young people's self-determination as they prepare and go	**Effectiveness** The intervention went on for 1 year and of the 69 initial young people who enrolled in the study, 61 young people completed. 29 from the intervention group and 32 from the comparison group. The study displays 'moderate to large effect sizes' directly after the

through transition. The intervention uses coaching to help young people identify their goals and mentors them throughout their transition process.	intervention and at the 1 year follow-up and there was a marked difference between the intervention group and control group. The outcomes, which are of relevance to this topic are self-determination, identification of transition goals, quality of life and service use. Overall there was no statistically significant difference between post and follow-up measures and we have therefore focused on the findings from 1-year follow-up. The effect sizes were calculated by dividing the difference between means by the estimated standard deviation (SD). Self determination – measured on the Arc Self-determination Scale. The 2 groups differed at baseline: comparison group score was 96.78 (SD=18.94) and the intervention group score was 102.38 (SD=19.30). The authors say that therefore 'this model was interpreted'. It is not entirely clear what this means, but they do say that they considered co-variance and factored this into their estimates. The intervention group showed significantly larger affects than the comparison group at follow-up, and they quote an effect size of 1.10 (p=.0069), but no SD or confidence interval is provided. This could be calculated since they provide detailed tables of sample size, means and SDs. Identification of transition goals – measured by asking young people to describe their goals. No evidence of effect found for either group. Quality of life – measured on the Quality of Life Questionnaire. The groups were the same at baseline but different at follow up, ES=0.77 (p=0.0008). Transition planning – measured by the Transition Planning Assessment. Post-intervention the results showed effects but this was not sustained to the follow-up. Use of transition services – measured by the Outcome Survey. The results at follow-up were statistically significant, favouring the intervention group, ES=0.65 (p=.0379), so the intervention group accessed more transition services than the comparison group.

Prestidge C, Romann A, Djurdjev O, et al. (2012) Utility and cost of a renal transplant transition clinic (-/++)

Intervention/aims	**Findings**

Transition clinic including a paediatric nephrologist, renal nurse, youth health specialist, renal pharmacist, renal dietician and a social worker. The service emphasised enhancing patients’ condition knowledge and self-management skills. To this end, the team provided education in terms of disease management and understanding, medication, health advice (e.g. sexual health and substance use). Three of the team members (nurse, dietician, youth health worker) also provided support and education using email, telephone calls and text messaging. The young people would be seen at 4–6 monthly intervals until their transfer to adult care. Time of transfer was flexible and agreed with the young person, their parents and also depended on the assessment of the multidisciplinary transplant team. After transfer the young person would continue to attend a standard solid organ transplant clinic, led by a multidisciplinary transplant team. Actual transfer to adults’ services was supported by a detailed letter from the transition nephrologist, and a verbal handover by the nurse specialist, social worker and dietician. In	**Effectiveness** In the 6 years preceding the introduction of a multidisciplinary team the hospital saw a total number of deaths or graft loss in young people of 8, compared with none in the group receiving the transition support education from the new team. While the sample numbers are very small in this study, as an observational study on change in practice, the lack of graft loss or death in young people receiving support from the multidisciplinary transition team supports the continuation of this service.

addition, the team tried to refer young people to adult transplant experts which were likely to be a good match.	

Price C, Corbett S, Lewis-Barned N, et al. (2011) Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes (+, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
'The purpose of this study is to evaluate one [transition] model in diabetes, the 'Transition Pathway' [TP] via interviews with young people who have experienced it first-hand' (p852). Aims were: 1. 'To evaluate the transition pathway (TP) in diabetes using qualitative methods in order to explore the experiences and suggestions of the	**Views and experiences** The findings are organised according to themes. Six themes: 1. the TP process; 2. the experience and organisation of transfer; 3. organisation of services; 4. information and education; 5. the healthcare consultation; 6. inclusion. The TP process – the young people did not recognise the transition process as separate from usual clinical care. The multidisciplinary approach of the transition process was not seen as out of the ordinary. The experience and organisation of transfer – most of the young people spoken to did not to see transition as much of an event, bar 1 who commented that they felt apprehensive. The authors suggest that this might be that the service is in the same hospital as the children's service and with specialised professionals. Young people did say that they appreciated being able to meet the professionals from adults' services ahead of transition. 'When you move up sometimes it can be a bit daunting and that and obviously they're coming down talking to you, it was just really relaxed and that so it made you feel better about moving up to here' (p856). Organisation of services – some of the young people were interviewed in the project before the transition clinic was implemented, and as such they commented that transition seemed abrupt.

young people concerned.’ 2. ‘To understand these in the context of theory regarding the psychosocial developmental tasks of adolescence’ (p854).	‘It seems as though you’re a kid and the next day you’re an adult and that was it. There was no like in between bit …’ (p856). Information and education – young people commented that they liked being provided with information on issues like drugs and alcohol. Not just at transition time, but throughout the process. Young people did not always want to talk these issues through but they did appreciate being offered information. The healthcare consultation – the study describes this as an ‘key issue’. Many of the young people spoken to had had poor experiences in the past. ‘I was completely sick of listening … by the time I’d left there and come here. It was just the same thing every time’ (p857). Other people found their relationships with staff as they got older improved: ‘Like they were helpful and … cos I was … got slightly fed up with my weight and they were like … maybe you should do this or maybe you should do that … to help yourself so I found that helpful’ (p857). The study found that young people did not so much value being paired with 1 professional as much as they value quality and consistency in all their interactions with staff. Young people liked relationships that felt like collaborations and that they were partners in their own care. The study identified two superordinate themes: appropriate adolescent health care and recognising individuality in healthcare. ‘… it’s not as though you come in to be told what to do but you come in and talk about it and then work out yourself what you’re going to do and it’s like more, it’s better that way’ (p857). A practitioner also said this was important: ‘it’s important not to generalize, you have to get to know the patient on a personal level before you can kind of tailor the advice for them and help them out in that way’ (p857). Inclusion – some of the interviewees, particularly those with communication difficulties, said that they might need longer than other people to understand the transition process and respond to appointments. This suggests that services need to be accessible to all. Appropriate adolescent health care – the interviews showed that young people did not want to be treated as children, as well as professionals recognising that individuals gain independence and maturity at different rates.

	‘I’m like a lot more advanced than people between 14, like 12 and 14 and then like they’re a lot more advanced than people below that as well. There’s a lot of difference’ (p858). Young people said that they did not want to be spoken to like children. ‘Um like the way the people talk to you, like they talk to you in a more mature manner sort of thing and like it’s like, how can I explain it um, like, like the procedures are the same sort of thing and you could through it and but like they do it in a more adult way’ (p858). Some young people were ready to move to a new service before they were 16. ‘I think there shouldn’t be a set age where the transition phase takes place, I think it should be an open thing like it should be suggested to say someone who is diagnosed at 12, it should be suggested to them that that’s going to happen at some point and that when they’re ready to take that step, they should say and that would make them feel more in control’ (p858). Some interviewees commented that they would like to be given more independence and not have to attend long appointments as in paediatric care. An important point was that the service needed to feel appropriate for the person’s age and level of maturity. The surroundings did play into this but it was the quality of personal interactions which made the most impact. Recognizing individuality in healthcare – several of the interviewees talked about the importance of building up a relationship in order to make the service respond to their individual needs. ‘you have to get to know the patient on a personal level before you can kind of tailor the advice for them and help them out in that way’ (p858). The importance of individualised care was found in all the interviews. The young people commented that they needed to feel comfortable with professionals and feel that they were being treated like adults. Being treated like an adult appeared to encourage young people to take control of their conditions. ‘I was going to stop going altogether to appointments and I went to that one because I wasn’t too well in myself and I enjoyed going after meeting him ’cos of the way he treat us. I only had him for a few appointments but he’s so down to earth and treat us like an adult’ (p859).

Reid GI, Shaw K, Southwood T, et al. (2004) Prevalence and correlates of successful transfer from paediatric to adult health care among a cohort of young adults with complex congenital heart defects (+/++)

Intervention/aims	Findings
To find out how many young people with congenital heart defects have a successful transfer from children's to adults' services, and consider the factors that contributed to this transfer.	**Barriers and facilitators** **Factors that hinder** - Young people with substance misuse problems were more likely to not transfer successfully to adult care. **Factors that help** 47% of young adults had a 'successful transition'. Factors associated with this: living near to the adult clinic, older age at their last visit to the paediatric service and 'having a recommendation from the paediatric cardiologist for [adults' services] follow-up' (p200). - The longer young people receive paediatric services, the more 'likely paediatric cardiologists are to make recommendations for adult care and patients are to have appropriate beliefs about adult care, in turn leading to successful transfer' (p201). - Young people with multiple conditions (comorbid medial conditions) were more likely to transfer successfully.

Richards M, Vostanis P (2004) Interprofessional perspectives on transitional mental health services for young people aged 16–19 years (++, relevance to this guideline: highly relevant)

Intervention/aims	Findings
The aim of the study was to establish themes of mental health service needs for young people aged 16–19 years, as perceived by professionals from all agencies involved in their care, i.e. mental health, education, social and non-statutory agencies.	**Barriers and facilitators** **Factors that hinder** 1. Older adolescents have multifaceted needs. - Practical needs – practical and social problems such as access to housing, especially for care leavers and young offenders. Services need to adopt a holistic and flexible approach to address such issues. - Ethical issues – confidentiality was a key worry for young people. Mental health professionals may find problems engaging with key professionals such as teachers if the

	young person has not made this public. - Confiding in mental health staff about risky behaviours – older adolescents were described as acting with a low concept of risk. Young people were unwilling to let professionals know the extent of their problem, or were not keen to get help. But many practitioners recognised the wider influences such as youth culture, family background and environment, during interactions with young people. 2. Statutory mental health services are not geared towards this age group. - Under-resourced services not socially sensitive/responsive – the full-time education distinction operated by CAMHS being seen as inappropriate and invalid. There was a need to make services more culturally appropriate by employing ethnically diverse staff and providing training. - Minority within child- and adult-centred services – interviewees stated that it was difficult gearing services towards young people. Their needs and sensitivities may be poorly understood or overlooked. - Adult service not comprehensive – some respondents felt that social, emotional and family issues may not be considered with older adolescents. - Need for user-friendly and age-appropriate interventions and settings. - Accessibility to specialist services – this was seen as delayed by requiring GP referrals. Out-of-hours support, drop-in clinics, assertive outreach, mentoring and group work were lacking. - Specific groups fall between services – young people with behavioural or relationship difficulties were deemed unsuitable for admission. Social services considered this group the responsibility of health, and mental health services as a mainly social care remit. This could lead to costly and inappropriate placements. - Need for professional support and training – some children's services staff said they were not trained to deal with older adolescents. Almost all adult services professionals felt they lacked knowledge and experience to deal with older adolescents. - Reducing stigma – non-statutory services were thought to be less stigmatising and

	potentially more engaging for young people. - Accessibility to non-statutory services – these were thought to be more flexible, and made efforts to engage with non-attendees, as well as actively supporting young people in engaging with other services, particularly those that accepted self-referral. 3. Communication between services is variable. - Communication difficulties existed at policy and operational levels, across and within agencies. - Services planned separately – communication difficulties were a result of services operating under different management structures, with separate planning and development processes and limited joint discussion. - Difficulties working in an interagency context – mental health professionals said they had no environment to jointly discuss issues that may crossover into other agencies. - Need for overview of services for users and referrers – the knowledge about what other agencies provided, including the referral process to mental health services, was poor. - Need for joined-up thinking – participants said they needed interprofessional service agreements, consistent age cut-offs, clarity of referral criteria and agency roles, as well as more joint work, shared training, compatible IT networks and single client records. 4. No formal transfer arrangements from children's to adults' services. - Child and adult services are very different. - Role duplication and poor information exchange – referrers were unsure whether referrals and case notes were received. Limited access to other service case notes due to incompatible IT networks and confidentiality issues. - Practical problems with transfer process – most transitions were seen as a routine process, especially for those with severe mental illness. But respondents mentioned lack of care planning for those young people who did not engage. In most cases young people were discharged from one service and often placed on a waiting list, or had to wait for a first appointment letter.

	- Need for uniformity in service age cut-offs and coterminous transitions. - Need for protocol governing transfer arrangements – there was lack of formal structures governing the handover procedure. - Need for transitional worker or team – continuity of services and clarity about who is responsible for young people who may not fulfil the remit of either child or adult mental health services were considered vital.

Sebastian S, Jenkins H, McCartney S, et al. (2012) The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists (+/++)

Intervention/aims	**Findings**
To identify, from the perspective of health professionals, the needs of young people with inflammatory bowel disease (IBD) and barriers to their successful transition into adults' services.	**Barriers and facilitators** **Factors that hinder** Main barriers to transition were comparable across adult and paediatric groups: lack of funding; lack of time; lack of support services; too few patients; lack of training. - 79% of adult gastroenterologists thought that: young people had a suboptimal preparation for transfer; young people lacked knowledge about their condition, how to manage it and coordination of care. - Paediatric staff rated coordination of care and lack of self-advocacy as the main concerns for young people transitioning into adults' services. - Paediatric gastroenterologists rated 'transition' as more important than their adult peers, confirming that 1 factor that hinders successful transitions into adults' services is priorities within adults' services themselves. - A lack of training and inadequate resources were seen as the main barriers to transition into adult care: 'The challenging aspects identified by adult gastroenterologists in managing individual IBD patients in the transition age group included patients' psychosocial needs, patients' lack of independence and high parental expectation' (p835). - Practitioners working in teaching hospitals rated transition as of higher importance than

	their peers working in general hospitals. **Factors that help** - The majority of survey respondents ranked age as the most common criterion for initiating transition. This goes against the suggestion of a flexible and needs-led transition. However, paediatric gastroenterologists tended to say that starting the transition preparation early was conducive to a successful transition, and many rated the importance of a flexible transfer time. - Paediatricians stated that remission of disease influenced the timing of transition planning and transfer. - Paediatric gastroenterologists considered young people's 'ability to attend clinics without parents' more important to transition than did adult gastroenterologists.

Shaw K, Southwood T, McDonagh J (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey (+/++)

Intervention/aims	**Findings**
To assess the needs of young people with juvenile idiopathic arthritis according to professionals, and to examine how these needs might be addressed by a transitional care programme.	**Barriers and facilitators** **Factors that hinder** - Professionals recorded concerns about: the actual transfer (n=78, 30%); young people's self-advocacy; and parents' hindering the transition process by being overprotective or in conflict with their child (more than 20% of the respondents). - Four risk factors mentioned by more than 20% of the health professional respondents were: family/parent dynamics (n=100, 38%) related to overprotective parents; reliance on financial benefits; lack of confidence and motivation; and poor social networks. Adolescent intrapersonal characteristics (n=78, 30%), related to dependence, psychosocial maladjustment, poor social skills, lack of knowledge. Complex/severe condition (n=78, 30%) related to comorbidity, delayed puberty, significant functional disablement. Socioeconomic factors (n=55, 21%) related to low income, low literacy, living in a rural area, limited access to transport.

	- Anticipated barriers related to the provision of care during the transition period were rated by 182 of the health professional respondents and topping this list was inadequate resources (n=124, 47%). **Factors that help** - Respondents (n=263) thought that addressing the transitional needs of young people with juvenile arthritis was 'very important' (75%), or 'moderately important' (23%). A multiprofessional approach is needed, and it is essential to provide information about transition - 77% thought that an individual transition plan was 'very important'. - Over 50% said that having a transition plan in their current practice would be 'very useful' and 28% thought it would be 'moderately useful'.

Shaw K, Watanabe A, Rankin, E, et al. (2014) Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility (+/++)

Intervention/aims	**Findings**
The study looked at satisfaction among patients in a number of adult and paediatric clinics. The study also looked at which transition models had been implemented. The study requested data from lead clinicians on the transition model employed at their clinic. The study sought to identify if the clinic met national guidance for 'transition and youth friendly services which included 100 criteria relating to topics such as accessibility, health	**Adult Services** The transitional care models used in the adult hospitals surveyed is the focus of this study. Twenty clinics provided information on their approach to transition care. The most common model was a combined clinic model and 14 reported having a transition programme in place, with more adult hospitals have a programme in place. Five clinics reported that their transition programme could be described as 'holistic' in that they addressed 'medical, psychosocial and vocational issues' (p666). The study found that more adult hospitals were adhering to national guidelines on transitional care. Adult hospitals scored medians of 23.5 in meeting guideline criteria. The link between transitional model and satisfaction levels was not found to be significant. However, satisfaction levels were improved in patients who visited a clinic with a transitional care programmes in place. The findings did reach a statistically significant level in parents of young people and young people themselves who visited a clinic which was 'holistic' in nature. The same was true of

promotion, confidentiality, appropriate environments, staff training and whether transitional care provision was holistic' (p664). **Study aim** The study aimed to examine how far a paediatric and nearby adult facility have mainstreamed transitional care guidance into practice. The study wants to ascertain how far they were adhering to national guidelines, and which transnational models in clinics were most satisfactory to patients.	patients and parents of young people who attended clinics which were classed as being 'young-friendly'.

Shropshire Parent and Carer Council (2011) Transition parent consultation findings (-, relevance to guideline: somewhat relevant)

Intervention/aims	**Findings**
Study aim 'To produce a report on families' experiences of transition in Shropshire ...The aim of the project was to gain a view on transition from the perspectives of parents and carers of young people with additional needs, provide feedback on the draft transition booklet and to make	**Views and experiences** The paper found that transition is a time of uncertainly and stress. Parents and careers who took part in the study viewed the process in negative terms. Main concerns were: the system delivering choice and options and allowing young people to access holistic services, respite etc.; a lack of information to help decision-making, particularly in relation to managing health conditions; information about getting the right services and benefits. - Informants said that they wanted information about provision from local authorities and information about what happens at key stages in transition. Information should be accessible

recommendations to public sector services to improve service delivery to meet the needs of parents, carers and young people during transition' (p3).	and in a variety of clear formats. - Information about benefits is also important. - Carers were concerned about the quality of services in adult care. - A lack of communication between children's and adults' services. - Unmet needs. - Lack of a person-centred transition. - Lack of a holistic approach. - A lack of will to recognise young people's potential and increase their independence. - No acknowledgement of the additional challenges for those living rurally.

Singh S, Moli P, Islam Z, et al. (2010) Transition from CAMHS to adult mental health services (TRACK): a study of service organisation, policies, process and user and carer perspectives (++, relevance to this guideline: highly relevant)

Intervention/aims	**Findings**
'The TRACK study aimed to identify factors that facilitate or impede effective transition of patients from CAMHS to adult services, and make recommendations about the configuration and delivery of services that will promote good continuity of care' (from study abstract).	**Barriers and facilitators** **Factors that hinder** - Ideological, structural, functional and organisational differences between CAMHS and AMHS produce complex challenges for all those involved in negotiating the boundary, including service users, carers and clinicians. - Health Select Committee (2000) report: failure of services to work together; the need for care management/planning led by a single practitioner who coordinates care across all relevant agencies; shortage of inpatient services for young people; the need for early intervention and poor liaison between various agencies. - Barriers to 'optimal transition' – training of professionals involved, different perceptions of young persons, parents and providers (both CAMHS and AMHS), attitudinal discomfort of professionals involved , difficulty accessing resources, poor intra-agency coordination, difficulties addressing parental issues, adolescent and family resistance,

	lack of institutional support, lack of planning, lack of appropriate adult specialists. - Barriers for specific groups – neurodevelopmental disorders, acute issues and young people in special circumstances. Young people with learning difficulties and those with ADHD, autism and Asperger's may also find it difficult to access the services if their conditions are mild. - Issues with transitions that take place in an acute or emergency setting. Here transitions can be abrupt and professionals are new to young people and parents. - Housing and care status may complicate transition – looked-after children and people from certain minorities might experience specific health complaints or struggle to access support. - Referrals from teams which were specifically for adolescents and young people were not more likely to reach transition. But referral to an early intervention AHMS team was more likely to successfully achieve transition. - Demographics, including gender, ethnicity, age, age of diagnosis and education did not affect actual or potential referrals. But actual referrals were more likely to be looked-after children, living alone and having a history of mental health issues in the family. - Potential referrals were affected by: 'parental attendance, admission to hospital, detention under MHA, being on medication at time of transition, diagnostic categories of serious and enduring mental illness, eating disorders, substance misuse, emerging personality disorder, and significant comorbidity' (p61). - Actual referrals were likely 'to have attended CAMHS with their parents, been admitted to [a] mental health hospital, to have been detained under the Mental Health Act and to have a serious and enduring mental disorder, substance misuse, an emerging personality disorder or more than one category of presenting problem (comorbidity); they were less likely to have an eating disorder' (p60). - Serious and enduring mental illness was found to be a key factor in actual referrals. **Factors that help** - Continuity of care (either engaged with AMHS 3 months post-transition or appropriately

	discharged). - A period of parallel care (a period of joint working where the service user is involved with both CAMHS and AMHS). - At least 1 transition planning meeting (meeting discussing the transition from CAMHS to AMHS, involving the service user and/or carer and key professionals, prior to the handover of care from CAMHS to AMHS). ‘Enduring mental illness severe enough to require admission to hospital and being on medication are the factors most likely to predict making a transition to AMHS …Those with emotional/neurotic and neurodevelopmental disorders are least likely to achieve transfer to AMHS … They are the most likely group to fall through the CAMHS-AMHS gap’ (p84). **Views and experiences** Section 5.3.3 gives accounts of transition, including the more informal arrangements. One interviewee (service user G) said that he was introduced to workers in adults’ services and met them a few times; the process was not pressured. ‘Gradually just slowly, slowly I moved up to the adult services when I was ready ... I think it was a good transition’ (p138). Service user A also had a smooth transition with information being given a month before transfer. Her parents said that more information about the AMHS team would have been beneficial. The parents of service user B also said that the transition was smooth but that B was unwilling to move to AMHS. Service user D was told early on in her CAMHS service that she would be moving into AMHS. ‘I was told about the transfer and I would be meeting the new care coordinator and the transfer would happen slowly … they explained how different it would be ...’ (p138). Informant H was told about the transfer just after starting to receive services, ‘which I didn’t think was … that great because I hadn’t been seeing her for that long … she couldn’t really do much with me because I’m going to be 17 soon’ (p139). Informant H said that she did not receive much help in preparing for transition but she did meet her

	AMHS worker beforehand. The same was true of informant C, who was referred to CAMHS a few months before her 18th birthday. Informant F was unhappy with the preparation she received for her transition. She was told in her last CAMHS appointment about the transition and did not receive any information or preparation. Informant J was told at his last appointment in CAHMS and then received a letter. He said that it ‘was just all of a sudden … I didn’t really like it’ (p139). Parental involvement The study found that the level of parental involvement varied. The study found that in cases where young people did not engage with adults’ services the parents had no involvement. In other cases parents continued their previous level of involvement in AMHS. Informant F’s mother continued to go with her to appointments. In 1 case a parent had increased their involvement in AMHS due to a good relationship with her worker, but this was seen as unusual. In general parents were less involved, or not involved at all after transition. Three young people were in favour of this. ‘The adult services they don’t tell your parents or anything, everything’s confidential and it’s between you and the person so it’s much better, it’s like a lot less stress’ (p139). One young person commented that his mother had not been involved but he would have liked more support. ‘It’s difficult sometimes if you’re isolated, ’cause I’d rather have people to support me’ (p140). Two parents said that they would like to be more involved in AHMS. They said that they did not know what was happening now that they were not attending appointments. One mother said that they would like a point of contact in AHMS. Two parents expressed similar opinions. Relationships with keyworkers The study found that some young people has positive relationships with their key workers or felt neutral towards these professionals. Some were well engaged with both their CAMHS and AMHS workers and others had better relationships with one or the other. Some young people had their keyworkers change and some did not know who the keyworker was, and experienced multiple changes in workers as they changed teams.

	Medication Medication was a significant issue for young people. Several of the young people who had transitioned had stopped taking medication. Others, with more serious conditions, continued to take medication. Two young people said that they felt that there was too much emphasis on medication and not enough on social and psychological support. Optimal transition cases Three of the cases interviewed were seen to be very good examples of transition. The study deemed that a good process included: ‘at least one transition planning meeting, a period of parallel care, good information transfer, and engagement or appropriate discharge at 3 months post transition’ (p141). When the young people were interviewed from these cases it became clear that the audit of case notes did not tell the whole story. D – reported that her transition had gone well, but other factors that had increased her stress during the transfer were related to accommodation, pregnancy and changing teams following transition. B – this young person said that the transition had gone well, but his mother said that she had wanted him to stay in CAMHS due to good relationships there. She had said that his health had deteriorated and she did not know who to speak to for help. G – this case was also recorded as going well. But the keyworker said that joint working had not happened, in conflict with the case notes.

Sloper P, Beecham, J, Clarke S, et al. (2011) Models of multi-agency services for transition to adult services for disabled young people and those with complex health needs: impact and costs (+/++)

Intervention/aims	**Findings**
There is no individual intervention discussed in this study. The approaches to multiagency transition services discussed are various. What each service shares is that it is draws	**Implementation** This study is very broad in its scope, and the findings below were extracted for their specific relevance to the question about implementation. The findings from the survey and interviews with parents relate mostly to the process of transition.

together health, social care, education and other services into a multiagency approach to providing care for young people in transition.	One of the study aims is to compare the implementation and operation of different models of transition services and to investigate the arrangements across local authority areas in England for multiagency assessment or planning and transition. Key findings: the survey isolated problematic issues with multiagency transition services which were: 1. partnership working; 2. resources and funding; 3. high levels of need; 4. lack of services; 5. need for a distinct team (p63). The survey also found key ‘helpful factors’ in multiagency transition services, multiagency partnerships/working, including: develop shared culture and relationships; good communication/share information; all agencies involved; shared goals and vision; senior management from partner agencies involved at strategic/steering level; share resources; joint planning and protocols; multiagency meetings. Other key factors were: accountability; involvement of young people and parents; using designated transition workers; and to plan based on young people’s outcomes. Twenty-one of 29 respondents raised issues with navigating competing agendas and working styles as well as working out roles, responsibilities and achieving a shared goal or vision. Other issues associated with partnership working included: ‘finalising agreement amongst all parties on a transition plan; ensuring communication between agencies; overcoming budget and expectation differences between partners; working with individual agendas; securing organisational commitment rather than on an individual level; partners delivering on agreed actions and attending meetings; overcoming cultural and practice differences’ (p62). One respondent commented that services having different assessment processes from one another and that this is a barrier. Funding and resources were highlighted by 5 respondents as issues with the multiagency approach. Each service might have its own funding steam and if services had insecure funding sources they might be less likely to enter into a partnership. The survey found that the following factors were helpful in the implementation and running of the service: ‘Multi-agency partnerships/working: shared culture and relationships, good

	communication/share information, shared goals and vision, senior management from partner agencies involved at strategic/steering level, share resources, joint planning and protocols, multi-agency meetings' (p64). Working well in partnership was most often identified as a facilitator to the multiagency approach. Factors which helped this included dovetailing vision and values, understanding roles and responsibilities, establishing common targets, communicating well, joint planning and sharing information effectively. The survey received 3 responses which emphasised the importance of a comprehensive strategic agreement at the start of the project: 'Full strategic agreement at the start of a project which involves a number of partner agencies is a must, and a clear project management capacity and agreed focus maintains the direction of travel' (p63). Another key issue for 3 respondents was accountability in terms of people taking responsibility for their work and also a continuity of working across the project; 1 respondent recommended a protocol to aid this. Two respondents recommended that young people and carers be involved in service planning and running, this was seen as a mean to 'check out your assumptions about your service' (p63).

Social Care Institute for Excellence (2011) Case study: Y-Talk counselling and therapy service, Sheffield YMCA (-/-)

Intervention/aims	**Findings**
'Y-Talk counselling and therapy service is a third sector service for 16–25 year olds who require emotional and mental health support. The service is based in Sheffield and provided in the city centre and outreach centres, including schools	**Barriers and facilitators** The findings are preliminary, as the service pilot is still in progress. Of those young people who fed back, 95% said that the counselling they had received had helped them 'a lot' or 'a bit', while 37% of young people completed the questionnaire. Almost 95% of young people gave a score of over 70% to indicate satisfaction, based on 56 forms. Client feedback is based around capacity-building and self-esteem. The study relates it

and community settings' (p1). **Study aim** The study is a case study of Y-Talk intervention: 'Y-Talk aims to provide an accessible and young person friendly counselling and therapy service. This is delivered in partnership with other organisations from places that young people already go, such as schools and youth and community centres. There is a diverse team of counsellors and therapists which helps the service to reach out and provide support to young people from many different backgrounds' (p1).	to the 6 Every Child Matters outcomes. Comments included: - changes in my confidence and how I can express how I feel - before I would just yell or cry; now if I have an issue I would try and talk it over with whoever is involved - I am more confident to be myself again - I am starting to accept myself - I found the sessions at Star House really helpful – I am going great! - I am a more confident and happier person - counselling has helped a lot. (p7)

Stein M, Morris M (2009) Increasing the number of care leavers in 'settled, safe accommodation': research review 3 (+/+)

Intervention/aims	**Findings**
The review focuses on young people leaving care and a need for them to enter 'settled, safe accommodation'. The review looks at evidence which shows that accommodation needs to be suitable for each person in relation to their needs, that accommodation is approved by the responsible authority, and that it takes account of the young person's wishes and needs. The interventions that the review looks at	**Barriers and facilitators** **Factors that help** - Being in safe and stable accommodation was found to increase engagement in employment or training, and to increase wellbeing. - Leaving care at a later age appears to contribute to being in safe and settled accommodation. - A gradual transition process from being in care to living independently is likely to contribute to young people's wellbeing, employment, and education and accommodation status after transfer out of care. - Young people value flexible services which focus on individual needs, and span practical

are: independent living programmes and leaving care services. **Study aim** The study aims to provide evidence that will help service providers improve services for care leavers and outcomes for children, young people and families.	and social needs. - Identifying groups early on in the transition process that are less likely to secure stable accommodation, or who have particular needs, such as young parents, those in care outside the local authority's borders, and young offenders. - Foster carers' training and support needs should be factored into the leaving care planning. 'An integrated approach with children's services, housing services and adult services is essential in preparing young people for adulthood' (p8). - Specific support for birth family contact, when young people want this. **Effectiveness** The review found no randomised studies evaluating independent living programmes, but it did find 8 papers which met inclusion criteria apart from randomisation since they had control groups. In almost all of these studies positive outcomes were found for those receiving independent living schemes. The review also found 10 papers which evaluated individual independent living schemes. The study isolated the following broad findings. The importance of preparation and good attendance at the scheme, involving young people in the planning of their own care, individualised transition planning, encouraging young people to practise the skills, developing specialised approaches for young people with mental health issues or disabilities, involvement of parents and carers. Leaving care services: the outcomes relevant to this topic are around social worker involvement in housing solutions for young care leavers. The study found that good communication between housing providers and social workers involved in the care planning is important. It was also found that young people should be adequately prepared for leaving care and be equipped with life skills and social skills, as well a positive sense of wellbeing.

Swift K, Hall C, Marimuttu V, et al. (2013) Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): a qualitative analysis of their experiences (++, relevance to this guideline: highly relevant)

Intervention/aims	Findings
‘The aim of the study is to explore the experiences of young people with ADHD during transition from CAMHS to AMHS’ (p2).	**Views and experiences** Findings are organised thematically. There are 4 themes. Clinician qualities and relationship Young people said that the qualities of the clinicians were key to their transition experience. The relationship between clinician and patient had a significant effect on the patients’ engagement with the service. The relationship with the clinician impacted significantly on how positively they viewed the transition service in general. Good qualities in professionals were perceived to be: ‘supportive and informative’; ‘non-judgemental’ (p2). The study states that the most important characteristic was good listening. This came up in a lot of the interviews. ‘It was quite good ’ cos it was more it wasn’t you didn’t sit down and it want like a face to face talking it was like a friend talking asking you a few questions it wasn’t really that direct’ (p5). ‘She listened to X and she never judged and she came up with good practical ideas that were achievable and realistic, whereas the one before was just, she didn’t listen’ (p5). The participants compared their experiences with different clinicians. The interviewees criticised things like gaps in the service and changes to their allocated clinician. The interviews revealed that patients appreciated clinicians who were prepared to ‘go the extra mile’ (p5). The interviewees were more impressed with clinicians who showed dedication to their cases and their transition. Some said that they felt ‘dumped’ in new services. When they perceived that their clinician was working hard for them the patients had a more positive view of the transition, even if it was a difficult process. ‘I always thought he was one of those people who always used to work hard for me, I don’t

	know about other people if they had different ones and different people. If I'd had to keep having different people every year then I couldn't have coped with that because I would've preferred a person I can trust and talk to' (p6). Responsibility for care The individuals spoken to were, in the most part, not responsible for their own care alone, they very often received support from their parents or other carers. The study questions whether young people with ADHD might need more assistance in adults' services and more information about differences in culture between children's and adults' services and the additional independence they might expected to have. 'I don't know' cos I can see where they're coming from 'cos he's an adult, but he's an adult with something wrong with him, and that and they know he won't go out the house and won't do certain things on his own yet he's got to go all the way up there and that's the point he won't do that' (p6). The lead professional was seen as having the most control over the transitions process and some interviewees felt that they had not been adequately prepared for transition and felt that their needs may not be met. Others, who had a better relationship with their clinician, felt that transition would be a positive experience. Ways in which participants can be prepared for transition: - meeting the new clinician - being given a written overview of the process - seeing the same clinicians consistently across the process. 'I think that there should always be, like if you finish with a child, there always should be someone on the end of that to pick you up always, even if you've got less of ADHD than what I have, you should always, there should always be a solution at the end, even if that person wants you to come off the tablets and you have no choice, at least you've got somewhere, somewhere to help you' (p6). Many of the participants had worked with a variety of clinicians. Some commented that they needed services to be consistent throughout transition and so if clinicians moved on

	they should make sure a clear handover process was undertaken. Some informants described a smooth transition but other did not see the need for a change. ‘I don’t see what age has got to do with who you’re seeing and where you see ’em. Right, we’re used to coming here, but now we’ve got to change and go somewhere else, so that’s a bit annoying’ (p6). Participants felt that they had been ‘dumped’ in adults’ services, others felt that it was not appropriate for them to be moved to adults’ services and others were worried that they would not be ‘accepted’ by adults’ services and that ‘no one cared about them’ (p7). Nature and severity of problems There seemed to be an issue with the compatibility of ADHD with adults’ services. Some patients found that they did not have eligibility for some services if they had ADHD and autism because their conditions were not severe enough. Expectations of adult care This was a key theme of the study. Parents and young people wanted to know what to expect from adults’ services and to be reassured that the services would be consistent. ‘When she gets to 18 is there going to be somebody there that can talk to us and talk to her? Is it going to happen because we don’t know? We just don’t know. And it worries you’ (p7). Some informants had unrealistic expectations of adults’ services and were expecting the same levels of attention that they had become used to in CAHMS. People wanted realistic expectations of what they would find in adults’ services. Parents wanted to feel they would still be involved and be able to talk to new clinicians. Young people were concerned that they would not be eligible for adults’ services, where they would have to go and the kind of appointments they could expect. In general, informants wanted to be kept informed about the process and be orientated as to what was going to happen. There was also a theme around a responsibility of continuing care, even if there was a lack of services.

Swift K, Sayal K, Hollis C (2013) ADHD and transitions to adult mental health services: a scoping review (++/+)

Intervention/aims	Findings
The studies found by the review team do not present much in the way of models for evaluation. One paper refers to the Life Transition Model, another reports on a transition clinic in Yorkshire. The review also looks at 2 longitudinal studies and a case review. **Study aim** The study aimed to describe literature which looks at the process of transition for young people with ADHD and to review current literature and policies surrounding ADHD and transitions.	**Barriers and facilitators** **Factors that hinder** - Lack of adults' services for this condition. - Differences in referral thresholds between children's and adults' services. - The need for multidisciplinary collaboration during transition (education, employment and housing needs as important as health concerns). **Factors that help** - One included audit suggests transition planning starts at age 13 for ADHD, and that young people have the option to re-refer themselves if they stop using services for a period. - One included study recommend that the following factors help with purposeful and planned transitions: 'timely preparation, joint working, good relationships with clinicians and parental support' (p4). This study found that those presenting with more complex problems made smoother transitions as it seemed that AMHS were more aware of the needs of these patients.

Tierney S, Deaton C, Jones A, et al. (2013) Liminality and transfer to adult services: a qualitative investigation involving young people with cystic fibrosis (++, relevance to this guideline: highly relevant)

Intervention/aims	Findings
To explore the experiences of transition from children's to adults' services among young people with cystic fibrosis.	The authors drew on Van Genneps' work on liminality – a concept used to describe the process of a person moving from one social status to another. This is described as 3 stages: separation (detachment from the initial group), marginal (help for transition through rituals) and aggregation (new roles and responsibilities are accepted). These 3 stages were used to present their findings, using different words to describe them.

	Paediatric staff started to initiate the transfer to adults' services, and young people felt that they did not address the emotional aspects of this. Because the transfer was not immediate, some young people felt that they were left 'on hold' while waiting to be seen in adults' services. Only 1 young person had experienced a 'goodbye' ('send off') from staff in the paediatric setting. This period also involved an expectation that young people would change behaviour in relation to their condition, moving from an uninvolved child or rebellious teenager to a responsible adult (p742): '… I've never took it [CF] so serious. I've just always pushed it to one side and just tried to live a normal life but then you've to, you can't always just put it to one side because at the end of the day it's a big part of your life ...'. Parents played an important part in young people's transition, alongside a wish for increased independence. Both young people and their parents have to reposition themselves during this period. Acclimatising (marginal) Starting the paperwork for transfer marked the beginning of this phase, and young people found it helpful that they were visited by staff (usually a nurse) from the adult setting. That this person showed them pictures of the new setting was found very helpful. Some young people really liked being spoken to directly (rather than the parent), but some found this confusing or difficult (p743): '... the doctor did ask me "what do you want to do?" ... In children's they wouldn't do that, they'd just say "you need IVs, you should come in". So it was quite a bit, it was a bit confusing because I didn't really know what to do myself. I was like, "I don't know, you tell me what I should do"'. Parents were still important to young people during this phase, and 1 young person described how having her mother there helped her ask more questions and be more confident at her first adult clinic appointment. Integrating (aggregation) For many of the young people other transitions (such as education) were given more priority than the health transition. Most young people felt OK with the adult setting once they got used to it. A rite

	of passage at this stage was their first inpatient experience on an adult ward. All young people regarded the adult unit as the right setting for them, as they were getting older.

van Staa AS, van A Heleen, Jedeloo S (2011) Readiness to transfer to adult care of adolescents with chronic conditions: exploration of associated factors (+/+)

Intervention/aims	**Findings**
To explore associations between adolescents' perception of their readiness to transfer to adult care and sociodemographic and disease-related characteristics, effect of the condition, self-management ability, and attitude toward transition.	**Barriers and facilitators** Transition readiness: the study reports that 56% of the young people who completed were either 'probably' or 'definitely' ready to transition into adults' services. Analysis of the data found that transition readiness was associated (in a positive way) with: - age: older young people were more ready to transition - gender: boys felt more ready for transition than girls; the association between disease status and readiness was less clear. In addition: - lower transition readiness was linked to physical limitations, more visible disability and missing school. - better QoL score and general health were linked to better transition readiness. Self-management: the attitude among respondents was generally found to be (moderately) positive toward transition: '70.2% indicated they were not looking forward to the prospect and admitted to being concerned about transition to a little or even a large extent. Only 28.6% stated they were not (at all) concerned about transition' (p299). - Attitudes toward transition were linked to good transition readiness scores. - The study found that transition was seldom discussed at consultations, with over 65% saying that it was never discussed. When it was discussed, it was mostly discussed with older patients. Those with whom it was discussed reported better transition readiness.

	Multivariate associations: age was found to be highly related to transition readiness, it was also found that non-Dutch ethnicity contributed to transition readiness. - Better self-efficacy skills and independence in a clinical setting also contributed to better transition readiness. - Other positive factors included better attitudes to transition and better discussions around transition planning with staff. - Lower levels of transition readiness was related to therapeutic regimen and missing school, other disease-related variables did not relate to readiness to transition.

Walleghem N, MacDonald C, Dean H, et al. (2009) Building connections: The Maestro Project. The evolution of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes (+/+)

Intervention/aims	**Findings**
The Maestro Project is a systems navigator model designed to assist young adults with type 1 diabetes. The Maestro is an administrative project manager, it 'maintains telephone and email contact with young adults to provide support and help identify barriers to accessing health care services' (p2). The model works with other community services to support patients. The model has a website, produces a newsletter, holds drop-in groups and hosts educational events.	**Effectiveness** The study indicates that the Maestro tool helped both those who has already passed into adults' services and those going through transition. The study provides data on 101 patients from the older group and 64 from the younger group. The findings suggest that the Maestro patient navigator was beneficial for the older age group in that it helped them to 'reconnect with adult medical services'. The Maestro model helped the younger group to remain in contact with services following transfer to adult care, and the dropout rate was lower in the young group who had received the intervention. In terms of medical outcomes both groups experienced complications which resulted in hospital treatment, but there was no difference between the 2 groups. Question relevancy: the individuals who received the Maestro intervention after they had transferred into adults' services were helped to reconnect with adult services is they had dropped out of care. 60% had visited a clinician at least once in the year before the intervention. Following the intervention this increased to 75% (p=0.001). This suggests that adults' service need to continue supportive intervention during and following transition to keep patients engaged in services. The findings about the ability of the intervention to improve medical

	outcomes were inconclusive. **Adults' services** The study provides data on 101 patients from the older group and 64 from the younger group. The Maestro model helped the younger group to remain in contact with services following transfer to adult care, the dropout rate was lower in the young group who had received the intervention. In terms of medical outcomes both groups experienced complications which resulted in hospital treatment, and there was no difference between the 2 groups. The individuals who received the Maestro intervention after they had transferred into adults' services were helped to reconnect with adults' services is they had dropped out of care: 60% had visited a clinicians at least once in the year before the intervention, following the intervention this increased to 75% (p=0.001).

Watson R, Parr J, Joyce C, et al. (2011) Models of transitional care for young people with complex health needs: a scoping review (-/++)

Intervention/aims	**Findings**
To explore successful models of care for young people with complex health needs when they move from children's to adults' services. Three conditions were used as exemplars: cerebral palsy, autism spectrum disorders and diabetes.	**Barriers and facilitators** Models of transitional care was undertaken focusing on 3 healthcare conditions: cerebral palsy (CP), autism spectrum disorders (ASD) and type 1 and type 2 diabetes; 18 service models were identified. **Factors that hinder** - A lack of any published models of transitional care for young people with ASD moving from child to adult healthcare provision. This finding is consistent with the TRACK study (Singh et al. 2010) that among young people with mental health problems, 'Those with neurodevelopmental disorders … were most likely to fall through the child and adolescent mental health services–adult mental health services gap'. Possibly due to perceived lack of need and the current lack of adults' services to transfer to (Department

	of Health 2010b; Singh et al. 2010; Sloper et al. 2010). - A lack of service evaluations and agreed process and outcome measures for transition, which hinder opportunities for comparing different service models and guide service development, e.g. review by McDonagh and Kelly (2010) has identified that there are no comprehensive validated measures of transition. - Lack of formal evaluation of the experience of users against any outcome measures. Service models highlight that young people have different individual experiences of transitional care and recognise the need for flexibility when supporting transfer of clinical care. It is important to be able to record these experiences in a systematic way. Quality of life and participation are crucial, personalised outcomes (World Health Organisation 2001) and these should be recorded in service evaluations. **Factors that help** - Most papers focused on the need to provide an individualised healthcare plan for each young person. - Two-thirds of studies reported an understanding of the need for flexibility in the timing of transfer. - Four papers provided some information about sustainability (future planning or funding) of the service. - In 1 service the costs of the diabetes transition programme were reported as being recovered through savings made by a reduction in hospital management of acute complications (Holmes-Walker et al. 2007). Three studies were identified with the highest number of combinations of transition categories and NPT elements: 1. Cuttell and colleagues (2005) describe a one-off weekend residential camp for young people with diabetes approaching transition; 2. Parfitt (2008) describes the process for young people with diabetes moving from an adolescent clinic into adults' services; 3.Betz and Redcay (2003) – transition model for young people with special healthcare needs, including CP. - Betz and Redcay (2003) reported that staff had an understanding of the need to consider all aspects of a young person's transition needs including healthcare, education, community living, employment and social and leisure activities.

	- Cuttell et al. (2005) reported that staff demonstrated an understanding of the adjustments that the young people needed to make when moving from child-oriented to adult-focused services.
	- Parfitt (2008) discussed the need to be flexible about the timing of the transfer as there is no one ‘right time’ for all young people.
	- The involvement of professionals providing the service was discussed in terms of the role of a champion or enthusiastic leader. For example:
	    - the model reported in Cuttell et al. (2005) was proposed and delivered by a youth worker in the service.
	    - Parfitt (2008) describes a paediatric diabetes nurse specialist, describing herself as ‘pivotal in the planning of the development, managing resources and co-ordinating the process’ (p30)
	    - Betz and Redcay (2003) reported that individual recommendations were always reviewed with the young person
	    - Cuttell et al. (2005) reported that all the young people expressed confidence about their transfer into adults’ services after taking part in a weekend residential camp.
	Effectiveness
	The researchers used framework analysis and coded transition models alongside 2 sets of variables: 1. frequently reported components of transitional care (drawing from policy, guidelines, health literature); and 2. 4 elements of normalisation process theory (NPT), identified as being important for the successful implementation of new services into established practice: collective action, coherence of service, cognitive participation, monitoring.
	When considering the papers against the 4 elements of NPT, the analysis found that most papers scored well on ‘collective action’, meaning that they provided a lot of information about how the transitional care service is provided.
	Little information was reported on service users’ and providers’ experiences of the new

	service as valuable (coherence of the service), and there was hardly anything on whether providers saw it as a legitimate part of their work, and whether it was supported by both groups (cognitive participation). They also found little evaluation of services (monitoring). The authors conclude that there is urgent need for evaluation studies on transition. There is further need for methodological developments to underpin this, because there is currently no shared understanding of which process and outcome measures to use.

Critical appraisal table – transition from children's to adults' services

Abbott D, Busby K, Carpenter J (2009) Transition to adulthood for young men with Duchenne muscular dystrophy and their families: final report to the Department of Health

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
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 **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • Yes **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 Data was analysed using SPSS and analysed using descriptive stats and inferential stats. **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 Context of care for young men	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly 'transition'?** • Yes **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • Yes Context of care for young men with muscular dystrophy is considered.	**Internal validity** • ++ A well conducted study, with a good account of sample, research methods and analysis. **External validity** • ++

The survey was a logical first step to gather initial information and find possible respondents for the in-depth interviews. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** • Yes Limitations are discussed, the study describes some of its limitations and opportunities for further research.	with muscular dystrophy is considered. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • Yes Findings are discussed in relation to the context of services for young men with Duchenne muscular dystrophy.		

Allen D, Channon S, Lowes L, et al. (2011) Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is a qualitative approach appropriate? • Appropriate **Is the study clear in what it seeks to do?** • Clear **How defensible/rigorous is the research**	**Is the context clearly described?** • Clear Most of the face-to-face interviews were carried out in young people's homes, with some in other places such as cafes. The interviews were not carried out jointly, but the other	**Are the findings convincing?** • Somewhat convincing It strengthens the findings that the study was actually primarily focused on the general experiences of young people and their parents during a period of transition. So it seems that the role of	**Internal validity** • + **Relevance to this guideline** • Highly relevant

design/methodology? • Defensible **How well was the data collection carried out?** • Appropriately Young people and their parents (in all cases mothers, identified by the young person as their primary care giver) were interviewed at 3 time points over 12–18 months. The first interview was face-to-face (approx. 1 hour), the second on the phone (approx. 30 min) and the third face-to-face (approx. 1 hour). **Was the sampling carried out in an appropriate way?** • Somewhat appropriate They wanted a purposively selected sample stratified by gender and spanning the full transition period as defined within each service. The sampling was conducted by service providers in the 5 service sites. They struggled to achieve the target sample size, and we do not know how the service providers selected young people to take part.	person (young person or mother) was sometimes present during the other's interview, according to their wishes. All interviewees were at one point interviewed without anyone else present. **Were the methods reliable?** • Reliable Semi-structured interviews. **Are the data 'rich'?** • Rich **Is the analysis reliable?** • Somewhat reliable Thematic analysis of experiences of living with diabetes and undergoing service transition, considering contrasting as well as common themes. Seven young people did not want their parents to be interviewed because they stated that they themselves were the primary caretaker of their condition. Their views are not included in the analysis.	parents emerged from the data, rather than being a preconceived idea. However, it would have strengthened the findings if the authors had included the views of the young people who did not want their parents to be interviewed. While it is unlikely that their views would have discredited those that were included (7 young people versus 43), it might have provided different perspectives on some of the concerns in regard to involvement of parents. **Are the conclusions adequate?** • Adequate	

Allen D, Cohen D, Hood K, et al. (2012) Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
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 **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)?** • Partly The study is clear in its scope but it does not clearly acknowledge its limitations.	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Are the outcomes relevant?** • Yes	**Internal validity** • + The Internal validity is hampered by the lack of detail about the characteristics of the sample. **External validity** • ++ The study has a UK focus and its aims dovetail with our review questions.

Andemariam B, Owarish-Gross J, Grady J, et al. (2014) Identification of risk factors for an unsuccessful transition from paediatric to adult sickle cell disease care

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Question appropriate and focused? • Poorly addressed	**Comparable populations?** • N/A	**Is the setting similar to the UK?** • No	**Internal validity** • - The study does not use a

The aims are covered adequately, but there is no account of what the study deems to be a successful transition. **Cases clearly defined?** • N/A No control group, but the intervention is well described. **Distinguishing of cases from controls?** • N/A	There is no control group. **Distinguishing of cases from controls?** • N/A **Exposure status** • N/A **Confounding factors** • Not addressed **Statistical analysis** • CI provided 'Statistical methods used for data analysis included chi-square tests for assessing association among categorical variables (e.g., transitioned (Y or N) vs. gender) and two-group t-tests for comparing group means (e.g., distance from home to the adult sickle cell centre, by transitioned, Yor N). When the assumptions of the chi-square were not met, we reported Fisher's Exact Test. All analyses were performed using SAS1 statistical software (SAS Institute, Inc., Cary, NC)' (p698). **Do conclusions match findings?**	US study – hard to compare to UK setting **Is there a clear focus on young people in transition?** • Yes **Are the outcomes relevant?** • Yes	control group which affects its validity. However as a retrospective study it achieves its aims and offers statistical findings. It does not discuss its limitations. **External validity** • + Given the difference in context it is hard to rate this study any higher.

	• Yes		

Barn R, Andrew L, Mantovani N (2006) Review of life after care: the experiences of young people from different ethnic groups

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
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 **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • Yes **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** • Yes Qualitative sample. The selection of research	**Is the process for analysing qualitative data relevant to address the research question?** • Yes Interview methods were a very good medium and complemented the profile information returned from quantitative questionnaires. Interviews were tape-recorded and transcribed verbatim. The researchers undertook thematic analysis using the Grounded Theory approach to identify the emerging and comparative themes under each topic area (Glaser 2002; Glaser and Strauss 1967). **Is the process for analysing qualitative data relevant to address the research question?** • No	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • Yes The researchers provide very detailed contextual information about the 6 local authority sites included in the study. This includes minority ethnic profile, percentage of 'looked-after' children (as at 2002); socioeconomic deprivation, etc. While acknowledging that the authority areas are not representative, the researchers assert that the ethnic diversity	**Internal validity** • ++ Every effort was made to ensure that the quantitative questionnaire would be accessible and engaging to young people. This included issues around language, relevance and sensitivity in the design. **External validity** • ++ The study has a clear focus on transitions and covers all the key variables from preparing to leave care, leaving care and moving on to independent living. Spanning a good cross section of ethnic groups and diverse local authority locations and contexts, findings can be generalised more widely.

participants (36) for the qualitative sample was appropriately sampled from the main sample of 261 to reflect the broad cross-section of views across different ethnic groups and gender. Broken down as 16 male, 20 female (11 African Caribbean, 8 Africans, 3 Asians, 10 mixed parentage and 4 white). The high proportion of teenage mothers in the sample (55), was also reflected proportionately in the sample. Thirteen managers and professionals were also interviewed from across the 6 leaving care teams. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** • Yes **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect**	The process of choosing participants, facilitating focus groups and gathering feedback is not clear. **Is there an acceptable response rate (60% or above)?** • Yes The response rate varied according to the geographic region and ethnicity of participants. The 3 London authorities had the highest number of minority ethnic respondents, but the overall response rate was lower compared to local authority areas outside London (p6). **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** • Yes Quantitative demographic questionnaire was designed to extract relevant profile data, including that on patterns and outcomes of care leavers. Questions covered age, gender and ethnic background, placement, length of time in	between areas allows us to generalise findings more broadly to other authority sites. In other words, conclusions drawn about issues such as preparation for leaving care, experiences since leaving care, housing/homelessness, education/employment/income, crime, neighbourhood, substance misuse, relationships, prejudice/discrimination and identity were comparable across different study sites. **Are the outcomes relevant?** • Yes	

of the mixed-methods question)? • Yes Quantitative demographic questionnaire targeted et all those involved with leaving care teams in the 6 research sites generated a sample of 261 respondents. **Is the sample representative of the population under study?** • Partly Yes, in so far as it represents those care leavers who are already in the system, i.e. in contact with social services leaving care teams. But does not represent the wider contingent of BME and white care leavers who are not in contact with the system and therefore whose circumstances may be totally different, even more problematic.	care, family contact, educational status, school exclusion, sex education, employment, housing/homelessness, substance misuse, social networks and teenage parenthood.		

Bent N, Tennant A, Swift T, et al. (2002) Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating

Question appropriate and focused? • Well covered The researchers hypothesised that young people receiving transitional care from a ‘young adult team’ would have a greater degree of participation in society than those receiving (ad hoc) services as usual. The study was designed to assess this hypothesis, and to also estimate the cost-effectiveness of both service approaches. **Participation rate for each group?** • Cases Leeds: n=93, interviewed n=74 (80%); Stoke-on-Trent: n=58, interviewed n=45 (78%) Controls Leicester: n=81, interviewed n=76 (94%); Birmingham: n=94, interviewed n=59 (63%) **Cases clearly defined?** • Well covered ‘Cases’ were included on the basis of their transition to adults’ services being supported by a	**Comparable populations?** • Well covered There were no significant differences between the groups in terms of age, disabilities, health or psychosocial measures. Young people in the areas with young adult teams reported less sleep impairment and less limitation on activity. **Distinguishing of cases from controls?** • Poorly addressed The reporting is unclear as to how the researchers knew that those in the control areas did not receive ‘young adult teams’, or any other types of transition support. They simply state that the ‘control’ areas only provided ‘ad hoc’ services, but not what these were. **Confounding factors** • Poorly addressed While the interviews did address key factors, they did find different activity levels in the 2 groups, with young people in the ‘young adult	**Is the setting similar to the UK?** • Yes The study was conducted in England (Leeds, Stoke-on-Trent, Leicester and Birmingham). **Is there a clear focus on young people in transition?** • Yes **Are the outcomes relevant?** • Yes The main outcome for this study is partly relevant to the scope for this guideline, in terms of ‘self-efficacy’.	**Internal validity** • + **External validity** • ++

multidisciplinary ‘young adult team’. ‘Controls’ were included on the basis of their transition being supported by services ‘as usual’ that is ‘Health services ... provided in an ad hoc manner by many different organisations, each with their own criteria for defining who receives support‘ (p1281).	team’ areas scoring higher on activity than those in the ‘ad hoc services’ areas. The researchers did address psychosocial factors and economic factors, but it is still unclear whether there were some underlying characteristics which might have explained the ‘participation’ outcome in either group. **Do conclusions match findings?** • Yes The authors acknowledge the problem with this being a retrospective study. However, their concerns about the possibility of conducting a prospective comparison study are questionable.		

Beresford B, Cavet J (2009) Transitions to adult services by disabled young people leaving out of authority residential schools

Internal validity, approach and Sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate The collection of views from	**Is the context clearly described?** • Clear Study sites were	**Are the findings convincing?** • Convincing	**Internal validity** • ++ **Relevance to this guideline**

frontline to senior managers across children's services (disabled children's team, education and child health), Connexions and adult social care services warranted a qualitative approach. **Is the study clear in what it seeks to do?** • Clear The study focus was transitions into adults' services from out authority schools based outside local authority catchment areas by disabled young people in 38- or 52-week placements. **How defensible/rigorous is the research design/methodology?** • Defensible Study sites were representative of different organisational and geographical authorities in England. Authorities which appeared to have higher numbers of disabled children and young people placed in out authority schools for 38- or 52-week placements	representative of different organisational and geographical authorities in England. And within each authority, researchers aimed to collect a cross-section of views from frontline to senior managers across children's services (disabled children's team, education, and child health), Connexions and adult social care services. **Was the sampling carried out in an appropriate way?** • Appropriate In each site the directors of children's services were contacted about the research and were the key link into project teams for potential research participants. The SENs leads in each local authority were chosen in each authority to identify the correct person within the SEN/education department to be 'education informant' for the project. During the interview, the 'education informant' was asked to propose contacts working in the disabled children's team,	**Are the conclusions adequate?** • Adequate The conclusion is appropriate and supports the findings that extra barriers to transition planning and heightened risks to poor transition outcomes exist for disabled young people in authority residential schools. It also confirms that some progress has been made in terms of achieving improved social care transitions, especially when in terms of identifying this group and the prompt active involvement of adult social care staff in transition planning.	• Highly relevant

(compared to the national average) were selected. Within each authority, researchers aimed to collect a cross-section of views from frontline to senior managers across children's services (disabled children's team, education, and child health), Connexions and adult social care services. **How well was the data collection carried out?** • Appropriately The research method consisted of phone interviews that lasted from half to 1 hour. A broad topic guide was used and tailored accordingly to each interviewee.	Connexions, child health and adults' services whom the project could contact to take part. This method of asking staff to suggest names for interview was repeated for all interviews in order to build up the sample in each authority. **Were the methods reliable?** • Somewhat reliable There was no triangulation of research methods, so findings are all based only on the outcome of phone interviews. **Is the analysis reliable?** • Reliable		

Beresford B, Harper H, Mukherjee S, et al. (2014) Supporting health transitions for young people with life-limiting conditions: researching positive practice (the STEPP project)

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate **Is the study clear in what it seeks to do?**	**Is the context clearly described?** • Unclear The context is clear in terms of the wider study, but not in	**Are the findings convincing?** • Convincing **Are the conclusions adequate?**	**Internal validity** • + Difficulties with assessing this study due to not having all available reports and

• Clear **How defensible/rigorous is the research design/methodology?** • Defensible **How well was the data collection carried out?** • Not sure/inadequately reported This is not clear from the 2 reports we are drawing on. **Was the sampling carried out in an appropriate way?** • Not sure We have not found information on the sampling in the 2 reports we have identified for this study.	terms of where the interviews were carried out, and by whom. **Were the methods reliable?** • Somewhat reliable While we have not found information on the analysis or details on the sampling, overall they have covered conditions relevant to their study aim and both reports contain quotes to back up their conclusions. **Is the analysis reliable?** • Somewhat reliable It is difficult to know since we have not found a report containing information on the analysis. It strengthens the findings that these are backed up by quotes.	• Adequate	information on methods and analysis. **Relevance to this guideline** • Highly relevant

Beresford B, Moran N, Sloper T, et al. (2013) Transition to adult services and adulthood for young people with autistic spectrum conditions (working paper no. DH 2525) (+/+)

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is the mixed-methods	**Is the process for analysing**	**Is the setting similar to the**	**Internal validity**

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 **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • Yes **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** • Yes Interviews with managers and practitioners, including commissioners and job centre workers. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or**	**qualitative data relevant to address the research question?** • Partly The analysis of this component focused on managers' and practitioners' experiences of providing support to young people during their transition into adulthood, as factors that help and hinder transition planning and subsequent positive outcomes. **Is the process for analysing qualitative data relevant to address the research question?** • Partly The topic guide for the qualitative interviews with parents covered difficulties experienced by the young person in moving towards adulthood and parents' experiences and views of planning for their child leaving school, of transfers from children's to adults' social care or health care services. Topic guide also covered support received from non-statutory	**UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Are the outcomes relevant?** • Partly This study focuses mainly on education and employment outcomes, and transitions into independent living.	• + This rating is based on the study's validity in relation to our question about how transition can best be supported for those receiving a combination of services. **External validity** • + Overall this study is highly relevant to this guideline. This initial appraisal is based on its relevance to the question about how to best manage transition for young people who receive a combination of different services. This study is more relevant to our question about what helps and hinders purposeful and planned transition, and our question about young people and parents'/carers' views, and it will be revisited for those questions.

results)? • Yes **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** • Yes **Is the sample representative of the population under study?** • Yes	services, the impact of impending or recent changes on the young person and the parents, hopes and aspirations, the young person's current needs, parents' overall views about what works well or does not work well regarding support for transition and suggestions for improvements. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • Yes This report provides detailed information about all 5 research sites, and the national policy frameworks and legislations operating at that time period. **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** • Yes This study used a questionnaire developed for a previous study with the same		

	focus, albeit a wider population.		

Betz C, Lobo M, Nehring, W, et al. (2013) Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition

Internal validity, methods	Internal validity, clarity of reporting	External validity	Overall rating
Appropriate and clearly focused question? • Yes The review questions focused on: (a) the identification of AEA-SHCNs' need for HCT services; (b) perspectives related to their anticipation of receiving HCT services; and (c) a post transition description of their HCT experience. **Inclusion of relevant individual studies?** • Yes The full-text articles or abstracts of articles generated from the initial database search were evaluated by two team members. A total of 144 articles were included if they were: (a) findings generated from AEA-SHCN respondents;	**Adequate description of methodology?** • Yes The authors clearly described the databases and search criteria used to search MEDLINE, PsycINFO and EBSCO. Inclusion criteria were then applied to these as follows: (a) findings generated from AEA-SHCN respondents; (b) studies published from 2005 to 2012; (c) studies published in English; and (d) publications containing the essential study elements needed for analysis. A total of 51 studies were reviewed and disagreements were resolved through discussion. A total of16 studies were excluded for other reasons including that they were not on the topic of or	**Is the setting similar to the UK?** • Yes From the 35 included studies, 10 were conducted in US, 14 in the EU (5 based in UK), 7 in Canada, 3 in Australia, and 1 in Hong Kong. **A clear focus on transition services?** • Yes **Are the population groups relevant?** • Yes	**Internal validity** • ++ The study reports its methods clearly including the process by which studies were screened to arrive at the final number to be included. **External validity** • + Given that the review was more biased towards non-UK studies (5 studies out of 35) some of the findings may not be generalisable to a UK population.

(b) studies published from 2005 to 2012; (c) studies published in English; and (d) publications containing the essential study elements needed for analysis. **Rigorous literature search?** • Yes MEDLINE, PsycINFO, and EBSCO databases were searched. Reference harvesting from this output retrieved studies including several major reviews of literature about HCT. A total of 519 articles were retrieved and reviewed for this initial stage. **Study quality assessed and reported?** • Yes The full-text articles or abstracts from the initial search were evaluated to identify research studies about HCT targeting AEASHCNs. Two reviewers reviewed the studies.	unclear reporting of some of the sample sub-groups. Review findings were compared with other reviews. The authors clearly described study types included and limitations within study designs. **Do conclusions match findings?** • Yes Authors' overall conclusions match with the findings presented in tables and more detailed text.		

Betz C, Smith K, Macias K (2010) Testing the transition preparation training program: a randomized controlled trial

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
How was selection bias minimised? • Randomised Random allocation stratified by gender. **Was the allocation method followed?** • Not reported **Did participants reflect target group?** •Yes **Were all participants accounted for at study conclusion?** • Yes	**Was the exposure to the intervention and comparison as intended?** • No The authors state that 5 people in the intervention group received only half of the intervention (1 workshop out of 2). However, the flow diagram also indicates that only 5 people received the allocated intervention (2 workshops), but this is not elaborated in the text. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** • Partly This is not explored in detail, but where they did find a statistically significant impact on an outcome variable, authors state that this reflects a difference which was also there at baseline. **Was the study sufficiently powered to detect an**	**Is the setting similar to the UK?** • Partly US study so some relevance to the UK **Are the population groups relevant?** • Yes **A clear focus on transition services** • Yes **Are the outcomes relevant?** • Partly These outcomes are not directly about the transition, but they are related to the outcomes listed in our scope, most notably 'self-efficacy'.	**Internal validity** • + This was overall a sound study, but the intervention 'dose' was very low and the authors acknowledge the lack of a follow-up booster session or contact from a transition coordinator. While they did not find any statistically significant effects it would have been good to present effect sizes to illustrate this better. However, they do present detailed findings tables so this could be estimated. There is some lack of reporting in terms of the randomisation and also how many people actually attended the workshops. **External validity** • + This is a US study, but its results are of relevance to the UK. There are some cultural similarities between the 2 countries and the intervention is not particularly coloured by their healthcare system (e.g. it

	intervention effect (if one exists)? • Not reported The study had a small sample size (n=65) **Were the analytical methods appropriate?** • Yes		does not relate to insurance policies or a particular health care act).

Bhaumik S, Watson J, Barrett M, et al. (2011) Transition for teenagers with intellectual disability: carers' perspectives

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
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 The combination of survey and interviews is suitable to address the aims of the study: 1) to map the number of teenagers with intellectual difficulties, 16–19; 2) to isolate carers perceptions of transition and where needs are not being met.	**Is the process for analysing qualitative data 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 the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Are the outcomes relevant?** • Yes	**Internal validity** • + **External validity** • ++

Is the integration of qualitative and quantitative data (or results) relevant to address the research question? • Yes **Are the sources of qualitative data (archives, documents, informants, observations) 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			

Binks J, Barden W, Burke T, et al. (2007) What do we really know about the transition to adult-centred health care? A focus on cerebral palsy and spina bifida

Internal validity, methods	Internal validity, clarity of reporting	External validity	Overall rating
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Yes **Rigorous literature search?** • Yes Database searches in Medline and Cinahl only, but author and citation searches of all relevant articles identified in the original search.	**Adequate description of methodology?** • Yes While they did not quality appraise included studies, they provide details on the process of identifying and analysing studies. **Do conclusions match findings?** • Yes **Study quality assessed and reported?** • No	**Is the setting similar to the UK?** • Partly This review was conducted in Canada; their presentation of findings does not appear exclusive to this setting. **A clear focus on transition services** • Yes **Are the population groups relevant?** • Yes	**Internal validity** • + Mainly due to the lack of quality assessment of included studies. The findings are backed up by citations but they do not tell us the strength of this evidence in terms of study quality. **External validity** • +

Bloom R, Kuhlthau K, Van Cleave J, et al. (2012) Health care transition for youth with special health care needs

Internal validity, methods	Internal validity, clarity of reporting	External validity	Overall rating
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Somewhat relevant They have included studies which clearly respond to their	**Adequate description of methodology?** • Yes They provide clear details on how they selected the studies, and they provide a table with key study characteristics. **Do conclusions match**	**Is the setting similar to the UK?** • Partly Two of the 15 studies were from the UK, all of them were from the minority world and countries which are fairly similar to the UK in terms of	**Internal validity** • ++ This is a high quality review which paid attention to study quality and reported evidence of no or negative effects, as well as improvements from transition interventions.

questions. They have also included studies which looked at the long-term outcomes of people with long-term conditions. It is not clear that all the studies considered whether people had received particular transition interventions or models, or not. **Rigorous literature search?** • Yes They developed a logic model to inform their search. They searched in 4 databases: Medline, PsycINFO, Cumulative Index of Nursing and Allied Health Literature, and Social Sciences Citation Index.	**findings?** • Yes The authors are cautious in their conclusions due to the quality of the evidence. They conclude that there is weak evidence to support interventions where young people meet adult providers in advance of the transfer to adults' services. **Study quality assessed and reported?** • Partly reported They did code the studies on characteristics and pay attention to design in their reporting. They did not grade the quality of studies, however, and it is not clear in the reporting whether the study was of high or low quality.	GDP, health system and culture. **A clear focus on transition services** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes?** • Yes **Inclusion of relevant social care outcomes?** • No **Exploring views on transition?** • Yes	Note: there was a poor match between the review questions and the included studies. They set out to address the impact of not receiving transitional support when transferring to adults' services, but the studies they included did not fit well with this question. **External validity** • ++ Although this was a review conducted in the US, they had an international perspective and did not frame the findings to the US context in particular.

Broadhurst S, Yates K, Mullen B (2012) An evaluation of the My Way transition programme

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is a qualitative approach appropriate? • Appropriate Given the focus of the	**Is the context clearly described?** • Clear **Was the sampling carried**	**Are the findings convincing?** • Convincing The findings appear	**Internal validity** • + Despite some apparent shortcomings in data collection

research questions, a qualitative approach is justified. **Is the study clear in what it seeks to do?** • Clear The research is clear in that it looks at the findings from interviews with young disabled people, carers and professionals and assesses outcomes. Outcomes were judged to be positive, neutral or negative by young people and others interviewed. 'Getting a life' was defined in terms of outcomes (already identified in previous research) that young disabled people want (Tarleton and Norah Fry Research Centre 2004) and include: getting a job; going to college; managing increased independent living; budgeting skills; making friends; having a partner; staying safe; and being in control. **How defensible/rigorous is the research design/methodology?** • Somewhat defensible	**out in an appropriate way?** • Not sure No reasoning is given on how the sample was chosen and from which study sites. It is possible that bias could have crept in if research participants were selected because of mainly positive experiences of the My Way transition programme. **Were the methods reliable?** • Somewhat reliable The methods were somewhat reliable in that a previous literature review was undertaken and helped to provide context. But a lack of detail on design of interviews, sampling, data collection and analysis leaves gaps in the process. **Are the data 'rich'?** • Mixed Overall, findings were reported in a very general sense. It would have been useful to see for instance how demographic profile (such as age, gender and ethnicity) or particular circumstances (e.g. time spent	convincing and reflect what other research has indicated about co-productive approaches to service provision that also harnesses the skills and resources of individuals and communities. **Are the conclusions adequate?** • Adequate The authors clearly describe the implications of the research and the merits of the My Way transition programme, with emphasis on how this sort of model might be rolled out on a wider scale, with buy-in from local authorities and extended to encompass the needs of self-funders.	and reporting methods, on the whole this is a good quality study. The researchers ensured coverage of views from a broad range of individuals from young people and their families, to a diverse range of professionals. Furthermore, data was gathered at 2 different points and the research was supported by other material in the form of a literature review summarising the issues faced by young disabled people and cost information in respect of different care packages. Given that this was independent evaluation, it is likely that bias was also minimised. **Relevance to this guideline** • Highly relevant

The authors clearly state the focus of the research in terms of key questions posed to interviewees. Also it is clarified who interviewees are. But there is no description of methodology or sampling. **How well was the data collection carried out?** • Not sure/inadequately reported The authors provide no more detail except to say that interview transcripts were content analysed and key themes were drawn from this content.	in care) may have had an impact on outcomes experienced by young people involved in the My Way transition programme. **Is the analysis reliable?** • Not sure/not reported There is no description of how the analysis was done. For instance, information on how interview transcripts were themed, if there was cross-checking with interviewees on findings, so it is hard to estimate how reliable the analysis is.		

Burgess C (2007) Staying afloat: effective interventions with young people in South Ayrshire. An evaluation of the impact of social work services and related agencies on outcomes for young people

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
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	**Is the process for analysing qualitative data relevant to address the research question?** • Yes **Is the process for analysing qualitative data relevant to**	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • No The age range is from 0–26,	**Internal validity** • ++ **External validity** • ++

mixed-methods question? • Yes **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • Yes Triangulating the findings through several methods helped to ensure the findings supported each other. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** • Yes	**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 Generally, it was possible to gather a reasonably accurate picture of the services delivered, by piecing together information from the forms, letter copies, case recording and reports available. The author notes that while forms which outline work planned with young people were clearly well designed and used, there was not generally a similar mechanism available to record whether this took place and over what period of time.	but it is possible to sift the data to take account of relevance to transition. **Is the intervention clearly 'transition'?** • No **Are the outcomes relevant?** • Yes	

Cadario F, Prodam F, Bellone S, et al. (2009) Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Question appropriate and	**Comparable populations?**	**Is the setting similar to the**	**Internal validity**

focused? • Well covered To investigate the outcomes of a structured versus an unstructured transition programme. **Participation rate for each group?** • Cases 84% participant rate (27 out of 32 young people) Controls 100% (30 out of 30) **Cases clearly defined?** • Adequately addressed All patients transferred to adults' services before the introduction of a transition support system, including a transition coordinator. There is no information about whether the comparison group consisted of all young people transferred during that time period (1 Jan 1994 to 31 Dec 1999), or whether this relates only to those who were recruited. **Distinguishing of cases from controls?** • Well covered	• Adequately addressed Relevant variables for each group are presented: sex, age, diabetes duration, BMI, multiple daily injections and daily insulin units. There is no information on other demographic data such as the presence of other health conditions, social economic group or income, or education levels. **Distinguishing of cases from controls?** • Well covered All controls were transitioning before the introduction of the transition support service, so it is clear that they did not receive this service. **Confounding factors?** • Poorly addressed There is no discussion of potential confounders and the data collected was restricted mainly to disease-related variables and clinic attendance. **Do conclusions match findings?** • Partly	**UK?** • Yes Fairly similar: Italy **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly related to service transition?** • Yes **Are the outcomes relevant?** • Yes	• - There is lack of clarity as to when the interviews were carried out. From the information about funding, it might be that the interviews were carried out in 2006 or after, which presents problems in regard to the recall information in the questionnaires for young people transitioned between 1994 and 1999. The authors have been contacted to ascertain timing of interviews. This is a very small study. The study is useful as an indication of the potential importance of providing transition support for young people, but its findings are not generalisable due to the study design and flaws in the execution of the research. **External validity** • ++

All controls were transitioning before the introduction of the transition support service, so it is clear that they did not receive this service.	The authors do not emphasise their findings that after 3 years HbA1c levels were the same in both groups, which indicates that initial poor outcomes from a poorly managed transition may change over time.		

Care Quality Commission (2014) From the pond into the sea: children's transition to adult health services

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Clearly stated aims or brief? • Partly No clear definition of aims apart from statement that CQC started a programme of 'themed' work to consider the transition arrangements for young people with complex health needs with the findings and challenges detailed in the report. **Stated methodology?** • Yes Methodology involved: 1. collection of background information on a range of things including the pathway and process of transition, staff skills and training and people's	**Clear authorial standpoint?** • Yes The summary makes clear that is unacceptable to find parents and young people to be victims of a healthcare system where the infrastructure to support transition from young people to adult services is lacking. **Work appears balanced?** • Yes Reference is made to both the factors that help and hinder transition. **Any limits clearly stated?** • Yes A total of 100 clinical commissioning groups (CCGs)	**Conclusions justified?** • Yes The report concludes that there is a general lack of provision for, and knowledge of, the specific needs of the young adulthood developmental phase, especially for young people with complex health needs. Staff lack the resources and training as well as failing to prepare, support and provide information to young people, their families and carers. The report concludes with recommendations to address these gaps. **Enriches research area?**	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

experiences after transfer to adults' services; 2. experiences also collected via: i) focus groups with young people, families and carers in Birmingham, Salford, Bristol, London, Salford and York; ii) telephone interviews with Experts by Experience, people in CQC involvement teams, or inspectors; iii) online web form for people who were not able to meet or talk with the research team.	were approached to help identify young people (aged 14-25 with complex physical health needs). This information was anonymised and used as the basis for selecting a sample of 19 areas to visit across England. CQC also inspected 23 CQC-registered services that provide care for young people during and after the period of transition to adults' services. These included residential care homes and colleges, short break services, home care services and hospices.	• Yes As well as exploring the experiences of young people and their families and others, the report provides examples of good transition planning, especially in specific health areas.	

Certo N, Mautz D, Smalley K, et al. (2003) Review and discussion of a model for seamless transition to adulthood

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
How was selection bias minimised?	**Was the exposure to the intervention and comparison**	**Is the setting similar to the UK?**	**Internal validity** • -

• No comparison group **Was the allocation method followed?** • Not reported **Did participants reflect target group?** • Partly Characteristics of participants are not described in a table. The authors do describe some characteristics of young people in one area, and also overall characteristics of those eligible for the programme. **Were all participants accounted for at study conclusion?** • Not reported	**as intended?** • Not reported **Was the study sufficiently powered to detect an intervention effect (if one exists)?** • No **Were the analytical methods appropriate?** • No The outcomes were collected and analysed like in an audit. The outcomes are very promising, but it is difficult to transfer the findings to recommendations due to the methods used.	• Partly: US **Is there a clear focus (guideline population)?** • Yes Young people with high support needs. **Is the intervention clearly defined?** • Yes **Are the outcomes relevant?** • Partly Partly relevant to our guideline scope. Employment is clearly an important outcome to young people, their families and society.	**External validity** • +

Cheak-Zamora N, Xuejing Y, Farmer J, et al. (2013) Disparities in transition planning for youth with autism spectrum disorder

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Objectives of study clearly stated?	**Measurements and outcomes clear?**	**Is the setting similar to the UK?**	**Internal validity** • +

• Yes Objectives clearly stated. **Clearly specified and appropriate research design?** • Partly The design uses existing survey data. This was collected by telephone and then statistically analysed. There is a lack of detail around the interview methods or the role of the researcher. **Subjects recruited in acceptable way?** • Yes The sample is large. The survey isolated a representative sample of households with children who had special healthcare needs. Households were distributed across 50 states. Data collection was completed in 192,083 households with children; 44,923 of these had children who were deemed to have special health needs; 40,723 children were eligible for the study. This was narrowed down by age,	• Yes The study describes how to work out the HCT variable. **Measurements valid?** • Yes **All important outcomes and results considered?** • Yes **Appropriate choice and use of statistical methods?** • Yes This is well described and the methods are reliable. **In-depth description of the analysis process?** • Yes There is good description of analytical methods and process. **Are sufficient data presented to support the findings?** • Yes	• Unclear This is a US study and therefore may have limited relevance to a UK context. **Is there a clear focus on our population?** • Unclear The focus is less on the process of transition and more on the amount of services different groups received. **Is the intervention clearly related to transition?** • Yes **Are the outcomes relevant?** • Unclear Some are, those that relate to successfully accessing services. But others relate to school and work which are outside the remit of this guideline. **Results can be generalised?** • Partly The study acknowledges its limitations: ‘Partitioning of the sample may have further reduced its representativeness. No family	This is a well conducted study, with a large data set and reliable analysis methods. Data is self-reported and the findings are broad. The data has not presented a more in-depth picture of transition for this group. **External validity** • +

participants were meant to be 12 to 17 leaving 18,198. Those with ASD were n=806. **Sample representative of defined population?** • Yes As far as it is reported the study seems to have sampled in a representative manner.		factors were shown to predict HCT services within this sample. These findings may be due to the lack of variation in many of the family factors such as health insurance status or educational level' (p452). **Do conclusions match findings?** • Yes	

Children's Workforce Development Council (2010) Do young people experiencing the transition from children's services to adult services understand the process and what their choices are?

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is a qualitative approach appropriate? • Appropriate Given the nature of the issues explored, a qualitative approach is most appropriate. **Is the study clear in what it seeks to do?** • Mixed The focus of inquiry is that young disabled people and their families are often ill informed about the transition process, and that it is incumbent on	**Is the context clearly described?** • Clear The researcher emphasises that existing research highlights the failings and inconsistencies of agencies involved in transition planning, and that more effective multiagency collaboration and person-centred planning should be embedded into practice. Within this context and the introduction of the government's ADHC	**Are the findings convincing?** • Not convincing Given the localised nature of the research and extremely small sample size (9 young people), the author stresses that the findings can be used to inform planning but should not be generalised more widely. However, the problem is that feedback was often orchestrated through parents and carers, if not the actual words of the parents and carers.	**Internal validity** • - This is a poorly conducted study overall. The positives included the fact that the researcher had made efforts to ensure it (the Council) had contacted young people from appropriate settings. But the drawback was the very small numbers (9) involved and the fact that the research suggests that their voices were being drowned out by parents and carers. So it is

professionals to make this a more positive experience with the best possible outcomes. The aim is to consider the effectiveness of transitions workers – their base being the adult and community services teams. **How defensible/rigorous is the research design/methodology?** • Somewhat defensible The researchers approached a group of young people with disabilities who were members of a local independence group with experience of transitions. Their input helped shape the questions to be used in the research. These questions were then streamlined after discussions to a set of 6 open questions reflecting what the young people thought were pertinent issues about the transition process. It is hard to gauge to what extent young people could influence study design, given the predetermined nature of the questions. **How well was the data**	programme in 2007 designed to improve service provision nationally, the research aims to understand how this local area is performing. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate The researchers approached staff within the 3 North Yorkshire disabled children's teams to draw their potential sample based on young people who had been referred to the adult and community services transitions workers. Three young people from each of the children's teams were recruited for interview by a researcher based in one of the other disabled children's teams so as to reduce interviewer bias. While researcher bias may have been addressed to some extent, it is possible that it may not have been totally eliminated, given the researcher's association to the wider service. **Were the methods reliable?** • Somewhat reliable The methods were somewhat	**Are the conclusions adequate?** • Adequate The researcher concludes that the relationships between parent/carer and young person can be fraught. It is acknowledged that the young person should be involved in planning of services and that professionals need to support this change. The researcher also acknowledges limitations in the methodology, e.g. getting to know young people better would have provided more scope to look for alternative forms of communication that would have helped young people to have more of a say. The researcher is cautious about making recommendations for practice based on this work, emphasising that it would be good to undertake a larger study to corroborate findings.	hard to know how valid the findings are. Furthermore, reporting of the data is very poor. Graphical information is ambiguous, often because it is not labelled properly. **Relevance to this guideline** • Highly relevant The topic is highly relevant but the research is flawed as stated. above.

collection carried out? • Inappropriately One aspect emerged as quite concerning, which was that all young people had their parents or carers present during interviews. This was an issue especially as some parents had deep reservations about the service provided by the transition process. All parents/carers encouraged the young people to speak up and even elaborated, possibly exaggerated on details as they perceived them. The other issue was that recording equipment was faulty so that some of the interviews could not be taped and researchers had to rely only on their notes. Eventually everything was transcribed. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate The researchers approached staff within the 3 North Yorkshire disabled children's teams to draw their potential sample based on young people who had been referred to the adult and community services	reliable in that researchers designed the interview schedule with input from a group of young people who were involved in an 'independence group'. The fact that a pre-existing framework was used may have partially influenced young people when feeding into the final design of the interview schedule. Two young people from the researcher's own caseload were involved in a pilot study and the questions and process were modified according to their feedback. As no further detail was provided it is hard to say how reliable this was. **Are the data 'rich'?** • Mixed The data are useful but do not describe findings in exacting detail. **Is the analysis reliable?** • Not sure/not reported Without information on how researcher theme and code transcripts/data. If so, how were differences resolved? Did participants feedback on the transcripts/data if possible and		

transitions workers. Three young people from each of the children's teams were recruited for interview by a researcher based in 1 of the other disabled children's teams so as to reduce interviewer bias. While researcher bias may have been addressed to some extent, it is possible that it may not have been totally eliminated, given the researcher's association to the wider service.	relevant? Were negative/discrepant results addressed or ignored? (p202)		

Clarke S, Sloper P, Moran N, et al. (2011) Multi-agency transition services: greater collaboration needed to meet the priorities of young disabled people with complex needs as they move into adulthood

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
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 For our question about how to transition young people who receive a whole combination of	**Is the process for analysing qualitative data relevant to address the research question?** • Partly There is limited information about the data analysis, but they did design a coding framework after reading through the interview transcripts. **Is appropriate consideration**	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • Partly	**Internal validity** • + The design fits our question well, but there appear to be limitations in terms of what can be drawn from this study. They do not speak about differences across the service models, and their focus is mainly on how young people and their parents had large levels of unmet needs, not whether different

services, a mixed-methods design can help consider different aspects of such transitions and from various standpoints. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • Yes Yes, a case study which tries to capture service delivery from the point of view of staff and service users works well for the question on how to deliver transition services for those using a whole range of services. **Are participants (organisations) recruited in a way that minimises selection bias?** • Yes The case study areas were selected so they varied in terms of geographical profiles (socioeconomic, ethnic, urban/rural), as well as applying different models for their transition work.	**given to how findings relate to the context, such as the setting, in which the data were collected?** • Partly The authors are clearly familiar with the policy and practice context of transition, at the time of the research. There is no description of how they considered this in terms of their own research, fieldwork and analysis. **Is there an acceptable response rate (60% or above)?** • No: 20% **Are measurements appropriate (clear origin, or validity known, or standard instrument)?** • Partly The questionnaire had been used previously and then adapted to this study. However, it was not a ‘validated’ questionnaire. **In the groups being compared (exposed versus non-exposed; with intervention versus without;**	The authors are clearly familiar with the policy and practice context of transition, at the time of the research. There is no description of how they considered this in terms of their own research, fieldwork and analysis. **Are the outcomes relevant?** • Yes	service models worked differently for them. This might be due to the questionnaires they used, it could be that the service models were not very different, or due to the low response rate to the services. **External validity** • ++

Questionnaires were sent out to all service users of these transition teams. **Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed-methods question)?** • Yes Sampling from 5 different areas with different transition models and different geographical make-up seems very relevant to the question of barriers and facilitators to service delivery since it gives room for comparison. **Is the sample representative of the population under study?** • No Considering the low response rate it seems reasonable to assume that the respondents are not representative of all service users in those areas.	**cases versus controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?** • Partly The researchers provide responses from pre- and post-transition service users, and comment on the drop-in needs, post-transition. They suggest that this might mean that some needs were met by services, but considering that transition from children's to adults' services occurs at the same time as other transitions in young people's lives (emerging social and biological adulthood tends to change expectations and relationships) the fact that there were modest drops in levels of need does not necessarily relate to service provision. **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? • Yes The survey was provided in different formats to include respondents with learning difficulties and had previously been used in another research project.		

Cobb R, Alwell M (2009) Transition planning/coordinating interventions for youth with disabilities: a systematic review

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Yes Mixed methods review including studies highly relevant to their focus. **Rigorous literature search?** • Yes The dates searched were 1984–2004, 3 databases are mentioned (ERIC, PsycINFO and Medline) but they say they searched more than these.	**Adequate description of methodology?** • Partly adequate The authors provide detailed information about methods up until the consideration of study quality of the final included studies. It is clear that they paid attention to it, and they say that they set inclusion criteria on requirements for internal and external validity (according to the WW Clearinghouse in the US and the Eppi-Centre in the UK). However, they do not provide	**Is the setting similar to the UK?** • Partly The authors do not provide country information about the studies, but these studies were analysed within a US framework. **A clear focus on transition services?** • Yes They focused clearly on transition within services (mainly education), and refer to another review where they focused on studies of life-skill	**Internal validity** • + This is a well conceptualised and comprehensive review. The rating is based on the lack of clarity in regards to the quality of the included studies, and also in describing the methodology. **External validity** • + This is a US study and its focus is mainly on outcomes which are outside of this scope. However, the focus on student participation in

The search plan was assessed by an information specialist. Electronic searches were complemented by author searches, reference lists and journal hand-searching. **Study quality assessed and reported?** • Partly reported The authors present a table with study characteristics which include sample size and attrition rate, but no further details on study quality.	descriptions bar 1 table which shows sample sizes of all included studies, as well as attrition. Information on focus, conceptualisation, theoretical approach, searching and screening is detailed and comprehensive. **Do conclusions match findings?** • Partly We considered the conclusions based on the student-focused interventions only, since these were closest to our scope and PICO. The authors appear to overemphasise the significance of the meta-analysis of these studies' results but their conclusion is underpinned by further evidence from qualitative studies.	interventions. Their definition of 'transition planning/coordinating interventions' includes reference to them being designed to facilitate young people's transition from school to post-school activities. **Are the population groups relevant?** • Yes Disabled young people about to leave secondary school, which corresponds with our PICO. **Inclusion of relevant health outcomes?** • No **Inclusion of relevant social care outcomes?** • Yes This is borderline, although the emphasis on student-centred planning is interpreted as being relevant to our PICO. **Exploring views on transition?** • Yes Included qualitative studies but note it is a mixed methods review so limited space, no	transition is very relevant, and so it has been rated to reflect this.

		quotes.	

Commission for Social Care Inspection (2007) Growing up matters: better transition planning for young people with complex needs

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
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 The methods for this study are appropriate to gain the experiences of young people, their parents and carers. However, the methods are poorly reported. There is very little account of how the interviewees were identified, the interview content or how the data was analysed. **How well was the data collection carried out?** Not sure/inadequately reported.	**Is the context clearly described?** • Clear **Was the sampling carried out in an appropriate way?** • Not sure Not reported. **Were the methods reliable?** • Not sure Very poor reporting on this. **Are the data 'rich'?** • Rich **Is the analysis reliable?** • Not sure/not reported	**Are the findings convincing?** • Somewhat convincing The interview data is good but the lack of reporting on methods make it hard to assess their validity. **Are the conclusions adequate?** Somewhat adequate	**Internal validity** • - This paper contain a good deal of rich data from young people, carers and professionals, but the methods are not adequately reported, severely limiting the validity of the findings. **Relevance to this guideline** • Highly relevant

Not reported. **Was the sampling carried out in an appropriate way?** Not sure, not reported.			

Cowen A, Duffy S, Murray P (2010) Personalised transition: innovations in health, education and support

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall assessment**
Report identifies who is responsible for intellectual content? • Yes **Are they reputable?** • Yes The authors have first-hand knowledge and experience of working in voluntary and statutory sector with special interests in independent living and self-directed support. Simon Duffy is the director of the Centre for Welfare Reform and developed the concept of individual budgets. Pippa's expertise is to portray the voices of young and disabled people, bolstered by the fact that she has personal life experience to draw from.	**Clear authorial standpoint?** • Yes **Work appears balanced?** • Yes **Adds context?** • Yes The report highlights that disabled young people going through transition face the normal emotional challenges, including making decisions about their future, but this is complicated further by the barriers created by the 'services and the system' that are designed to assist them. For example: 1. ending relationships with children's education, social care and health and starting new relationships within adults'	**Conclusions justified?** • Yes **Any limits clearly stated?** • Yes The findings of the report are limited to Talbot School in Sheffield, but lessons learned have wider applicability and need to be modified to take into consideration local contexts. **Enrichens research area?** • Yes The report contains case studies (p21) of young disabled people using self-directed support to achieve their goals and aspirations through innovative means that break away from the traditional	**Internal validity** • - **Relevance to this guideline** • Highly relevant

Clearly stated aims or brief? • Yes **Stated methodology?** • Partly No detail about sample size and so on, but one sentence (p57) outlining what process was used: 1. interviews with parents and professionals; 2. workshops gathering the views of disabled young people; 3. young people's views also captured through the support planning process; 4. learning from regular evaluation workshops over 3 years collected information and associated published evaluations such as 'Just look at us now' (Murray 2008).	services; 2. a lack of appropriate advice about funding and support after leaving school – entitlements are unclear and usually become apparent long after young people have left school, making planning within school impossible; 3. joint planning and continuity are promoted through facilitating greater communication between all the different professionals, often leaving young people and families feeling excluded.	method of service delivery. **Strengthens or refutes a current position**? • Yes This report supports the concept of personalised transition and highlights that providing the environment where young disabled people (and their families) can finalise their plans for the future and have individual budgets agreed results in better outcomes than for school leavers from previous years.	

Craston M, Thom G, Spivak R (2013) Impact evaluation of the SEND Pathfinder Programme research report

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is the mixed-methods research design relevant to address the qualitative and quantitative research questions (or objectives), or	**Is the process for analysing qualitative data relevant to address the research question?**	**Is the setting similar to the UK?** • Yes **Is there a clear focus on**	**Internal validity** • ++ This is a very broad and rigorous study. It clearly

the qualitative and quantitative aspects of the mixed-methods question? • Yes **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • Yes **Are the sources of qualitative data (archives, documents, informants, observations) 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)?** • Yes **Are participants (organisations) recruited in a way that minimises selection bias?** • Unclear	• 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 **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?** • Yes **Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and**	**young people in transition?** • No There is some explicit reference to transitions but this study looks at support across a wide age range. **Is the intervention clearly 'transition'?** • No **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • Yes **Are the outcomes relevant?** • Partly Some of the developmental and educational outcomes are not relevant to this guideline.	reports its methods. **External validity** • + Some broad relevancy to transition but very little explicit evidence about service transitions.

Are participants (organisations) recruited in a way that minimises selection bias? • Unclear	**outcomes?** • Yes		

Crowley R, Wolfe I, Lock K, et al. (2011) Improving the transition between paediatric and adult healthcare: a systematic review.

Internal validity, methods	Internal validity, clarity of reporting	External validity	Overall rating
Appropriate and clearly focused question? • Yes The objective was to review the evidence of effectiveness of 'transitional care interventions in improving health outcomes in a broad range of conditions (any chronic physical or mental illness or disability), in order to identify key features on which clinicians can base future services and research' (p549). **Inclusion of relevant individual studies?** • Yes **Rigorous literature search?** • Yes Searched MEDLINE, HMIC, PsycINFO and Embase. The	**Adequate description of methodology?** • Partly adequate The authors provide a good description of the search, but only a sentence on how the studies were assessed and synthesised (referencing the Cochrane handbook). Also, they exclude the studies which did not find statistically significant findings from the interventions, which means that the review's conclusions are biased. **Do conclusions match findings?** • Partly It is not really possible to assess this because of the lack of information on the 4	**Is the setting similar to the UK?** • Partly There is no information on where the included studies were conducted. The review itself was carried out in the UK. **A clear focus on transition services** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes?** • Yes **Inclusion of relevant social care outcomes?** • No	**Internal validity** • - This rating is based on the fact that they only present findings from studies which found a positive and statistically significant effect from the intervention. They do not provide information about the findings of 4 studies which they excluded from their analysis. **External validity** • ++ This is a review conducted by UK researchers and with a UK focus, and their review questions and scope fits wholly within ours.

search strategy contained terms relevant to the population and topic. It also appears they applied a methods filter for evaluations, which makes the search more specific.	studies which did not measure any statistically significant outcomes from the intervention. What they say based on the 6 included studies does match the findings of these studies, however, they present findings from comparison studies alongside findings from pre-post measure without a comparison group, and this is partly confusing in terms of the strength of the evidence. **Study quality assessed and reported?** • Partly reported The authors state that the methodological quality of the included studies was poor, they list some reasons for this (lack of equivalent comparison groups), but they do not provide information on the individual studies beyond this, nor describe how the studies were assessed by the reviewers.		

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate – a case study methodology **Is the study clear in what it seeks to do?** • Clear **How defensible/rigorous is the research design/methodology?** • Defensible – this is a hard to reach and vulnerable group, focus groups in a neutral location seems appropriate. **How well was the data collection carried out?** • Appropriately The focus groups were recorded and transcribed, as were interviews. **Was the sampling carried out in an appropriate way?** • Appropriate Eligible individuals were identified from a central database of transition-age patients. Suitable individuals	**Is the context clearly described?** • Clear **Were the methods reliable?** • Reliable Focus groups are shown to be a good way to elicit views and more in-depth interviews were carried out with some young people, parents and professionals. **Are the data 'rich'?** • Rich **Is the analysis reliable?** • Somewhat reliable At times it is hard to tell where quotations have been taken from, whether it's parents, professionals or young people themselves. The reporting of findings lacks clarity at times.	**Are the findings convincing?** • Convincing The findings are reported thematically and supported by quotes. There could be more detail. **Are the conclusions adequate?** • Adequate	**Internal validity** • + **Relevance to this guideline** • Highly relevant

for focus groups were identified through discussions with keyworkers and service managers.			

Donkoh C, Underhill K, Montgomery P (2006) Independent living programmes for improving outcomes for young people leaving the care system

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Unclear No studies were found to meet inclusion criteria. **Rigorous literature search?** • Yes **Study quality assessed and reported?** • Unclear No studies found to be quality assessed in full.	**Adequate description of methodology?** • Yes **Do conclusions match findings?** • Yes They did not find any studies that met their inclusion criteria, and so they make no conclusions. Note, however, that they chose to exclude studies without randomisation to groups.	**Is the setting similar to the UK?** • N/A **A clear focus on transition services?** • Unclear **Are the population groups relevant?** • Unclear **Inclusion of relevant health outcomes?** • Unclear **Inclusion of relevant social care outcomes?** • Unclear **Exploring views on transition?** • Unclear The 'unclear' ratings are due to	**Internal validity** • ++ This study employed good systematic reviewing methods and reports fully on its processes. Its methods were appropriately rigorous and the study made the decision not to include any studies which did not meet its criteria. **External validity** • + A relevant approach but no relevant studies found.

		lack of included studies. The review focus was relevant.	

Doug M, Adi Y, Williams J, et al. (2011) Transition to adult services for children and young people with palliative care needs: a systematic review

Internal validity, methods	Internal validity, clarity of reporting	External validity	Overall rating
Appropriate and clearly focused question? • Yes 'The scope of this systematic review was to evaluate the evidence on transition from child to adult services for young people with palliative care needs, exploring the impact of the transition process on continuity of care, young people and their families' experiences and to identify models of good practice' (p79). **Inclusion of relevant individual studies?** • Yes The review had very wide inclusion criteria though, including guidelines and surveys. **Rigorous literature search?** • Yes	**Adequate description of methodology?** • Partly adequate There is good description of the searching, quality assessment and data extraction, and good description of findings within disease areas. No details provided on the synthesis, although reference to further details in online appendices. Lack of clarity on how they drew on such a varied evidence base, e.g. they say that only 34% (31 out of 92) of articles were primary research. **Do conclusions match findings?** • Yes	**Is the setting similar to the UK?** • Yes A considerable proportion of included papers were from the UK (n=27), and the other included countries were mainly the US and Western Europe. **A clear focus on transition services?** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes?** • Yes **Inclusion of relevant social care outcomes?** • No **Exploring views on transition?**	**Internal validity** • + This score is due to the lack of information on how the varying quality of studies was treated in the analysis. **External validity** • ++ This is a UK-based review with an international focus, and their review questions fit wholly within ours.

Searched MEDLINE, CINAHL, PsychINFO, British Educational Index, and the IBSS, from 1995–2008, plus reference checking. **Study quality assessed and reported?** • Yes They used a validated scoring system and cite the source for this (Hawker et al. 2002). Double coding at data extraction.		• Yes	

Downing J, Gleeson H, Clayton P, et al. (2013) Transition in endocrinology: the challenge of maintaining continuity

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Question appropriate and focused? • Adequately addressed. The study is quite brief but outlines its aims adequately. **Cases clearly defined?** • N/A **Distinguishing of cases from controls?** • N/A	**Comparable populations?** • N/A **Distinguishing of cases from controls?** • N/A **Exposure status** • N/A **Confounding factors** • Adequately addressed The study discusses its limitations comprehensively. It acknowledges that its findings	**Do conclusions match findings?** • Yes **Is the setting similar to the UK?** • Yes UK setting. **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly related to service transition?**	**Internal validity** • + The lack of a control group affects the validity of this paper; the sample is also small and there may be some young people missed out, who did complete transition. **External validity** • + This study is UK based and has a clear focus on young

	may not be generalisable because it looks at 1 service in 1 area. The sample size was also small and may not have taken into account all the young people who transitioned. There is also little data on the characteristics of the patients which may have affected their transition experience.	• Yes **Are the outcomes relevant?** • Yes The outcomes relating to young people remaining engaged with services are relevant and the approach is interesting in that it looks at retention at a young persons' transition clinic rather than adults' services.	people passing through transition. The study has a relatively simple design which looks at attendance of transition services. Reasons for attendance or non-attendance are linked to demographic and attendance to clinics pre-transition, but other factors like satisfaction are not discussed.

Everson-Hock E, Jones R, Guillaume L, et al. (2011) Supporting the transition of looked-after young people to independent living: a systematic review of interventions and adult outcomes

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Yes There is a table of intervention characteristics and this indicates that some of the intervention components were not directly about independent living, family planning, advice on socialisation, decision-	**Adequate description of methodology?** • Yes **Do conclusions match findings?** • Yes	**Is the setting similar to the UK?** • Partly Mainly US studies, one from the UK. **A clear focus on transition services?** • Yes Clear focus on transitioning out of children's services (looked-after young people). **Are the population groups**	**Internal validity** • ++ The study reports its methods well and uses a rigorous literature search and critical appraisal process. **External validity** • - This paper does not include outcomes which relate to health or social care, which affects it relevancy, despite its focus on care leavers and

making/problem-solving. **Rigorous literature search?** • Yes Searched 18 databases, on population only. This resulted in 20,000 hits which were then searched on intervention. Included supplementary search on reference lists and citations, and consultation with experts. **Study quality assessed and reported?** • Yes		**relevant?** • Yes Looked-after young people, so users of children's services. **Inclusion of relevant health outcomes?** • Yes For this group, but no for this guideline. None of the outcomes were related to service use, but to long-term situations (education, crime, employment and housing). **Inclusion of relevant social care outcomes?** • Unclear The outcomes are not always directly tied to social care staff or interventions, affecting its applicability for this guideline. **Exploring views on transition?** • N/A	transitions and relevancy to a UK context.

Fair C, Albright J, Lawrence A, et al. (2012) The pediatric social worker really shepherds them through the process: care team members' roles in transitioning adolescents and young adults with HIV to adult care

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is a qualitative approach	**Was the sampling carried**	**Are the findings convincing?**	**Internal validity**

appropriate? • Appropriate This approach seems appropriate for gathering view on the involvement of different professionals in the transition process. **Is the study clear in what it seeks to do?** • Clear **How defensible/rigorous is the research design/methodology?** • Defensible The qualitative approach is good in that it gains rich data on the everyday working of a transition, and gives an account of the range of tasks undertaken by social work staff. This kind of information may not have been captured by a different methodology. **How well was the data collection carried out?** • Appropriately The study used purposive snowballing methods to gain informants, which is justified in the methods section. Terms were defined in interviews and	**out in an appropriate way?** • Appropriate **Is the context clearly described?** • Clear **Was the sampling carried out in an appropriate way?** • Appropriate Purposive sampling seems appropriate to gather informants, but a larger sample would have been good. But this approach is justified in attempting to gain 45-minute interviews with busy professionals. **Were the methods reliable?** • Somewhat reliable The paper does not discuss possible bias of interviewers or any issues with self-reporting, but the approach is reasonable for qualitative interviews. **Are the data 'rich'?** • Rich Quotes from interviews are included. **Is the analysis reliable?** • Reliable An account of the analyses	• Convincing **Are the conclusions adequate?** • Adequate The study acknowledges its limitations in terms of sample size and the different professionals it was able to interview. The study was also not able to measure patients' outcomes from good professional relationships/working.	• ++ **Relevance to this guideline** • Highly relevant

qualitative data were analysed using Atlas.ti software and coded to identify major themes.	procedure is given and seems rigorous.		

Fegran L, Hall E, Uhrenfeldt L, et al. (2014) Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes The objective was to synthesise qualitative studies of how adolescents and young adults with chronic diseases experience the transition from paediatric to adult hospital care. **Inclusion of relevant individual studies?** • Yes Included studies from 1999 to Nov 2010 and until February 2011. Reports were included through 'berry picking' (Sandelowski and Barroso 2007). Study met following inclusion criteria: 1) adolescents'	**Adequate description of methodology?** • Yes Qualitative metasynthesis (a specific focus on systematically interpreting and integrating findings in reports of qualitative research). Five steps involved: systematically devising the aim and rationale; searching for and retrieving qualitative research reports; critically appraising included reports; classifying the findings; and synthesising the findings. The Scandinavian–German research group PRANSIT (Patient Transition in Transfer), consisting of 5 nurse researchers, completed the	**Is the setting similar to the UK?** • Yes Eight studies from the 18 in the overall review are set in the UK and this is an acceptable figure from which to make a generalisation to a UK context. **A clear focus on transition services?** • Yes **Are the population groups relevant?** • Yes Yes. Focus on young adults with chronic diseases who transition from paediatric to adult hospital care.	**Internal validity** • ++ This review is of very high quality with transparent reporting of each stage of the review process from databases searched to final retrieval and analysis of relevant studies. **External validity** • ++ Eight out of the 18 studies were based in the UK. The objectives of the review clearly match the questions in the C2A scope and the findings can be generalised to a UK context.

or young adults' experiences of transition from a paediatric to adult ward; 2) study participants have a physical health condition; 3) published in English, German or a Nordic language. **Rigorous literature search?** • Yes Systematic searches covered the period between 1999 and November 2010, and up to Feb 2011. Reports were included through 'berry picking' (Sandelowski and Barroso 2007). Two of the authors developed a search strategy using the keywords 'teenager OR young adult OR adolescent' AND 'chronic disease OR special health care need' AND 'transfer OR transition' AND 'qualitative study OR phenomenology OR grounded theory OR hermeneutics' AND 'hospital OR intra-hospital'. The search strategy was tailored to fit each database. Studies eligible for inclusion were 'subject to forward chaining and ancestry searching in reference lists'. Almost 50% of the included studies were retrieved	review as the first phase in the development of a planned intervention to improve patient transfer in the healthcare system (Campbell and Tracey 2000). **Do conclusions match findings?** • Yes The authors' overall conclusions match with the findings presented in tables and more detailed text. The authors conclude that transition is a challenging phase and includes young people feeling in limbo and redundant. But despite this, young people value the increased responsibility and move forward. Nursing can facilitate the process through assessing preparedness, resources, relationships and responsibility as part of individual transfer plans. In Table 1, influence of researcher was unaddressed for the majority of studies. Implications? Table 2 illustrates that the majority of studies (14 of the 18) contained reference to the 4 sub-themes emerging from the	**Exploring views on transition? (qual)** • Yes	

through sources other than the initial database search and this process repeatedly adjusted to reflect all steps in the inclusion process. **Study quality assessed and reported?** • Yes The authors found that the majority of studies presented findings clearly based on the data collected, and no study that met the inclusion criteria was excluded due to poor quality (Carroll et al. 2012; Sandelowski et al. 2012). One vital inclusion criterion from the appraisal checklist was 'Is the patient's voice adequately represented?'. Table 1 describes the characteristics of the included studies providing detail on the methodology used for each individual study, and whether or not researcher bias was addressed. Studies with limited description of methods were not excluded as validity of their findings could be justified as data were relatively equally distributed across the sub-	review.		

themes (Table 2).			

Garvey K, Wolpert H, Laffel L, et al. (2013) Health care transition in young adults with type 1 diabetes: barriers to timely establishment of adult diabetes care

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Research design clearly specified and appropriate? • Yes The survey design was informed by a literature review, focus groups, expert review and testing on the population group. **Survey population and sample frame clearly described?** • Yes The survey contacted all eligible population. **Representativeness of sample is described?** • Yes **Design** • Measures for contacting non-responders? Not discussed. • Response rate? 53%.	**Describes what was measured, how it was measured and the outcomes?** • Yes **Measurements valid?** • Yes The analysis was carried out using SAS 9.2 software 'In multivariate analyses, barriers were dichotomized as not at all/small versus moderate/major in order to sharpen the distinction between those subjects who perceived significant barriers to the establishment of adult care and those who did not. Similarly, we dichotomized gaps at ≤6 months or >6 months for comparison with other reports (16–18), given the American Diabetes Association recommendation	**All appropriate outcomes considered?** • Yes The survey data is analysed using multivariate analysis to isolate all the themes. **Results discussed in relation to existing knowledge on subject and study objectives?** • No Results are discussed in isolation but context is described. **Limitations of the study stated?** • Yes The study outlines a variety of limitations, that include: 1) the cross-sectional design limits conclusions about the causes of transition barriers; 2) the views of patients were taken post-transition so detail may	**Internal validity** • ++ The study presents its methods, analysis and limitations clearly and used accepted methods for analysis. The survey tool was conscientiously developed. **External validity** • + The US context limits the applicability of this paper.

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 large enough to achieve its own objectives, but relates to a specific context. **Data suitable for analysis?** • Yes **Results internally consistent?** • 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?**	that insulin-treated patients >18 years of age have diabetes visits at least every 6 months' (p948). **Measurements reliable?** • Yes **Measurements reproducible?** • Yes **Basic data adequately described?** • Yes Findings are described in narrative findings, statistics and a graph describing the informants enduring each barrier to transition. **Results presented clearly, objectively and in enough detail for readers to make personal judgements?** • Yes **Methods for handling missing data described?** • No The study just focuses on the response it received. **Difference between non-respondents and respondents described?**	have been forgotten; 3) the provider perspective would have been useful; 4) the non-response rate is a problem. **Results can be generalised?** • Partly The study is US, so questions of insurance are not relevant. **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** • Partly Survey is not the most robust methodology, but the study looked at how representative the sample was and undertook rigorous analysis of the data, as well as analysing its limitations. **Conclusions justified?** • Yes	

• Yes	• Yes Non-responders were often male, but other characteristics were similar to respondents.		

Gilmer T, Ojeda V, Fawley-King K, et al. (2012) Change in mental health service use after offering youth-specific versus adult programs to transition-age youths

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Question appropriate and focused? • Well covered **Participation rate for each group?** • Cases: 931 • Controls: 1,574 **Cases clearly defined?** • Well covered **Distinguishing of cases from controls?** • Adequately addressed Young people who first used adult services and then swapped to young people-focused services were analysed as belonging to the young people-services group. Young people who started using adult services prior to	**Comparable populations?** • Well covered **Distinguishing of cases from controls?** • Adequately addressed Young people who first used adult services and then swapped to young people-focused services were analysed as belonging to the young people-services group. Young people who started using adult services prior to October 2006 were excluded from the sample. **Exposure status** • Adequately addressed Days in each programme are stated, but not the nature of service contact.	**Is the setting similar to the UK?** • Partly This is set in the US, with a very different health care system, but culturally there are some similarities. **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly related to service transition?** • Yes **Are the outcomes relevant?** • Yes	**Internal validity** • + **External validity** • +

October 2006 were excluded from the sample.	**Confounding factors** - Adequately addressed Young people's diagnoses are listed, as is Medicaid coverage, race and ethnicity. Nothing about service needs, which might explain differences in service contact after one year. **Statistical analysis** - No CI provided **Do conclusions match findings?** - Yes		

Hagner D, Kurtz A, Cloutier H, et al. (2012) Outcomes of a family-centred transition process for students with autism spectrum disorders

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
How was selection bias minimised? - Randomised Students were randomly allocated to either receiving the intervention, or being on a waiting-list control and receiving the intervention after 1 year. **Was the allocation method**	**Was the exposure to the intervention and comparison as intended?** - Yes **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** - Yes This was tested on age,	**Is the setting similar to the UK?** - Partly US study, conducted in Maine and New Hampshire. **Is population relevant?** - Yes Young people at leaving compulsory school age, diagnosed with autistic	**Internal validity** - - This is mainly due to the small sample size, combined with missing values. For example, if we were to recalculate the findings using numbers needed to treat for missing values, the results are likely to change considerably. Considering 'self-

followed? • Not reported **Did participants reflect target group?** • Partly All of the participants had been diagnosed as having autistic spectrum disorder, 39 with autism, 8 with Asperger's disorder, and 2 with pervasive developmental disorder – not otherwise specified. However, all of the sample was white, and only 2 were young women. **Were all participants accounted for at study conclusion?** • Partly Two students dropped out of the study, and these are mentioned but not included in the pre- and post-measures. Almost all data collection had missing values for some participants.	gender, ethnicity and adaptive behaviour. **Was the study sufficiently powered to detect an intervention effect (if one exists)?** • No **Were the analytical methods appropriate?** • Partly It is commendable that they provide detailed information on the outcome measures and also results, but it would have been preferable if they had conducted more advanced statistical tests.	spectrum disorder. **Is the intervention relevant?** • Partly This intervention was embedded in education and school, but the study was included due to its reference to adult services. **Are the outcomes relevant?** • Yes Self-determination corresponds to what we have called 'self-efficacy' in our PICO. Expectations for the future corresponds to 'transition readiness', although this latter interpretation is borderline.	determination' only, 9 (37.5%) students in the intervention group and 6 (26%) in the control group did not complete this survey questionnaire. **External validity** • + This is a US study and focused on education and employment, however it does measure some outcomes of relevance to our scope and also the intervention includes liaison with community agencies outside of education.

Hamdani Y, Proulx M, Kingsnorth S, et al. (2014) The LIFEspan model of transitional rehabilitative care for youth with disabilities: healthcare professionals' perspectives on service delivery

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**

Is a qualitative approach appropriate? • Appropriate The aim of this study was to examine professionals' experiences of delivering services within the LIFEspan model of transitional care. **Is the study clear in what it seeks to do?** • Clear Very clear aim, and the methods and conceptual framework fits with that. **How defensible/rigorous is the research design/methodology?** • Defensible This is a qualitative arm of a longitudinal outcome study of the LIFEspan model of transitional care. They wanted to know about practitioners' experiences of working within this model, and so a qualitative approach was highly appropriate. **How well was the data collection carried out?** • Appropriately Semi-structured in-depth	**Are the data 'rich'?** • Rich All identified themes from the analysis are underpinned by quotes from the respondents.	**Are the findings convincing?** • Convincing The findings are underpinned by the conceptual framework and what people said in the interviews, as well as previous studies linked to the larger LETS study. **Are the conclusions adequate?** • Adequate The conclusions flow directly from the findings.	**Internal validity** • ++ This is a well-conducted qualitative study. The sample is quite small, and only with people delivering the services, which does limit the reliability of the analysis. However, it could be argued that for the purposes of this paper these 14 people were the exact ones they wanted to hear from. **Relevance to this guideline** • Highly relevant This study is relevant to several questions, but most notably the question about implementation.

interviews, and data is represented by quotes. **Is the context clearly described?** • Clear There is a description of the LIFEspan model and the large LETS study of which this qualitative study was part. There is also a description of the participants, showing that they had different professional backgrounds. The hospitals in which they worked are not described well. **Was the sampling carried out in an appropriate way?** • Not sure It is not clear how large the LIFEspan teams were and whether the 14 participants in this study comprised all professionals working there. The authors do not say how the 14 were selected, but the text might be understood as these 14 comprising all LIFEspan team members in both hospitals. **Were the methods reliable?** • Somewhat reliable			

This was quite a small sample of 14, and only focused on the experiences of professionals, not young people, carers, parents, administrators, commissioners or other people involved in young people's transition. The interviews seemed to cover all important concerns of the study.			

Heslop P, Abbott D (2007) School's out: pathways for young people with intellectual disabilities from out-of-area residential schools or colleges

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate Appropriate for gathering parents' views on the factors which help and hinder satisfactory transition. **Is the study clear in what it seeks to do?** • Clear Objectives are outlined. **How defensible/rigorous is the research design/methodology?** • Defensible	**Is the context clearly described?** • Clear **Was the sampling carried out in an appropriate way?** • Appropriate **Were the methods reliable?** • Somewhat reliable The methods were somewhat reliable in that findings could be compared across different groups (i.e. young people, parents and professionals). However, only one method	**Are the findings convincing?** • Convincing Parent views are supported by professional views where appropriate. **Are the conclusions adequate?** • Adequate The conclusions reflect the findings adequately. There are no discrepancies between what the authors conclude and the findings more generally.	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

The methods used were comprehensive and the researchers designed their process so as not to exclude the views of young people, e.g. by offering to undertake interviews in the residential school/college of the young person; and offering various means besides verbal communication (e.g. pictures), to express views. **How well was the data collection carried out?** • Appropriately The interviews with the young people were held at their residential school or college and were inclusive so as to enable young people with differing levels of communication and conditions (e.g. physical impairments) to participate. For those able to communicate verbally, interviews were tape-recorded with consent. Another group of young people used pictures to express their views and these were written up, while a third group of young people used gestures and activities to	was used. **Are the data 'rich'?** • Rich Methods are based on semi-structured/unstructured techniques that allow for in-depth exploration of participant views and experiences, and appear not to be led by the researcher. **Is the analysis reliable?** • Reliable Participants (parents and professionals) were given the opportunity to read through the transcripts of interviews and amend them for inaccuracies. Two researchers independently checked texts and coded them into themes and sub-themes while a random sample of text was also checked for any errors or inconsistencies.		

express opinions. Interviews with parents used a semi-structured interview format and were taped with their consent.			

Hiles D, Moss D, Thorne L, et al. (2014) ‘So what am I?’ multiple perspectives on young people’s experience of leaving care

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate In terms of the aims of this study to collect views and experiences of young people, a qualitative approach is clearly appropriate. **Is the study clear in what it seeks to do?** • Clear It clearly sets out its aims as well as its rationale for study design and methods – including the ethnographic stance of the researcher and how this aspect fed into the research methods (i.e. reflective journal entries). The study is supported by a good literature base and underpinned by various	**Is the context clearly described?** • Clear The lead researcher presents the context clearly with a detailed literature review to present the case before launching into the research. He also describes the process by which participants were identified and sampled for the research. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate Perhaps because this was a pilot study, sampling was not as rigorous. The author acknowledges that by choosing to include participants from an already existing care leavers’ group,	**Are the findings convincing?** • Convincing The study is presented in a clear and coherent way with plenty of narratives from the focus groups. Contextual material and other data is also referenced clearly. **Are the conclusions adequate?** • Adequate The lead researcher concludes by acknowledging some of the limitations in the study and reconfirming that change in policy, practice and continuing research is the way forward.	**Internal validity** • ++ This is a very high quality study, albeit a pilot. It sets the foundation for further inquiry into the issues explored. Findings are reported clearly in the form of rich narrative from both young people and professionals. The research methods are transparent and limitations are also acknowledged. **Relevance to this guideline** • Highly relevant

theories. **How defensible/rigorous is the research design/methodology?** • Defensible **How well was the data collection carried out?** • Appropriately The focus group was then facilitated by the lead researcher and a support worker from CAMHS. Permission was taken to tape-record the discussions which lasted 70 mins. For the focus group with staff, another researcher facilitated this. The lead researcher also fed in his observations and reflections alongside his co-researcher to help prompt further discussion. Again, this meeting was audio-taped. **Were the methods reliable?** • Reliable The researcher made the research process transparent by clearly demarcating interviewee narrative from his own which he had taken from his reflective journal. The	he may automatically be excluding the voices of those who are not heard. Furthermore, no females were included as the care leavers' group was all male at the point in time when the research happened. **Are the data 'rich'?** • Rich Rich descriptions in terms of narrative from both young people and professionals cover a broad range of topics and are supplemented with the lead researcher's insights taken from his reflective journal. **Is the analysis reliable?** • Reliable The transcripts from the focus groups were analysed by separate thematic analysis for each group after being loaded into a specialist qualitative research software (nVivo). The process of analysing and the reasoning behind many of the decisions made was recorded in a reflective journal for the sake of transparency and		

journal was his record of his perceptions about his own experiences, beliefs and influences on the research process.	transcripts from this journal relating to the research process were also analysed. Discussions in the second focus group were verified with research participants to ensure group discussions were accurately represented.		

Hiles D, Moss D, Wright J, et al. (2013) Young people's experience of social support during the process of leaving care: a review of the literature

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes This review's purpose was to collate and synthesise research relating to young people's experiences of social support during their transition from care. **Inclusion of relevant individual studies?** • Yes Search items: 1200 from the	**Adequate description of methodology?** • Partly adequate The review clearly describes the research methodology in terms of searching the literature to identify what items were relevant for inclusion. However, there is no discussion of the more explicit detail on how researchers managed the process of agreeing papers for	**Is the setting similar to the UK?** • Yes **A clear focus on transition services?** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes? (quant)**	**Internal validity** • + The authors acknowledge that the method used to theme papers was quite basic and the validity of this process could have been verified by an external reviewer. Furthermore, one author's particular interests in the topic area would have meant that bias inevitably crept in when deciding what material

initial search were assessed for inclusion in this review only if they met all of a set of specific inclusion criteria – including that studies must be primary research and must be about care leavers’ views about the process of leaving care. This process of reviewing the literature against inclusion criteria included removing duplicates, reviewing titles and abstracts and removing papers not on topic, sourcing full texts of papers and again excluding papers not on topic until 47 items were identified for inclusion. These studies were then reviewed against a set of guidelines for qualitative research and studies were included so long as care leaver views were apparent. Metasynthesis was used to group common themes related to social support within these studies under 5 headings. **Rigorous literature search?** • Yes A systematic search of 3 electronic databases (‘PsycInfo’ via OvidSP, ‘Social Care Online’	inclusion and, where there were discrepancies between reviewers, how this was managed. Furthermore, the authors acknowledge that the method used to theme papers was quite basic and the validity of this process could have been verified by an external reviewer. **Do conclusions match findings?** • Yes The authors’ conclusions are in line with the findings.	• N/A **Inclusion of relevant social care outcomes? (quant)** • N/A This question on outcomes is not applicable in terms of operationalising the extraction of views papers.	to include. **External validity** • ++ Despite the inclusion of a considerable proportion of international literature, many of the young people’s experiences of social support appeared common across multiple countries. The reviewers focused on including these common experiences, with an emphasis on that which appears relevant within the UK policy context. Well known UK authors such as Munro and Holt were also referenced throughout, which helps to boost confidence in the narrative. Furthermore, the findings run parallel with what wider UK literature has reported as well.

and ‘SocIndex’) was carried out, using key search terms including: ‘in care’, ‘looked after’, ‘leaving care’, OR ‘care leaver*’, and ‘social network*’. The date range was all items published between 1 January 2001 and 27 September 2012. Some 1200 items were identified, including some duplicates. No dedicated literature reviews were found which fully met the aims of this review, though there was some overlap with others (e.g. Mainey et al. 2009; Oliver 2010; Stein 2005, 2006a). **Study quality assessed and reported?** • No Assessment and reporting of study quality is not clearly presented. The key premise for choosing a paper for inclusion was that its subject matter was the views of care leavers regarding social support. The authors acknowledged that this over-inclusive focus meant that poorer quality studies also made it through the screening process even if they did not meet quality			

criteria set out in the guidelines for qualitative research. Furthermore, the review acknowledges that the choice of some papers might have been partly influenced by the background and advocacy stance of one of the key reviewer who was a trained clinical psychologist and also had a particular interest in understanding the experience of leaving care for care leavers.			

HMI Probation, HMI Prisons, Care Quality Commission, et al. (2012) Transitions: an inspection of the transition arrangements from youth to adult services in the criminal justice system

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Stated methodology? • Yes A literature review was undertaken regarding case transfer and transitions within the criminal justice system and allied sectors such as health and ETE. Inspection criteria were developed and agreed by members of a reference group of officials from YOTs, probation trusts and central	**Work appears balanced?** • Yes The report provides a balanced view both of factors that help and hinder the transition process for young people. **Meaningful content?** • Yes **Adds context?** • Yes The report clarifies the	**Conclusions justified?** • Yes The conclusions of this report mirror the findings that both in custody and the community more effective processes and use of better professional judgement, as well as access to information and training, are necessary to improve outcomes for young people. **Any limits clearly stated?**	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant References to health and social care included.

government departments. The inspection methodology, including case assessment tools for custodial and community cases, was then piloted in the Thames Valley area and YOI Swinfen Hall. Wherever possible, the same criteria for custody and community cases were used, the main difference being that in custody all young adults whose cases were being inspected were interviewed, and in the community young people were interviewed irrespective of whether their case was included in the sample for case assessment. There is, therefore, a greater weighting given in our custody findings to the views of young adults than in our community findings. **Clearly stated aims or brief?** • Yes The terms of reference were: to assess the quality of work undertaken to promote an effective transition for young people subject to community and custodial sentences, at	complex landscape between service provision for young people (under-18s and those aged 18 and over) in custody and in the community. It provides contextual information regarding the development of policies such as the Crime and Disorder Act 1998, which brought together a range of local agencies – social services, education, police, probation, health and, in some cases, housing. Information is also enriched further with case studies. **Enriches research area?** • Yes The inspection examined the work that takes place to enable young people as they transition from youth-based to adult-based services and how frontline practitioners were promoting this effectively. This was not an inspection of the quality of the core work undertaken before and after transfer.	• Yes YOTs and probation trusts in 6 areas of England and Wales, and 4 YOIs. The focus was the work done by practitioners in YOTs, probation trusts, custodial establishments and others who provided interventions (including ETE, substance misuse, physical health and mental health services) to help young people move from working with youth-based to adult-based services during the course of their sentence (either under community supervision or in custody).	

the age of 18, from youth-based to adult-based provision			

Huang J, Terrones L, Tompane T, et al. (2014) Preparing adolescents with chronic disease for transition to adult care: a technology program

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
How was selection bias minimised? • Randomised Random block assignment stratified by condition, performed by the study's statistician after baseline data collection. **Was the allocation method followed?** • Yes **Did participants reflect target group?** • Yes **Were all participants accounted for at study conclusion?** • Yes Two in the treatment group and 4 in the control group were lost to follow-up.	**Was the exposure to the intervention and comparison as intended?** • Yes **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** • Yes The ages differed across the 2 groups in terms of conditions, but not for the whole group (so similar ages in the intervention and the control group). There were no significant ethnic or gender differences between the 2 groups, and no differences between the dropouts and the main cohort by age, gender or ethnicity. There were also not statistically significant differences in relation to	**Is the setting similar to the UK?** • Partly: USA **Is there a clear focus on population?** • Yes **A clear focus on transition services?** • Partly This is an intervention to prepare people for transition, but it isn't about changing structures or practice in terms of transition, apart from responding to young people's contacts in a new way (through texting). **Are the outcomes relevant?** • Partly The outcomes are relevant but again they are not directly related to whether young	**Internal validity** • ++ Note the small sample size. **External validity** • + The outcomes are proxy in terms of improving transition, and the setting is outside of the UK.

	condition status (specific condition scales, function, and quality of life). **Was the study sufficiently powered to detect an intervention effect (if one exists)?** • Not reported They do not report on power but they acknowledge that the sample size was ‘relatively small’ (p e1645). **Were the analytical methods appropriate?** • Partly The authors’ present means and standard deviations per group per time point, but they have not calculated standardized mean differences and standard errors, or similar effect sizes, for each outcome. They base their conclusions on arguing that one group’s change over time was statistical significant whereas the other one’s was not. This is a very crude way of analysing the data.	people’s transition was improved or not.	

Jordan L, Swerdlow P, Coates T, et al. (2013) Systematic review of transition from adolescent to adult care in patients with sickle cell disease

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Yes **Rigorous literature search?** • Partly rigorous They searched Pubmed and also some more specific websites for evidence. The search was not comprehensive for example it did not include CINAHL, which is an important database for nursing literature, or MEDLINE.	**Adequate description of methodology?** • No There is information about the search, but they do not describe how the studies were selected and assessed, nor anything about synthesis bar what is in the tables. **Do conclusions match findings?** • Yes **Study quality assessed and reported?** • Unclear There is no information on how they assessed the studies for quality.	**Is the setting similar to the UK?** • Partly This study quotes studies from the UK, but the findings are interpreted for a US context. **A clear focus on transition services?** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes?** • Yes **Inclusion of relevant social care outcomes?** • Partly This review addresses the wider needs of young people transitioning out of paediatric services, but not in any depth. **Exploring views on transition?** • Yes	**Internal validity** • + While information is lacking on their methods, overall this is a transparent review which means their findings could be checked against their included studies. **External validity** • + This review is highly relevant to our guideline, the only thing is that it is interpreted with an emphasis on the US context and private healthcare.

Kaehne A (2011) Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is a qualitative approach appropriate? • Appropriate As no research has been done in the area of mental health transitions for young people with learning disabilities, a scoping study using a qualitative approach was appropriate and provides in-depth information and context for follow-up research. **Is the study clear in what it seeks to do?** • Clear **How defensible/rigorous is the research design/methodology?** • Defensible The research design (deliberatively explorative interview) is suitable given the	**Is the context clearly described?** • Clear The researchers purposively selected 3 local authorities in Wales which had set up protocols for partnership work in transition for young people with intellectual disabilities. The author acknowledges that within the confines of a limited sample size, the respondents identified the key areas of transition planning and service cooperation in the 3 local authorities, but the study only managed to identify key themes for further research on service organisation and the involvement of mental health services in transition partnerships. **Was the sampling carried**	**Are the findings convincing?** • Convincing **Are the conclusions adequate?** • Adequate The research concludes that there are particular barriers to enable smooth transition. These barriers are emphasised and clearly presented through original quotes from interviewees.	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

aims of the study and the importance of extracting as much background information in an area that is under-researched, i.e. partnership work in transition for young people with intellectual disabilities from the view of mental health. **How well was the data collection carried out?** • Appropriately Data collection was systematic and involved semi-structured, face-to-face interviews, which were recorded and transcribed. Major themes were identified first in individual interview transcripts, then across all interviews. These themes were brought together into broader categories and checked by reading the transcripts again. Two researchers did the analysis independently and compared thematic groups.	**out in an appropriate way?** • Appropriate The study balanced the perspectives of both CAMHS and AMHS. **Were the methods reliable?** • Reliable Only one method was used. Though research findings were not triangulated, as this was a scoping study, future research will be able to either refute or support the findings. **Are the data 'rich'?** • Rich Quotes enhance and provide context to the findings. **Is the analysis reliable?** • Reliable Two researchers independently themed the narratives from the research.		

Kelly B (2013) Don't box me in: disability and transitions to young adult life

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**

Is a qualitative approach appropriate? • Appropriate Semi-structured interviews are the most appropriate method for this study as they facilitate in-depth exploration of the subtle meanings and complex experiences of individual respondents. **Is the study clear in what it seeks to do?** • Clear The aim of the study was to explore the transitional and life experiences of young people with learning disabilities. The objectives were to: 1. investigate the experiences of young people with learning disabilities and their identity narratives; 2. explore the impact of services on the lives of people with learning disabilities; 3. identify the type and range of service options available for people with learning disabilities and highlight key challenges for service providers seeking to meet the needs of young	**Is the context clearly described?** • Clear The author provides a clear description of the context and the rationale for this study. **Was the sampling carried out in an appropriate way?** • Appropriate Participants were selected from a sampling frame of 21 young adults who were involved in the earlier study (2000–2) who were now aged 18 years and over (excluding deceased and closed cases) (Kelly 2003, 2005, 2007). Because of the time that had elapsed, 7 young adults had moved to other areas or no longer had contact with social care services, and did not respond to invitation letters sent to their last known address. In 4 cases, consent was refused for various reasons. Ten young adults who were included in the final sample. **Were the methods reliable?** • Reliable	**Are the findings convincing?** • Convincing Although the focus was on the lives of 10 young people with learning disabilities, the researcher verified, after consulting professionals and the Barnardo's Northern Ireland Sixth Sense Group, that many of the themes that emerged from the research findings are relevant to a range of disabled young people experiencing transition. **Are the conclusions adequate?** • Adequate This research concludes that the research has significant implications for policy and practice in this area, as well as a need to continue to raise awareness of the issues affecting young people with learning disabilities.	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

people with learning disabilities. **How defensible/rigorous is the research design/methodology?** • Defensible The research is rigorous in its multifaceted approach and coverage of issues. Its integrity is improved by the triangulation of methods. As well as examination of case files and preparing case studies of young people. **How well was the data collection carried out?** • Appropriately Data collection methods were carefully considered to ensure sensitivity and enable participants to be fully involved. Interviews with parents were conducted before the interviews with young people to collect background information that would help the researcher construct sensitive questions for the interviews with young people. In the previous study, this process was found to be	Interviews with parents (p16 in main report). In addition to interviews, the researcher read adult social care case files, with prior consent, to gather documentary information about services used over the past decade. This information allowed the researcher to contextualise interview questions and provided an opportunity to triangulate information across 3 data sources (young adults, parents and case file records). **Are the data 'rich'?** • Rich Semi-structured interviews allowed for in-depth exploration of the subtle meanings and intricate experiences of research participants. **Is the analysis reliable?** • Reliable The analysis of the findings is very reliable. Interview data was analysed through an inductive and systematic analytical process, which was based on the narratives of		

helpful. In the interviews with young people, the researcher also offered different mediums for feedback such as the use of a digital camera to ensure that young people with various communication needs and preferences could fully participate.	research participants. Common themes were identified by a constant comparative approach coded and organised with the assistance of the MAXqda qualitative software analysis package. Case file audit records were analysed separately towards the beginning of the research to inform interviews. Descriptive data from this analysis were stored anonymously and combined with qualitative data from the interviews at final stages of analysis to compare patterns between these methods. Analysis was strengthened further by the involvement of a professional advisory group.		

Kime N, Bagnall AM, Day R, et al (2013) Systematic review of transition models for young people with long-term conditions: a report for NHS Diabetes

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes	**Adequate description of methodology?** • Yes	**Is the setting similar to the UK?** • Partly	**Internal validity** • + This is a thorough and

1. What models or components of models are effective in ensuring a successful transition process for young people with long-term conditions? 2. What are the main barriers and facilitating factors in implementing a successful transition programme? 3. What are the key issues for young people with long-term conditions and professionals involved during the transition process? (p1) **Inclusion of relevant individual studies?** • Yes But note this is a health-focused review which excluded social care transitions. **Rigorous literature search?** • Yes Searched electronic databases from inception to August 2012: MEDLINE, EMBASE, PsychINFO, CINAHL, ASSIA, Social Services Abstracts, Academic Search Complete and Web of Science – Social Science Citation Index. They	**Do conclusions match findings?** • Yes	There is not enough information on the studies included in the reviews to make a judgement on that, but the individual studies were all similar to the UK (although carried out in other minority world countries). **A clear focus on transition services?** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes?** • Yes **Inclusion of relevant social care outcomes?** • No Some of the outcome measures of interest are highly relevant to social care, but they explicitly excluded transitions in social care, community-based mental health and education as well as foster care and social services.	comprehensive review but it is not clear as to how they treated studies in terms of no effects, or harmful effects, from the intervention. **External validity** • ++ This is a UK-based review with a UK focus, and their review questions fit wholly within ours.

also searched the Cochrane and Campbell libraries and provide a full search strategy in an appendix. **Study quality assessed and reported?** • Yes The process for assessing Internal validity and study scoring is described on p8.			

Kingsnorth S, Lindsay S, Maxwell J, et al. (2010) Implementation of the LIFE span model of transition care for youth with childhood onset disabilities

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate This approach is appropriate for gathering data on staff experiences of the LIFEspan model and details about how well the service works and how the implementation process was done. **Is the study clear in what it seeks to do?** • Clear	**Was the sampling carried out in an appropriate way?** • Appropriate Interviewees were identified through a review of the projects steering committee, and a range of professionals were selected. **Were the methods reliable?** • Reliable **Are the data 'rich'?** • Rich A good deal of detail and	**Are the findings convincing?** • Convincing The data rich and the study achieves its aims in gaining 100% response rate. It also does not claim that the findings can be generalised and may be specific to this partnership. **Are the conclusions adequate?** • Adequate The study presents the key themes in terms of barriers and facilitators to the	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

How defensible/rigorous is the research design/methodology? • Defensible Eighteen key stakeholders of a possible 21 eligible were interviewed. A good range of professionals were interviewed and interviews were in depth. **How well was the data collection carried out?** • Appropriately The study details the types of open-ended questions asked and how it encouraged interviewees to 'talk freely about their experiences' (p551). Data was gathered by two interviewers, a standardised script was used and interviews were recorded. **Is the context clearly described?** • Clear The context of the LIFEspan services is well described.	quotation is provided. Data is presented in key themes.	implementation of the model. It acknowledges that these findings may be specific to this partnership and so cannot be generalised. It also acknowledges that the sample is small.	

Kipps S, Bahu T, Ong K, et al. (2002) Current methods of transfer of young people with Type 1 diabetes to adult services

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Question appropriate and focused? • Well covered **Participation rate for each group?** • Cases Numbers across the 4 groups were 56, 67, 65 and 41. **Cases clearly defined?** • Adequately addressed Not all young people transferred within the region, but it seems the figures on post-transfer only relate to those who did. It is clear what the main differences were in terms of transitional care across the 4 areas. **Distinguishing of cases from controls?** • Adequately addressed The case note review meant that it was clear which young people came from which area.	**Comparable populations?** • Poorly addressed The study provides information on sex and age, but no other information about the participants. **Distinguishing of cases from controls?** • Adequately addressed The case note review meant that it was clear which young people came from which area. **Confounding factors** • Not reported There is no analysis of any potential confounders apart from pre-transfer HbA1C and clinic attendance. The researchers do say that those going on to university had a higher post-transfer attendance rate than those who did not, indicating a link between clinic attendance and education	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly related to service transition?** • Yes **Are the outcomes relevant?** • Yes **Do conclusions match findings?** • Yes They do not make strong claims, but suggest that mode of transition/transfer might be an important factor in clinic attendance after transfer to adult services.	**Internal validity** • - **External validity** • ++

	levels.		

Kirk S, Fraser C (2013) Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: a qualitative study

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate This study looks at the views of young people with life-limiting conditions transitioning into adult care. **Is the study clear in what it seeks to do?** • Clear A clear set of objectives is presented **How defensible/rigorous is the research design/methodology?** • Defensible The interviews were conducted by experienced researchers. The sample is purposive, which seems appropriate given the target group. **How well was the data collection carried out?**	**Is the context clearly described?** • Clear Participants characteristics are described. Including, age, sex, condition and carer support. **Were the methods reliable?** • Somewhat reliable Transcripts were analysed. It does not say whether this was done by multiple researchers. Analysis section lacks detail. **Are the data 'rich'?** • Rich The data is complemented by long quotations and the themes identified seem appropriate. The context is described. **Is the analysis reliable?** • Reliable The interview data is well presented although the	**Are the findings convincing?** • Convincing **Are the conclusions adequate?** • Adequate The findings are internally coherent and presented in detail. There is additional material for a question on practitioners' views.	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

• Appropriately Participants were identified by hospice staff. The sample size is quite good (n=35). Interview topic guides were produced and interviews were semi-structured. **Was the sampling carried out in an appropriate way?** • Appropriate Purposive sampling seems appropriate given the specificity of the group.	analysis reporting lacks detail.		

Lee Y, Wehmeyer ML, Palmer S, et al. (2011) The effect of student-directed transition planning with a computer-based reading support program on the self-determination of students with disabilities

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
How was selection bias minimised? • Randomised Randomised by campus level, for practical reasons: teachers trained to provide the intervention would otherwise be teaching both intervention and control students. **Was the allocation method followed?**	**Was the exposure to the intervention and comparison as intended?** • Partly The intervention comprised 10 sessions. In the control group teachers completed an average of 7.4 sessions (SD=5) and in the intervention group teachers completed an average of 7.2 lessons (SD=5). **Were exposure and**	**Is the setting similar to the UK?** • Partly: US **Is the population relevant?** • Unclear The study focused on young people with learning difficulties, but it is not entirely clear that the sample matched this aim entirely. **Is the intervention relevant?**	**Internal validity** • + This was in many ways a well conducted study, but there is some information missing about follow-up and lack of clarity in terms of numbers. **External validity** • + This is a US study which primarily focused on education, but it did measure some

• Not reported **Did participants reflect target group?** • Partly The study wanted to provide the intervention to students having reading difficulties. However, relatively large proportions (3%, n=28 of the control group) and 16.3%, n=14 the intervention group were at proficient reading levels, which meant they were at the expected level for their grade. One student in the control group and 3 students in the intervention group were above the expected reading level for their grade, rated as ‘exemplary’ readers. The study also quotes students’ disabilities, but these are not necessarily related to reading abilities, apart perhaps from ‘learning disability’ and the proportions of this characteristic within the groups was 59.8% (n=49) in the control group and 33.7% (n=29) in the intervention group.	**comparison groups similar at baseline? If not, were these adjusted?** • Partly The authors present key characteristics of both groups. The groups were also tested at baseline on a self-determination scale and the 2 groups did not differ significantly on this. However, there was a statistical difference between the groups at baseline in terms of their IQ scores, with those in the control group scoring higher on this than those in the intervention group. The exact wording used is ‘IQ within normal limit’ and n=79 (96.3%) in the control group, n=58 (67.4%) in the intervention group. This was adjusted for in the analyses. **Was the study sufficiently powered to detect an intervention effect (if one exists)?** • Yes The authors based their analysis on results from previous studies and exceeded	• No This was an education transition intervention so mainly outside of scope. **Are the outcomes relevant?** • Yes The outcomes in this study correspond to ‘transition readiness’ and ‘self-efficacy’.	relevant outcomes and the intervention appeared to relate to their service transition not just developmental transition.

Were all participants accounted for at study conclusion? • Not reported	the requirement for each group. **Were the analytical methods appropriate?** • Yes		

Lewis S, Noyes J (2013) Effective process or dangerous precipice: qualitative comparative embedded case study with young people with epilepsy and their parents during transition from children's to adults' services

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
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 The research design is presented in rather complex way. The study aims to compare the	**Is the context clearly described?** • Unclear The context of the services is not that clearly described. The 2 service seem to offer broadly the same transitions service. The interview data does not differentiate between those who attended a transition clinic or similar service and those who were transferred directly. What we do gain are the experiences of young people passing through transition	**Are the findings convincing?** • Convincing The findings are organised by theme and the study uses quotations to illustrate its points. **Are the conclusions adequate?** • Adequate	**Internal validity** • + At times the reporting around the context methods is over complicated and some of the methods are unclear. There is a lack of detail around participant's characteristics. **Relevance to this guideline** • Highly relevant

experiences of young people at 2 hospitals. There is no decent breakdown of the participants' characteristics and it is also not clear why these 2 services were chosen as examples. Interviews seem to have been carried out proficiently. Young people with learning difficulties were sometimes represented by their parents. **How well was the data collection carried out?** • Somewhat appropriately The differences between the two services are not presented that clearly. It seems that in both cases some young people experienced a transition 'service' of some kind but other were transferred directly into adults' services. There is no rationale given for either approach. It is difficult to tell which data was gathered from which of the multiple methods the study employs. There are detailed and	which is valuable, but the data is not presented in relation to what kind of service they received. **Were the methods reliable?** • Somewhat reliable The paper does not describe how many young people with epilepsy were approached in the first instance so it is hard to say how well the recruitment was carried out. **Are the data 'rich'?** • Mixed There is a deal of data presented in detail. However, we know little about how inclusive the sample was and what kinds of services and interventions the young people had encountered as they had gone through transition because the context is not well described. **Is the analysis reliable?** • Somewhat reliable The analysis is presented in very complex terms. But essentially the study uses a thematic analysis of interview		

complex diagrams describing the theoretical approach to analysis but it is not clear how the interview data was analysed by researchers. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate It is unclear how participants were selected.	data.		

Mackie AS, Islam S, Magill Evans J, et al. (2014) Healthcare transition for youth with heart disease: a clinical trial

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
How was selection bias minimised? • Quasi-experimental Determined by patients' week of attendance. **Was the allocation method followed?** • Yes **Did participants reflect target group?** • Yes **Were all participants accounted for at study conclusion?** • Yes	**Was the exposure to the intervention and comparison as intended?** • Yes **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** • Yes **Was the study sufficiently powered to detect an intervention effect (if one exists)?** • Yes The researchers estimated that	**Is the setting similar to the UK?** • Partly: Canada **Is there a clear focus (guideline population)?** • Yes **Is the intervention clearly (guideline intervention)?** • Yes **Are the outcomes relevant?** • Partly	**Internal validity** • + **External validity** • +

	they would need 23 patients in each intervention group and they exceeded this number in each group. **Were the analytical methods appropriate?** • Partly There is one paragraph which clearly described the findings by outcome, including confidence intervals. There are some figures which are difficult to read and so it is hard to know the exact findings.		

Marriott A, Townsley R, Ward L (2009) Access to independent advocacy: an evidence review

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Unclear There is no list of studies and overview of methodologies of the included studies and so it is difficult to ascertain what type of evidence their findings are	**Adequate description of methodology?** • Yes **Do conclusions match findings?** • Yes	**Is the setting similar to the UK?** • Yes **A clear focus on transition services?** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes? (quant**)	**Internal validity** • + **External validity** • ++

based on. **Rigorous literature search?** • Yes **Study quality assessed and reported?** • Yes		• No **Inclusion of relevant social care outcomes? (quant)** • Yes	

Mills J, Cutajar P, Jones J, et al. (2013) Ensuring the successful transition of adolescents to adult services

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Report identifies who is responsible for intellectual content? • Yes RCN Publishing Company. **Are they reputable?** • Yes **Clearly stated aims or brief?** • Yes A retrospective clinical audit with aims to collect data on: the age of each client at referral; the age of each client at transition; the specialty of	**Clear authorial standpoint?** • Yes The author's introduction makes clear that poor transition is an issue that causes problems for both young people and their families, with the question of responsibility not defined clearly between agencies. He stresses the importance that this problem that needs to be addressed appropriately. **Work appears balanced?**	**Conclusions justified?** • No The author does not discuss any conclusions at length. A discussion section retells some of the findings in the earlier section, without any exploration of the author views. **Any limits clearly stated?** • Yes Adolescents referred from children's to adults' learning disability services at a Nottinghamshire Healthcare	**Overall assessment** • + The subject matter is very relevant to this area of transition. Triangulating the results with the views of professionals or young people would have strengthened the findings. **Relevance to this guideline** • Highly relevant

each referring organisation; information communicated in the referral; whether each of the service users had a named care coordinator; any problems that arose during referral. **Stated methodology?** • Yes A retrospective clinical audit of case notes, with no examination of patient care. All cases were anonymised and ethical approval obtained from the trust ethics committee. After inputting data into spreadsheet software, simple statistical tests were carried out.	• Partly **Meaningful content?** • Yes **Peer-reviewed?** • Yes This article went through a process of double-blind review and has been checked using anti-plagiarism software.	NHS Trust between August 2011 and March 2012.	

Milner C (2008) Experiences of health transition for young people with learning difficulties and complex health needs in Northumberland (+, relevance to this guideline: highly relevant)

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is a qualitative approach appropriate? • Appropriate This approach is appropriate in eliciting the views of young people and their carers about their experiences of care and	**Is the context clearly described?** • Unclear Information about the demographic of the local area was collected in the mapping exercise which is separate	**Are the findings convincing?** • Somewhat convincing The findings are useful but the lack of detail around their analysis is problematic. We are not given enough detail about how the data was analysed	**Internal validity** • + The study reports some of its methods well but leaves out some detail when it comes to sampling and analysis. **Relevance to this guideline**

the transition process. **Is the study clear in what it seeks to do?** • Clear The study lays out its aims quite clearly. **How defensible/rigorous is the research design/methodology?** • Somewhat defensible The detail about the approach is quite good. The study details each stage of the consultation process and how interviews were conducted. There is not very much detail about how young people were recruited or how the sample was made up. **How well was the data collection carried out?** • Somewhat appropriately There is very little detail about the collection and analysis of the data. The data was not analysed using software and there is no discussion of how many people analysed the material or how the themes that are detailed emerged. **Was the sampling carried out in an appropriate way?**	from the consultation. We are given no details about how representative the sample is for the area. **Was the sampling carried out in an appropriate way?** • Not sure There is very little detail around sampling. **Were the methods reliable?** • Not sure The methods are quite poorly described. **Are the data 'rich'?** • Not sure It is hard to assess the diversity of the perspectives because the detail of the sample is not provided. But a lot of quotations are included. **Is the analysis reliable?** • Not sure/not reported	and how the themes and recommendations were formulated. **Are the conclusions adequate?** • Somewhat adequate	• Highly relevant

• Not sure There is very little detail around sampling.			

Mitchell F (2012) Self-directed support and disabled young people in transition (part 2)

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Somewhat appropriate This approach is appropriate for a very preliminary look at the pilot SDS site. But a more controlled approach would be preferable to look at outcomes for young people. The study is vague about the outcomes it hopes to achieve with SDS but it does give us an idea of the potential problems and benefits of this approach. **Is the study clear in what it seeks to do?** • Mixed The study does not lay out its aims that clearly. It is a bit vague about its sample in the focus groups, We are not told who attended or how many were there. The study says	**Is the context clearly described?** • Not sure The study describes the types of people it wanted to recruit for the focus groups but it does not describe the pilot site in any detail. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate The study is essentially purposive, it attempted to involve service users, practitioners and policy-makers. Because of the lack of detail around the focus groups it is hard to say whether they achieved this. **Were the methods reliable?** • Not sure The lack of description makes it difficult to assess how well	**Are the findings convincing?** • Somewhat convincing This study just gathers some ideas about the barriers and facilitators to an SDS approach, so the findings are very broad. **Are the conclusions adequate?** • Somewhat adequate The reporting is quite poor, but the findings are adequate for this stage in the study.	**Internal validity** • + The study has some interesting qualitative findings but does not describe its methods very clearly, nor the outcomes the intervention is expected to achieve. There is also no reporting on ethics. **Relevance to this guideline** • Somewhat relevant The SDS approach is not that specifically aligned to transition services. The study is a very preliminary report of self-directed support for young people in transition.

that it aims to describe the implementation of the SDS approach but it more describes attitudes to the idea of the service than give details of the implementation process. **How defensible/rigorous is the research design/methodology?** • Somewhat defensible The study does describe the realistic evaluation approach in detail, but the methodology is not that well described. This is really a preliminary paper to be followed up with more comprehensive findings. **How well was the data collection carried out?** • Not sure/inadequately reported The study does not detail the ways in which the researchers handled the data either at the focus group or in the interviews.	the data collection was carried out and therefore how reliable the findings are. **Are the data 'rich'?** • Mixed The findings are described according to theme, but there is a lack of detail about what the focus groups said and also a lack of direct quotes from the interviews. **Is the analysis reliable?** • Not sure/not reported The modes of analysis are not reported, it seems like thematic analysis was carried out.		

Montano C, Young J (2012) Discontinuity in the transition from paediatric to adult health care for patients with attention-deficit/hyperactivity disorder

Internal validity, methods	Internal validity, clarity of reporting	External validity	Overall rating
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Somewhat relevant It is unclear which studies were included, but in addition to the 12 retrieved from their electronic search which was ADHD-focused, they say they found 58 through citation searching and that these went beyond ADHD transition to include studies on all health conditions. **Rigorous literature search?** • Partly rigorous The only searched Medline and Pubmed but did do citation searches of the 12 studies found in this search. **Study quality assessed and reported?** • No Reason given that there is a paucity of research in this area.	**Adequate description of methodology?** • No They do describe the search but nothing else in terms of selection of studies or analysis (synthesis). **Do conclusions match findings?** • Partly The purpose of this paper appears to be primarily to argue for continued medication of ADHD into adulthood. This point emerges with increased emphasis throughout the paper, which means that the argumentation increasingly diverts from the original question of continuity of care during transition from children's to adults' services.	**Is the setting similar to the UK?** • Partly Some UK studies are referenced, but overall the perspective is on the findings' relevance to the US context. **A clear focus on transition services** • Unclear Initially there is a clear focus but this changes during the paper, turning to medication rather than overall healthcare for ADHD. **Exploring views on transition?** • Unclear They start by saying that they want to explore transition and continuity of care from the perspective of the adult primary care provider, but this does not seem to be followed up by inclusion of studies of professionals' views or perspectives.	**Internal validity** • - **External validity** • -

Munro E, Lushey C, National Care Advisory Service, et al. (2012) Evaluation of the Staying Put: 18 + Family Placement Programme: final report

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
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 **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • N/A **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** • Yes The selection of research participants for face-to-face interviews is appropriate and the group is broken down as	**Is the process for analysing qualitative data relevant to address the research question?** • Yes Transcripts of young people's interviews were manually coded by peer researchers who were supported by the research team at CCFR, Loughborough University and NCAS. Data was grouped and analysed by theme by the CCFR research team using qualitative software analysis package NVivo 8. Methodology designed to maximise participant input within the timescale and budget available. **Is the process for analysing qualitative data relevant to address the research question?** • Yes Thematic analysis of all the data by the CCFR research	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly 'transition'?** • Yes **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • Yes The 2-year timeframe for evaluation (when young people are eligible to stay put for up to 3 years) and restricted budget had implications, namely: the 'in-depth' sample of young people who did not stay put is smaller than ideal to gain a clearer perspective on similarities and differences in their pathways and	**Internal validity** • ++ **External validity** • ++

follows: 32 young people, 21 young people who stayed put and 11 who did not stay put, including: 5 cases where young people opted out of staying put ('young person led opt out'); 4 cases where foster carers were not willing or able to accommodate young people once they reached legal adulthood ('foster care opt out'); and 2 cases where the local authority did not allow the young person to stay in their foster placement post-18.	team using qualitative software analysis package NVivo 8. Key focus on: variations in practice within and between authorities, including experiences of those who stayed put and those who did not; and similarities and variation in the views of young people, foster carers and leaving care personal advisers. Rich qualitative data were obtained through a methodology that helped to maximise participant input within the timescale and budget available.	experiences compared with that of those who stayed put. There is a lack of data on young people's transitions from staying put to independence as the majority of young people had not yet made this transition. It has not been possible to ascertain the proportion and characteristics of those who stay put up to age 21. Outcome data are limited. **Are the outcomes relevant?** • Yes	

Munro E, Lushey C, Ward H, et al. (2011) Evaluation of the Right2BCared4 pilots: final report

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
How was selection bias minimised? • Unmatched groups The study does use a control group, but the numbers are far smaller than that of the intervention group. The participants were not matched	**Was the exposure to the intervention and comparison as intended?** • Partly There appears to be an issue with securing the follow-up interviews with the baseline sample. Only 41 of the original	**Is the setting similar to the UK?** • Yes **Is there a clear focus (guideline population)?** • Yes **Is the intervention clearly (guideline intervention)?**	**Internal validity** • - This study does not provide a particularly comprehensive evaluation of the intervention because the comparison group was much smaller that the intervention group. The

at baseline other than they were all preparing for, or going through, transition. The groups are not matched in terms of gender, ethnicity or age range. The groups were also not randomly assigned or blinded. Young people were selected based on the pilot being part of their local authority. **Was the allocation method followed?** • No Allocation was not randomised **Did participants reflect target group?** • Partly The participants were all approaching transition, but there is a lack of representation from ethnic minorities and also far more women than men participated. **Were all participants accounted for at study conclusion?** • Yes The study accounts for all its participants, there was a significant issue with contacting individuals for the	184 young people completed the follow-up survey. Not all young people who received the intervention from the pilot local authorities received the extra help the intervention offered. Sometimes they dropped out or that their transitions plans were already complete. Comparison was also difficult between different pilot sites because approach differed within a broad remit. An additional problem was that, with the Care Matters agenda, more and more of the characteristics that informed the pilot intervention were becoming embedded in the practices of other local authorities. So practices were similar between pilot and control sites. **Was the study sufficiently powered to detect an intervention effect (if one exists)?** • Partly It is difficult to say in the case of this study because of the differences between the intervention and comparison	• Partly Some of the outcomes discussed are outside the scope of this guideline (e.g. housing, employment and education). **Are the outcomes relevant?** • Unclear This study is inconclusive on its findings due to methodological issues with data collection and high dropout rates at follow-up.	intervention and comparison groups were are also not presented to be comparable at baseline. The study also experienced issues with securing follow-up data from most of the original sample. **External validity** • + The study does have a focus on the UK and sets out to measure some outcomes relevant to this topic, but it also has a focus on outcomes which fall outside of the scope. The findings relation to outcomes are also not particularly convincing because of the methodological issues experienced by the study.

follow-up survey. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** - No The intervention and comparison group are not matched in terms of numbers or characteristics. Young men are particularly underrepresented, there were no young men in the comparator group.	groups and also the lack of outcome data at follow-up. **Were the analytical methods appropriate?** - Partly The study does acknowledge differences between groups and attempts to account for these and incorporate them into the logic models. But there is a lack of outcome measures which are capable of assessing the effects of the intervention on each outcome individually.		

Nakhla M, Daneman D, To T, et al. (2009) Transition to adult care for youths with diabetes mellitus: findings from a universal health care system

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Question appropriate and focused? - Well covered The researchers wanted to consider the rate of hospitalisation and attendance of eye clinic appointments after transfer to adult care. **Participation rate for each group?** - Cases	**Comparable populations?** - Poorly addressed The researches considered the populations on the basis of neighbourhood income, gender, distance to nearest specialist providers and the type of transfer to adult model operated by the centres. While they use the type of transfer model as an analytical variable	**Is the setting similar to the UK?** - Yes Canada **Is there a clear focus on young people in transition?** - Yes **Is the intervention clearly related to service transition?** - Yes	**Internal validity** **- -** **External validity** - ++

Because this study is not a case control study, there are no proper cases and controls. **Cases clearly defined?** • Poorly addressed It is not absolutely certain that the young people were assigned to the correct transfer model. The transfer models were ascertained by questionnaire survey to clinic directors attending a meeting. The young people were considered within a clinic on the basis of their post code. This leaves room for inaccuracies in the date (e.g. the young people might have moved but remained with their previous health team, or be living on the border of health teams and not attending the one originally intended for their street).	to interrogate the outcome data, they do not show group characteristics by transfer model received. So we do not know whether certain types of transfers were more prevalent in centres near to certain areas, for example. **Distinguishing of cases from controls?** • N/A Again, because this is primarily a study looking at associations between variables, there are no clear cases and controls. **Do conclusions match findings?** • Partly The researchers put a lot of emphasis on the association between transfer model and hospitalisation outcomes, but do not explore the association with neighbourhood income.	**Are the outcomes relevant?** • Yes Albeit limited to hospitalisation and eye clinic appointment.	

Nesmith A, Christophersen K (2014) Smoothing the transition to adulthood: creating ongoing supportive relationships among foster youth

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating

How was selection bias minimised? • Unmatched groups Young people were recruited from 2 agencies. One was the intervention agency and 1 was the comparison agency. There is no information on how they were selected other than their being in care at the time of recruitment. **Was the allocation method followed?** Not reported There was no allocation method as such, but also they do not say much about the recruitment and how they went about doing it. **Did participants reflect target group?** • Yes **Were all participants accounted for at study conclusion?** • Partly They state that 3 people in the intervention group and 5 people in the comparison group were unavailable at follow-up, but they do not	**Was the exposure to the intervention and comparison as intended?** • Yes The paper states that all participants in the CORE intervention were exposed to the agency-level changes and the new review meeting protocol (p5). **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** • Yes **Was the study sufficiently powered to detect an intervention effect (if one exists)?** • No **Were the analytical methods appropriate?** • Partly This study appears more like a pilot study for an intervention than a full-scale evaluation. Their sample size is small, and their presentation of outcome findings is limited. They asked some in-depth questions and present this data too, and this	**Is the setting similar to the UK?** • Partly: US **Is there a clear focus (guideline population)?** • Yes **Is the intervention clearly (guideline intervention)?** • Yes **Are the outcomes relevant?** • Partly	**Internal validity** • + **External validity** • +

explore this much further, and they are not included in the analysis.	strengthens the report.		

Newman G, Collyer S, Foulis M, et al. (2009) A multi-agency consultation project with young people with support needs at the transition between children's and adults' services

Internal validity, approach and Sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate **Is the study clear in what it seeks to do?** • Clear The study clearly sets out the Scottish context and the purpose for initiating the research. It describes the consultation topics (Appendix 1) agreed between the agencies, which include: outcomes, understanding of transition planning, meetings, information and 'ownership' of the planning process. These questions were addressed as appropriate to the relevant individual. **How defensible/rigorous is the research**	**Is the context clearly described?** • Clear The study acknowledges the increasing recognition of young people's right to be consulted with and included in decision making. Scottish government funds local government through a Concordat (Scottish Executive 2007), with nationally set outcomes for local authorities that require evidence of consulting young people to identify whether the outcomes have been met. A transitions coordinator was employed to help design a new transitions policy and procedure and accompanying guidelines. The coordinator met professionals	**Are the findings convincing?** • Convincing Findings are convincing though the lead author states that being based predominantly in a rural area of Scotland, and the most accessible parts at that, meant that it was not possible to examine how 'rurality' affected young people's experience of transition – an issue that impacts a significant proportion of the young people in the Highlands. **Are the conclusions adequate?** • Adequate The author concludes that the key message coming from young people is that they must be listened to and be central to	**Internal validity** • ++ This study is full of rich data. High internal validity, despite methods not being explicitly stated. **Relevance to this guideline** • Highly relevant The research has informed a formal report and steered the development of new joint education, social work and health services transitions policy, procedure and guidelines (THC 2007, 2008a, 2008b). At the time of publishing, the research was also being used to inform the development of a transition protocol (THC 2008c) dealing specifically with transition within health services.

design/methodology? • Defensible The design is appropriate to the research question posed by this study. Cases were selected to take account of a diversity of learning and communication needs of young people. The study also clearly describes how it approached potential participants and its justification for using different data collection methods to enable all young people to participate in a way that they felt comfortable with. **How well was the data collection carried out?** • Appropriately Data collection methods took account of the diverse range of communication and learning needs of young people. Tools or media were chosen by the young people, so helping people to articulate themselves properly. This approach is in line with the Mosaic approach (Clark and Moss 2001). **Was the sampling carried out in an appropriate way?** • Appropriate	working with young people (including the Highland Children's Forum, who engage and represent children and young people – transition being an issue raised). This forum initiated consultation with young people with a range of transition support needs about their experience of planning for adulthood with the key aim of developing new transitions guidance for professionals. Professionals working with young people were employed to undertake the research, a key advantage being their in-depth knowledge of the specific circumstances of individual interviewees. However, it is possible for bias to creep in under these circumstances where perhaps a researcher has a specific agenda (e.g. securing funding for a service). **Was the sampling carried out in an appropriate way?** • Appropriate The research was as inclusive as possible. Attempts were made to engage with young people with disability by	the planning process. Transitions planning must start early enough to offer opportunities for young people to practise life skills (e.g. making choices or managing money) and opportunities for social and work experience. Information needs to be widely available and in different formats and young people need to be supported to use it. Parents of young people also need information in advance about the changes in benefits, services and respite as a result of transition into adults' services.	

The research was as inclusive as possible. Attempts were made to engage with young people with disability by approaching 3 special needs schools, 2 special needs leisure clubs, the Vision Impairment Service and the Deaf Education Service as well as members of the Highland Children's Forum.	approaching 3 special needs schools, 2 special needs leisure clubs, the Vision Impairment Service and the Deaf Education Service as well as members of the Highland Children's Forum. **Were the methods reliable?** • Reliable Professionals involved in the research adapted the methods to take account of the different learning and communication needs of young people involved. Methods included face-to-face interviews, photo diaries, video, and questionnaires. For instance, for young people with a disability, the medium of video and camera worked well and individuals were able to express their experiences based on the consultation framework designed by the researcher (p47). For those who chose video, they were supported to plan a story using the consultation framework and filmed in a location of their choosing. Two young people did a joint slideshow based on their photographs and told their story through this, as well as each		

	being involved in an interview. **Are the data 'rich'?** • Rich **Is the analysis reliable?** • Somewhat reliable There was not much detail in the report except to say that young people's stories were written up and checked back with individuals for accuracy and amended as necessary, the method used being inductive thematic analysis.		

Noyes D, Sax C (2004) Changing systems for transition: students, families, and professionals working together

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate A case study design is appropriate to consider service transitions for those using a combination of different services. **Is the study clear in what it seeks to do?** • Clear **How defensible/rigorous is**	**Are the data 'rich'?** • Not sure The description of the data-gathering process indicates that there should be a rich set of data for each case study, comprising interviews with all important stakeholders, observations and document reviews. However, the presented data is thin, and reads mainly as a list of positive and negative aspects	**Are the findings convincing?** • Somewhat convincing The findings of this study are not remarkably different to those of other studies which have researched the transition process of young people with intellectual disabilities. There appear to be structural impediments to successful transition, such as lower expectations and community exclusion, which makes it	**Internal validity** • - The lack of transparency of data gathering and analysis, the lack of presentation of data, and the lack of connection between research questions, theory and findings, means that there is limited applicability of this small-scale study. **Relevance to this guidance**

the research design/methodology? • Somewhat defensible While 4 case studies drawing on multiple data sources might have worked well, the findings are presented as a list of complaints. This means that while the design in itself was defensible, it seems that it was not well executed in this study. **How well was the data collection carried out?** • Somewhat appropriately The study presents 4 case studies, and the authors say they interviewed the young people, their families and their service providers, as well as carrying out observations. However, the reporting is not underpinned by any quotes or matrix of data analysis. It is unclear as to how much data was gathered for each person. **Is the context clearly described?** • Clear The authors provide information about the service model, and provide references	of the experiences.	difficult for services to provide holistic planning. **Are the conclusions adequate?** • Somewhat adequate The lack of in-depth analysis and presentation of data limits the application of this study.	• Highly relevant

to relevant further sources of information about it. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate The students were all categorised by the POTSIP model as having undergone smooth transitions into adult life. This indicates that the sampling focused on ‘success’ stories rather than a combination of different experiences. However, it transpires that the ‘smoothness’ of these transitions varied, and only 1 of the case studies showed an example where all stakeholders were positive about the transition process. **Were the methods reliable?** • Somewhat reliable There is little information about the data-gathering tools, and because of the limitations of the analysis, it is difficult to use this study effectively in addressing our question.			

Paul M, Street C, Wheeler N, et al. (2014) Transition to adult services for young people with mental health needs: a systematic review

Internal validity, methods	Internal validity, clarity of reporting	External validity	Overall rating
Appropriate and clearly focused question? • Yes **Inclusion of relevant individual studies?** • Somewhat relevant The study acknowledges that some of the studies it has included are not of very high quality, and are affected by bias and small sample groups. It also acknowledges that there is a lack of relevant impact studies from the UK around interventions to assist transitions in mental health services. **Rigorous literature search?** • Yes **Study quality assessed and reported?** • Partly reported Study quality is covered in the methods and studies were subject to a quality assessment and critically appraised. A	**Adequate description of methodology?** • Yes **Do conclusions match findings?** • Yes The study offers what conclusions can be gained from the poor field of literature and concludes that the lack of evidence makes recommendations difficult, and so there is a need for more high-quality research.	**Is the setting similar to the UK?** • Partly The studies are a mix of UK and US material. **A clear focus on transition services** • Yes **Are the population groups relevant?** • Somewhat There is inclusion of studies which address ‘young adults’ who are over 18 and so have passed through transition. **Inclusion of relevant health outcomes?** • Yes The study does review material which looks at positive health outcomes. **Inclusion of relevant social care outcomes?** • Partly Some of the studies included look at outcomes like quality of	**Internal validity** • ++ This is a comprehensive and sound review. The tables might have been more clearly presented, so that it is obvious to the reader which studies addressed which question. At present all studies are listed together, and while some are clearly about effectiveness, others are about barriers and facilitators, and others about stakeholders’ perspectives. **External validity** • ++

detailed breakdown of this process is not given.		life and self-efficacy. But many also look at outcomes which are outside the scope of this guideline, like education and employment. **Exploring views on transition?** • Yes The study looks at qualitative studies which survey user perspectives on transition services.	

Pilnick A, Clegg J, Murphy E, et al. (2011) ‘Just being selfish for my own sake ...’: balancing the views of young adults with intellectual disabilities and their carers in transition planning

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate The nature of the topic (conversation analysis) lends itself to qualitative study design. **Is the study clear in what it seeks to do?** • Clear Best practice in the delivery of care services is enhanced when users of services and their	**Is the context clearly described?** • Clear **Was the sampling carried out in an appropriate way?** Somewhat appropriate **Were the methods reliable?** • Reliable The methods were reliable and used the theory of conversation analysis to examine interactions between parents and other	**Are the findings convincing?** • Convincing **Are the conclusions adequate?** • Adequate	**Internal validity** • + Though of a satisfactory quality, the paper is very theoretical and does not entirely fit with the remit of our guideline. So in actual fact, it might be worthy of a ++, but has been marked down as it is not entirely on topic. **Relevance to this guideline** • A bit relevant

carers are able to make decisions about their care and support needs. But in respect to transition planning, this paper asks ‘How do professionals manage interactionally when parents or carers express different views or wishes to those of the young adults they care for about a suitable future course of action?’ **How defensible/rigorous is the research design/methodology?** • Defensible The research comprised individual interviews or group discussions with the young people (where possible), and observation of interactions during meetings. **How well was the data collection carried out?** • Appropriately This paper draws on audio tape-recorded data collected from 8 multiparty meetings, 4 transition review meetings and 4 leavers’ 3-month review meetings, where the initial arrangements that have been agreed for	stakeholders in transition-related meetings for young people. **Are the data ‘rich’?** • Rich Conversation analysis (CA) was used to examine themes. **Is the analysis reliable?** • Reliable The data was analysed using CA. This follows an inductive approach and does not use predetermined codes upon data. It uses naturally occurring, audio- or video-recorded data, and transcribes these data according to a detailed transcription system (Jefferson, as reproduced in Atkinson and Heritage 1984) that aims to retain as much detail as possible about content but also show how content was verbalised. The particular nuances in expression have as much meaning as what was said.		

transition are reviewed. These meetings were held in the educational setting that the young person was currently attending, and on most occasions was chaired by a teacher involved in the young person's education. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate			

Pole JD, Alibhai SM, Ethier MC, et al. (2013) Adolescents with acute lymphoblastic leukaemia treated at paediatric versus adult hospitals

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Question appropriate and focused? • Well covered The question is appropriate for this study, although this design is a weaker option than for example a randomised trial. **Participation rate for each group?** • Cases The researchers relied on administrative data and there was good coverage of data. Missing data was only in terms	**Comparable populations?** • Adequately addressed The researchers provide a table of key characteristics of each group. It is clear that the young people treated in adult settings were much more likely to be diagnosed later (at ages 18 or 19), whereas those treated in paediatric centres were much more likely to have been diagnosed at earlier (at ages 15 and 16). This is to be expected, but illustrates how	**Is the setting similar to the UK?** • Partly: Canada **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly related to service transition?** • Unclear Partly: this is about where to treat young people who are undergoing transition, not about transition in itself.	**Internal validity** • - **External validity** • +

of the income quintile data, which was measured on the basis of people’s post codes. In the paediatric group data was missing for 3 people on this variable. • Controls The researchers relied on administrative data and there was good coverage of data. Missing data was only in terms of the income quintile data, which was measured on the basis of people’s post codes. In the adult group data for 9 people was missing on this variable. **Cases clearly defined?** • Adequately addressed It is clearly defined that they are interested in comparing paediatric treatment settings with adult treatment settings for a specific age group and in relation to a specific outcome. However, they acknowledge that the outcome considered is limited.	the two groups differed in terms of a key characteristic. **Distinguishing of cases from controls?** • Adequately addressed The researchers say that it is possible that there was some contamination across groups, (e.g. that some patients might have been diagnosed and then treated initially in a paediatric setting but be having further treatment in an adult setting). In this scenario, the patient would have been analysed as having been treated in a paediatric setting, when in fact both settings were involved. **Do conclusions match findings?** • Partly The authors conclude that there are no differences in survival outcomes for young people treated in adult versus paediatric treatment units, and suggest that this is due to a change in treatment regimes in adult units, adapting paediatric protocols. Considering the weakness of the study design,	**Are the outcomes relevant?** • Yes	

	the limitations in the analysis (in terms of confounders and also differences between the two groups), the findings are less reliable than indicated by the authors.		

Por J, Goldberg B, Lennox V, et al. (2004) Transition of care: health care professionals' view.

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Objectives of study clearly stated? • Yes To identify healthcare professionals' opinion of the main issues regarding the transition of care for adolescents with chronic condition from children's to adults' services. **Clearly specified and appropriate research design?** • Yes A survey design was selected as the most suitable method to address the stated aim and collect descriptive data from a large sample.	**Measurements and outcomes clear?** • Yes Items included in the questionnaire covered criteria for assessing readiness for transfer, healthcare professionals' previous experience, issues during transition period, needs of young people, families/carers and healthcare professionals, and how these needs can best be met. **Measurements valid?** • Yes Content validity in terms of evaluating the relevance and suitability of the questionnaires	**Results discussed in relation to existing knowledge on the subject and study objectives?** • Yes **Results can be generalised?** • Partly As the study was based in 1 hospital, the results cannot be generalised more broadly, but they do provide a useful insight into the subject. **Do conclusions match findings?** • Yes The conclusions reflect the findings of the study, which revealed particular gaps in the transition pathway for young	**Internal validity** • + This was a good study, but it fell short of adequate description of its data collection methods, lack of detail in the responses from study participants and the absence of views from certain professionals such as adult doctors and adult nurses working in accident and emergency and outpatient departments. The low response rate may also be a reflection of the possibility of respondent bias towards those who were more involved and had an interest in the transition

Subjects recruited in acceptable way? • Yes The sample was drawn from paediatric and adult care settings in a London teaching hospital. All the healthcare professionals who are currently involved in the care of adolescents with chronic conditions. **Sample representative of defined population?** • Yes Sample was broad enough to reflect service provision for the population of interest (i.e. adolescents with chronic conditions). Sample consisted of paediatric and adult health care professionals working in the same hospital trust – i.e. doctors, nurses, physiotherapists, psychologists, pharmacists and dieticians.	was agreed by a panel consisting of four experts in children's and young adults' services. The questionnaire was also piloted with 5 staff. **Setting for data collection justified?** • Yes **All important outcomes and results considered?** • Yes All important outcomes were considered, including coverage of professionals' opinions on what they thought were the issues for young people and families/carers. But more in-depth responses on all aspects would have been useful. **Tables/graphs adequately labelled and understandable?** • Yes **In-depth description of the analysis process?** • Partly The data was analysed both quantitatively and qualitatively. Descriptive results are presented according to	people. The authors acknowledge that there is need to develop a transition programme for adolescents with chronic illness and a need for research-based practice and continued evaluation of health services. **Is the setting similar to the UK?** • Yes **Is there a clear focus on our population?** • Yes **Is the intervention clearly related to transition?** • Yes **Are the outcomes relevant?** • N/A	process. **External validity** • ++

	emerging categories and themes from the analysis of questionnaires. Two researchers organised and checked the content analysis following methodology suggested by Burnard (1991). **Are sufficient data presented to support the findings?** • Partly Superficial presentation of facts, with no in-depth examination of context.		

Powers L, Geenen S, Powers J, et al. (2012) My life: effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
How was selection bias minimised? • Randomised The participants were randomly assigned to the control and the intervention groups. **Was the allocation method followed?** • Partly It is not made clear how the	**Was the exposure to the intervention and comparison as intended?** • Yes The service used a fidelity of implementation checklist to make sure that the key components of the intervention were delivered. The fidelity of delivery averaged 90%. Data was also collected on how	**Is the setting similar to the UK?** • Unclear The setting is US, which might make it different from the UK system in some ways. However, the care system described seems similar to a UK context. **Is the population group relevant?**	**Internal validity** • + The study employs robust methods and had a low dropout rate, participants were comparable at baseline, efforts were also made to standardise the intervention between individuals. One issue with the study is the small sample size which means that the study

randomisation was carried out. **Were all participants accounted for at study conclusion?** • Yes The attrition rate for this study is quite low. Of the 69 young people assessed at baseline, only 9 dropped out of the study or could not be located at the 1-year follow up. The attrition rate was: 13% at post-intervention and 11% at follow-up.	many intervention meeting the participants attended in different waves of the intervention. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** • Yes Groups were similar at baseline in terms of age, both groups had more males than females. Ethnically the groups were broadly comparable, the control group had a higher Hispanic population. The groups were similar in the type of placement they had been living in, be it a group home, kinship care or non-relative. The intervention group had been in care for longer than the control group (average 6.6 years as opposed to 8). There were differences between the groups in terms of their levels of special educational needs. **Was the study sufficiently powered to detect an intervention effect (if one exists)?**	• Yes **Is the intervention relevant?** • Yes **Are the outcomes relevant?** • Yes Some of the outcomes relating to education and employment are not relevant.	has limited power to show outcome effects over time. **External validity** • + This study has a good level of relevance to this topic and includes a social care focus. The study is from the US which might limit applicability to a UK context.

	• Partly The study has a small sample size may mean that the study is ‘underpowered to detect omnibus effects across assessment periods’ (p2185). Other issues were that the comparison group experienced fewer interventions that the intervention group and there was no control group against which to judge the absolute value of the Take Charge service. **Were the analytical methods appropriate?** • Partly The study acknowledges the problems of its small sample size but shows how the groups show consistent and non-significant differences at baseline and then significant differences post-intervention and at follow-up. The study uses tried and tested models for analysis.		

Prestidge C, Romann A, Djurdjev O, et al. (2012) Utility and cost of a renal transplant transition clinic

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**

How was selection bias minimised? • Unmatched groups This was a convenience comparison where the comparison group was made up of young people who transitioned prior to the introduction of transition teams. The researchers considered the equivalence between the groups, and they differed in terms of donor status, gender and cause of ‘end stage renal disease’. **Was the allocation method followed?** • Yes This is not really relevant in this study, because the comparison group was a retrospective cohort, and the intervention group included all patients transitioned into adults’ services after the introduction of the transition team. **Did participants reflect target group?** • Yes All participants were renal transplant recipients and moving on to adult services.	**Was the exposure to the intervention and comparison as intended?** • Not reported This study does not say anything about whether the young people included actually received services from the transition team, or how many. Similarly, there is no information about the actual service received by the included young people in the comparison group. **Were exposure and comparison groups similar at baseline? If not, were these adjusted?** • Partly The groups were very small. There was a higher percentage of deceased donation in the comparison group (n=19, 58%) compared with the intervention group (n=4, 33%). The groups also differed in terms of gender, living distance from the hospital, and cause of end-stage renal disease. **Was the study sufficiently powered to detect an intervention effect (if one exists)?**	**Is the setting similar to the UK?** •Partly: Canada **Is the population relevant?** • Yes **Is the intervention relevant?** • Yes **Are the outcomes relevant?** • Yes	**Internal validity** • - **External validity** • ++

Were all participants accounted for at study conclusion? • Yes The researchers state that young people for which they did not have information on death, allograft loss or creatinine at 2 years after transfer were excluded from the study. One patient in the pre-transition team group was lost to follow-up due to missing data.	• No This study only included 33 young people in the comparison group and 12 young people in the intervention group. If the researchers continue to collect data, the sample will naturally increase over time as long as the intervention continues at this hospital. **Were the analytical methods appropriate?** • Partly They present raw data in the form of number of graft loss and deaths in each group, and serum creatinine levels. They do not conduct any statistical analysis but that is probably due to the very small numbers.		

Price C, Corbett S, Lewis-Barned N, et al. (2011) Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is a qualitative approach appropriate? • Appropriate **Is the study clear in what it seeks to do?**	**Is the context clearly described?** • Clear **Were the methods reliable?** • Reliable	**Are the findings convincing?** • Convincing The thematic analysis is in-depth and findings are internally consistent.	**Internal validity** • + This is a good paper with a deal of rich data and some very illustrative quotations. However, the sample is small

• Clear **How defensible/rigorous is the research design/methodology?** • Defensible The design is defensible for investigating the experiences of young people using the transition process. Interviews were repeated 1 year later to follow-up. Only 2 young people agreed to the follow-up interview. **How well was the data collection carried out?** • Appropriately Interviews were semi-structured and conducted after the young people had had their first appointment at the transition clinic. The data was gathered by 2 researchers and a thematic framework was developed over time. The data was triangulated between the researchers and the themes were analysed and subdivide into 6 themes and 2 superordinate themes. **Was the sampling carried out in an appropriate way?**	The interview data seems to have been collected and analysed proficiently. **Are the data 'rich'?** • Mixed There are a variety of quotes included, although it is not clear when the study is referring to follow-up interview material, if at all. There is also no account of the gender or ethnicity of the participants. **Is the analysis reliable?** • Somewhat reliable There is no account of whether the comments are taken from initial or follow-up interviews. The diversity of informants is also not taken into account, except from in the 'inclusion' theme.	**Are the conclusions adequate?** • Adequate	and there is not adequate reporting on the sampling and the characteristics of the participants. The response rate for follow-up interviews was also disappointing. **Relevance to this guidance** • Highly relevant

• Somewhat appropriate Young people were approached as they entered the service to participate. The way in which this was done is not described.			

Reid GI, Shaw K, Southwood T, et al. (2004) Prevalence and correlates of successful transfer from paediatric to adult health care among a cohort of young adults with complex congenital heart defects.

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Clearly specified and appropriate research design? • Yes **Subjects recruited in acceptable way?** • Yes **Sample representative of defined population?** • No The exclusion criteria were quite stringent, so people with developmental disabilities were excluded, as were those who did not speak English. **Setting for data collection justified?** • Yes	**Measurements and outcomes clear?** • Yes **Measurements valid?** • Yes **All important outcomes and results considered?** • Partly This being a cross-sectional study, it focused on quite simplistic measures of 'transition success'. So, for example, they do not report on young adults' involvement in the transition process. Also, the outcome measure for success was 1 appointment in adult centres only, and presumably this could be due	**Results discussed in relation to existing knowledge on the subject and study objectives?** • Yes **Results can be generalised?** • Partly These results are indicative only, due to selection process. **Do conclusions match findings?** • Yes **Is the setting similar to the UK?** • Unclear Partly: this study was conducted in Canada. **Is there a clear focus on our**	**Internal validity** • + **External validity** • ++

	to a transition clinic and not the young person being settled in adult services. **In-depth description of the analysis process?** • Yes **Are sufficient data presented to support the findings?** • Yes	**population?** • Yes **Is the intervention clearly related to transition?** • Yes **Are the outcomes relevant?** • Yes	

Richards M, Vostanis P (2004) Interprofessional perspectives on transitional mental health services for young people aged 16–19 years

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate A qualitative approach using semi-structured interviews was appropriate for in-depth exploration of the need for transitional mental health services for young people as perceived by professionals from mental health, social, education and non-statutory	**Is the context clearly described?** • Clear The characteristics of the participants and settings are clearly defined. Sampling involved identifying the mental health representatives across CAMHS, AMHS, specialist mental health services, social care and education. Data collection and analysis was	**Are the findings convincing?** • Convincing **Are the conclusions adequate?** • Adequate The authors conclude that the most difficult issue arising from the findings, which has direct resource implications, is about the development of	**Internal validity** • ++ Overall, a sound study methodology with clear data collection methods and independent analysis of the findings. **Relevance to this guideline** • Highly relevant

services. **Is the study clear in what it seeks to do?** • Clear The study clearly sets out its purpose in the aims. **How defensible/rigorous is the research design/methodology?** • Defensible The research design is sound and is based on a semi-structured interview informed by relevant national policies and research literature and a pilot study with senior practitioners and managers from children's and adults' services. Sampling involved identifying relevant mental health representatives across different agencies. Data collection and analysis was rigorous. **How well was the data collection carried out?** • Appropriately Data collection was thorough and involved tape-recording interviews and transcribing these verbatim. Analysis was	rigorous. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate The authors claim that some bias may have affected the findings in that individuals who agreed to take part may have been more supportive in their views about older adolescents or their own agency, and may have been more enthusiastic about the development of transitional services. **Were the methods reliable?** • Reliable The findings were not triangulated with, for instance, the views of young people and their parents/carers. But despite this, findings were consistent with previous research with young adults in contact with mental health services (Smith and Leon 2001). Also, the fact that several managers involved in the study were also practitioners, meant that it was possible to get a dual perspective.	transitional mental health services. They propose several models, which need to work alongside interprofessional policies, and build in evaluation, as well as involve mental health professionals, social workers, education professionals and non-statutory agencies.	

based on grounded theory to generate themes and categories, which were then checked by 2 researchers to ensure relevancy and accuracy.	**Are the data 'rich'?** • Rich The data are supported by abundant reference to views from various professionals across the board. **Is the analysis reliable?** • Reliable Themes and categories were generated from the data. These were checked by 2 researchers who constantly refined and grouped categories into core themes as part of the overall process of data collection and analysis.		

Sebastian S, Jenkins H, McCartney S, et al. (2012) The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Objectives of study clearly stated? • Yes **Clearly specified and appropriate research design?** • Yes **Subjects recruited in**	**Measurements and outcomes clear?** • Yes **Measurements valid?** • Partly The survey is briefly described, but there is no information about the validity of this survey. However,	**Results discussed in relation to existing knowledge on the subject and study objectives?** • Yes **Results can be generalised?** • Yes **Do conclusions match**	**Internal validity** • + Low response rate for 1 of the groups (adult gastroenterologists below 50%) **External validity** • ++

acceptable way? • Yes **Sample representative of defined population?** • Partly There is no information about the representativeness of the sample, but the inclusion criteria were relevant (interest in inflammatory bowel disease and practising professionals), recruited through professional body membership.	considering the focus of the study, the focus of the survey seems appropriate. **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?** • Yes **In-depth description of the analysis process?** • Partly **Is the setting similar to the UK?** • Yes **Is there a clear focus on our population?** • Yes **Is the intervention clearly related to transition?** • Yes **Are the outcomes relevant?**	**findings?** • Yes **Are sufficient data presented to support the findings?** • Yes	

	• Yes		

Shaw K, Southwood T, McDonagh J (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Research design clearly specified and appropriate? • Yes **Survey population and sample frame clearly described?** • Partly **Representativeness of sample is described?** • Partly **Design** • Measures for contacting non-responders? Yes, reminders were sent when possible. **Subject of study represents full spectrum of population of interest?** • Yes **Study large enough to achieve its objectives,**	**Describes what was measured, how it was measured and the outcomes?** • Yes **Measurements valid?** • Yes **Measurements reliable?** • Unclear **Measurements reproducible?** • Yes **Basic data adequately described?** • Partly Results for health professionals only **Results presented clearly, objectively and in enough detail for readers to make personal judgements?**	**Results discussed in relation to existing knowledge on subject and study objectives?** • Yes **Limitations of the study stated?** • Yes **Results can be generalised?** • Partly **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** • Partly **Conclusions justified?** • Yes	**Internal validity** • + **External validity** • ++

sample size estimates performed? • Partly **Clear description of data collection methods and analysis?** • Yes **Methods appropriate for the data?** • Partly Unclear why they included so many non-health professionals if they weren't going to include their answers in the analysis.	• Partly **Results internally consistent?** • Yes **Data suitable for analysis?** • Yes **Statistics correctly performed and interpreted?** • Partly The statistics are very basic, simply percentages and p-values. **Response rate calculation provided?** • No **Methods for handling missing data described?** • No **Difference between non-respondents and respondents described?** • No		

Shaw K, Watanabe A, Rankin, E, et al. (2014) Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Research design clearly specified and appropriate? • Yes **Survey population and sample frame clearly described?** • Yes population numbers and characteristics presented clearly. **Representativeness of sample is described?** • No **Design** • Two measures for contacting non-responders? No. • Response rate? 23 clinics participated in the study. A total of 457 eligible patients out of a possible 995 agreed to take part, 326 in the PH and 131 AH. **Subject of study represents full spectrum of population**	**Describes what was measured, how it was measured and the outcomes?** • Yes The study measured patient satisfaction and also demographic data and clinical data. The study also looked at what transitional care model was provided by each clinic that participated. **Measurements valid?** • Yes **Measurements reliable?** • Yes **Measurements reproducible?** • Partly The model used to measure satisfaction may be reproducible. **Basic data adequately described?** • Yes	**All appropriate outcomes considered?** • Yes The study looks at how satisfaction levels and guidance adherence relate to one another. **Results discussed in relation to existing knowledge on subject and study objectives?** • Yes **Limitations of the study stated?** • Yes **Results can be generalised?** • Partly **Appropriate attempts made to establish 'reliability' and 'validity' of analysis?** • Yes	**Internal validity** • + **External validity** • ++

of interest? • Unclear **Study large enough to achieve its objectives, sample size estimates performed?** • No The study experienced low response rates.	**Results presented clearly, objectively and in enough detail for readers to make personal judgements?** • Yes **Results internally consistent?** • Yes **Data suitable for analysis?** • Partly The methods around data collection are not a robust as they might be but the data can be analysed. **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?**		

	• No		

Shropshire Parent and Carer Council (2011) Transition parent consultation findings 2011

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
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?** • Somewhat appropriately. There is scant detail of the methods of data collection. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate There is little detail around the sampling of the respondents.	**Is the context clearly described?** • Clear **• Was the sampling carried out in an appropriate way?** • Somewhat appropriate There is little detail around the sampling of the respondents **Were the methods reliable?** • Not sure It’s hard to say given poor reporting. **Are the data ‘rich’?** • Rich Lots of detail provided. **Is the analysis reliable?** • Not sure/not reported	**Are the findings convincing?** • Not sure **Are the conclusions adequate?** • Not sure	**Internal validity** **• -** The methodology is not adequately described. Particularly around the analysis of data, this not discussed. **Relevance to this guideline** • Somewhat relevant Although there is a deal of educational focus.

Singh S, Moli P, Islam Z, et al. (2010) Transition from CAMHS to adult mental health services (TRACK): a study of service organisation, policies, process and user and carer perspectives

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
Is a qualitative approach appropriate? • Appropriate Interviews are appropriate for gathering data on the transition process. **Is the study clear in what it seeks to do?** • Clear To interview young people who has passed through transition within mental health services. **How defensible/rigorous is the research design/methodology?** • Defensible The study used purposive sampling to identify 20 young people, 10 who had remained engaged with services post transition and 10 who had not remained in contact with	**Is the context clearly described?** • Clear This is a large study with 5 elements. The background to the study and a literature review precede the section. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate Sampling was purposive, which has its limitations. The study also struggled to achieve its desired sample of 20 interviews; 11 interviews were carried out. **Are the data 'rich'?** • Rich The study provides a lot of detail of the data gathered and it is arranged thematically. Detailed case study material is also included. Views are taken	**Are the findings convincing?** • Convincing Findings are presented coherently and according to themes. Limitations are also discussed in detail. **Are the conclusions adequate?** • Adequate	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

services. This sample was not achieved, but 11 interviews were carried out. **How well was the data collection carried out?** • Appropriately The aim was to gather information in more detail that the case note audit, which was another element to this study. A coding frame was developed to analyse interview material.	from young people, practitioners and parents. **Is the analysis reliable?** • Reliable The topic guide and framework appear to have been carefully developed. All the themes that appeared in data were taken account of. NVivo was used to store and code material.		

Sloper P, Beecham, J, Clarke S, et al. (2011) Models of multi-agency services for transition to adult services for disabled young people and those with complex health needs: impact and costs

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
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 The study makes an attempt to draw together qualitative	**Is the process for analysing qualitative data relevant to address the research question?** • Yes **Is the process for analysing qualitative data relevant to address the research question?** • Yes The process of analysis is	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly 'transition'?** • Yes **Are the outcomes relevant?**	**Internal validity** • + The paper documents its methodology and findings in detail. However the study was hampered by issues with recruitment and a lack of will among services to discuss their costs. It also does not measure outcomes for service users in a reliable manner.

information and outcome measures. The papers describes the difficulty in evaluating multiagency services, especially those which are being piloted or are newly implemented. The various stages of the study take in both professional and service user feedback on the services. The final stage of the study, the economic component, aims to provide a picture of the costs associated with these types of transitions services. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • Yes The approach is relevant to addressing the research aims. **Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?** • Partly	reasonably well described. Interview data was transcribed and analysed to identify themes. A coding framework was developed and a qualitative analysis programme was used to isolate themes. Analysis was carried out by 2 researchers. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • Yes The study details problems with recruiting participants, gives details about how long services had been up and running for and the background of multiagency services. The study also isolates a problem around what is considered a multiagency team. It seems that understandings of this term differ and some services which professed to be multiagency turned out not to be. **Is appropriate consideration**	• Yes	The survey portions of the study gain a broad sense of the services but the data cannot be generalised. **External validity** • ++ The study has a high level of relevance to this guideline because of its focus on the UK and on transitions services.

Little detail is provided on how the survey was analysed. The authors say that the data was analysed using SPSS and the frequencies of answers calculated. **Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)?** • Yes The limitations and strengths of this research design are discussed at length. The limitations of survey responses and problems with recruitment are discussed against response rates. The economic component and qualitative components of the study remain largely separate. There is an issue in this study related to a lack of reliably measured outcomes.	**given to how findings relate to the context, such as the setting, in which the data were collected?** • Partly The study does describe how the interviews were in-depth and lasted around an hour. The study acknowledges how this in-depth approach is appropriate given the complexity of the services.		

Social Care Institute For Excellence (2011) Case study: Y-Talk counselling and therapy service, Sheffield YMCA

Internal validity, approach	**Internal validity,**	**External validity**	**Overall rating**

and sample	performance and analysis		
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? • Unclear This report gives preliminary findings, it does not discuss its methods in depth and only gives general findings. **Is the integration of qualitative and quantitative data (or results) relevant to address the research question?** • Partly The final report will probably provide better information on methods. **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?** • Unclear **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?** • No **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • No	**Is the setting similar to the UK?** • Yes **Is there a clear focus on young people in transition?** • Unclear The study is not clearly about service transitions. It seems quite developmental in focus but does mention transitions and transition readiness. **Is the intervention clearly 'transition'?** • No The counselling intervention seems more aimed at improve self-esteem, and social relationships and coping strategies. **Is appropriate consideration given to how findings relate to the context, such as the setting, in which the data were collected?** • No **Are the outcomes relevant?** • Partly They could be linked to transition readiness but seem	**External validity** • - **Internal validity** • - The study does not report its methods in any detail and provides confusing information about the sample.

Is appropriate consideration given to the limitations associated with this integration, such as the divergence of qualitative and quantitative data (or results)? • No		very developmental in scope.	

Stein M, Morris M (2009) Increasing the number of care leavers in 'settled, safe accommodation': research review 3

Internal validity, methods	Internal validity, clarity of reporting	External validity	Overall rating
Appropriate and clearly focused question? • Yes The study is very broad in its approach but it does have a focus. **Inclusion of relevant individual studies?** • Yes The study acknowledges a lack of robust research around interventions for care leavers moving into independent accommodation. **Rigorous literature search?** • Yes	**Adequate description of methodology?** • Partly adequate The methods are outlined but there is a lack of depth in the methods section. **Do conclusions match findings?** • Yes The study acknowledges the limitations of its data and is careful to state that recommendations are not the result of randomised trials for the most part. **Study quality assessed and**	**Is the setting similar to the UK?** • Partly The review used English language material from UK, Ireland, USA, Canada, Australia or New Zealand. **A clear focus on transition services** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes?**	**Internal validity** • + This study appears to employ good systematic reviewing methods but does not present its methods particularly well in places. **External validity** • +

The search included database searching and hand searching. Inclusion criteria and critical appraisal are in evidence.	**reported?** • Partly reported It is partly reported, but a table of the search is not provided. There is also not a breakdown of critical appraisal procedure.	• Unclear The study focuses in accommodation and although it does mention outcomes relevant to this guideline around wellbeing and mental health status it does not look at these outcomes in detail. **Inclusion of relevant social care outcomes?** • Unclear This study does look at the role of social workers in the transition planning process for young care leavers in independent accommodation, but it does not present these outcomes in depth or provide much in the way of effects or findings. **Exploring views on transition?** • Yes The study does provide views material from young people, practitioners and families around transition.	

Swift K, Hall C, Marimuttu V, et al. (2013) Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): a qualitative analysis of their experiences

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
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 Semi-structured qualitative interviews in appropriate for gathering views. **How well was the data collection carried out?** • Somewhat appropriately The study attempted to identify all eligible young people in the area. This failed and so the size of a representative sample it is not known. The sample is small – 10 individuals. Interviews were carried out with or without parents and all	**Is the context clearly described?** • Clear Background to study well described. **Were the methods reliable?** • Reliable The interviews were undertaken in a systematic way, recorded and coded by 2 researchers. Interviews based around 5 set questions. **Are the data 'rich'?** • Rich The content of the data is well described according to themes and quotes are provided. The data was well analysed. **Is the analysis reliable?** • Reliable Two researchers analysed and coded the interview data.	**Are the findings convincing?** • Convincing The findings are coherently presented according to themes. **Are the conclusions adequate?** • Adequate	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

had passed through transition recently. **Was the sampling carried out in an appropriate way?** • Somewhat appropriate The study failed to find out the total number of individuals in the population. The sample is small (n=10).			

Swift K, Sayal K, Hollis C (2013) ADHD and transitions to adult mental health services: a scoping review

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Unclear The aims of the study are not laid out that clearly, the study states that it searched for material that 'noted the process of transition' and review literature and policy documents. **Inclusion of relevant individual studies?** • Yes The included studies do have a focus on ADHD transitions but the methods lack rigour.	**Adequate description of methodology?** • Partly adequate The search seems rigorous and includes a hand-searching element. But there is not much detail around critical appraisal etc. **Do conclusions match findings?** • Partly The paper provides a summary of the kinds of issues and approaches around transition for this group but no outcomes.	**Is the setting similar to the UK?** • Partly The review describes US and UK studies. **A clear focus on transition services** • Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes?** • Unclear The study looks more at the process of transition services	**Internal validity** • ++ **External validity** • +

Rigorous literature search? • Unclear The details of the search are not presented that clearly, although a good range of databases were included. **Study quality assessed and reported?** • No		rather than their outcomes specifically; outcomes are poorly reported. **Inclusion of relevant social care outcomes?** • Unclear The study talks about 'successful transition' but does not look at outcomes specifically. **Exploring views on transition?** • Yes Most of the included studies have a qualitative element including surveys or interviews.	

Tierney S, Deaton C, Jones A, et al. (2013) Liminality and transfer to adult services: a qualitative investigation involving young people with cystic fibrosis

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Is a qualitative approach appropriate? • Appropriate **Is the study clear in what it seeks to do?** • Clear **How defensible/rigorous is**	**Is the context clearly described?** • Clear Yes, the interviews were carried out in the adult cystic fibrosis clinic and the authors consider the possibility of a different setting producing	**Are the findings convincing?** • Convincing **Are the conclusions adequate?** • Adequate	**Internal validity** • ++ **Relevance to this guideline** • Highly relevant

the research design/methodology? • Defensible **How well was the data collection carried out?** • Appropriately **Was the sampling carried out in an appropriate way?** • Somewhat appropriate Eligible young people were identified by their clinician in the adult setting. It is possible that only those who were quite happy with the clinic were approached. For example, two participants were identified as having too many problems (psychosocial difficulties).	different results. They note that email interviews and phone interviews did not throw up different themes than those conducted at the clinic. **Were the methods reliable?** • Reliable **Are the data 'rich'?** • Rich **Is the analysis reliable?** • Reliable While framework analysis might have constricted the findings to some extent, the analysis was conducted with several people and ongoing during the data collection.		

van Staa AnneLoes, van A Heleen, Jedeloo S (2011) Readiness to transfer to adult care of adolescents with chronic conditions: exploration of associated factors

Internal validity, approach and sample	**Internal validity, performance and analysis**	**External validity**	**Overall rating**
Objectives of study clearly stated? • Yes 'In a large sample of adolescents with all kinds of chronic conditions, we explored the associations	**Measurements and outcomes clear?** • Partly The study does describe how it measured outcome variables.	**Results discussed in relation to existing knowledge on the subject and study objectives?** • Partly **Results can be generalised?**	**Internal validity** • + **External validity** • +

between adolescents' perception of their TR and the following factors: (a) socio-demographic characteristics; (b) disease-related factors; (c) effect of the condition; (d) self-management ability; and (e) attitude toward transition' (p296). Aims are clearly stated. **Clearly specified and appropriate research design?** • Yes **Subjects recruited in acceptable way?** • Yes Subjects were recruited from the hospital database who were receiving treatment for somatic long-term conditions. All had been receiving treatment for some time and remained engaged in services. **Sample representative of defined population?** • Partly It is not clear if the sample is representative of a region or just those using the services of 1 hospital.	**Measurements valid?** • Yes The study analysed the data from the electronic questionnaire via SPSS, and used accepted measures for statistically significant findings. **Setting for data collection justified?** • Yes **All important outcomes and results considered?** • Unclear **Tables/graphs adequately labelled and understandable?** • Yes **Appropriate choice and use of statistical methods?** • Yes **In-depth description of the analysis process?** • Yes **Are sufficient data presented to support the findings?** • Yes	• Yes The study uses a big sample. **Do conclusions match findings?** • Yes **Is the setting similar to the UK?** • Unclear Dutch context. **Is there a clear focus on our population?** • Yes **Is the intervention clearly related to transition?** • Yes **Are the outcomes relevant?** • Yes	

Walleghem N, MacDonald C, Dean H et al. (2009) Building connections: the Maestro Project. The evolution of a systems navigator model for transition from paediatric to adult care for young adults with type 1 diabetes

Internal validity, approach and sample	Internal validity, performance and analysis	External validity	Overall rating
How was selection bias minimised? • Unmatched groups The study is not clear about how selection bias was minimised. It says that 2 cohorts of patients were identified through a database. One group had left paediatric services between Jan 1995 and July 2002, and so were receiving adults' services but received the intervention if they had graduated to adults' services within 7 years. The second group were moving from paediatric to adult care between Aug 2002 and Aug 2004 and received the intervention as they were experiencing transition. **Was the allocation method followed?** • No The groups were not concealed, and there is no	**Was the exposure to the intervention and comparison as intended?** • Not reported The study lacks detail about how the intervention was carried out. It also does not explain how the intervention was delivered to those who had gone through transition and were using adults' services. **Comparable populations?** • Adequately addressed The study clearly outlines its primary and secondary aims. **Distinguishing of cases from controls?** • Poorly addressed The characteristics of the 2 groups are barely discussed, the only distinction is that the second cohort of patients have already passed through transition and are older.	**Is the setting similar to the UK?** • Partly The study is Canadian. **Is there a clear focus on young people in transition?** • Yes **Is the intervention clearly related to service transition?** • Yes **Are the outcomes relevant?** • Unclear Outcomes are not measured in a reliable way. But they do look at self-efficacy and medical outcomes. There is less discussion about the role of adults' services.	**External validity** • + **Internal validity** • +

distinct intervention or comparison groups. **Did participants reflect target group?** • Yes The group is not very diverse, ethnically. But there was 60/40 split of genders. Details of socioeconomic position are not given. The study achieved its recruitment as intended. **Cases clearly defined?** • Adequately addressed The criteria for cases is simply those who are receiving the intervention once the service has been implemented.	**Do conclusions match findings?** • Yes		

Watson R, Parr J, Joyce C, et al. (2011) Models of transitional care for young people with complex health needs: a scoping review

Internal validity, methods	**Internal validity, clarity of reporting**	**External validity**	**Overall rating**
Appropriate and clearly focused question? • Yes Yes, with a caveat: it is not entirely clear what kind of evidence they were looking for. **Inclusion of relevant**	**Adequate description of methodology?** • Partly adequate The main problem is lack of clarity on what kind of evidence they included in the review, and whether there was any scrutiny of papers on the basis of their quality (apart	**Is the setting similar to the UK?** • Yes The papers describe practice in a wide range of countries, but these included the UK. **A clear focus on transition services**	**Internal validity** • - The reviewers took an interesting approach to consider transition evidence (key components of good practice and normalisation process theory), however there is reason to be

individual studies? • Somewhat relevant It is not clear whether the reviewers searched specifically for evaluation, or whether they included any kind of description – the inclusion criteria for material are not clear. **Rigorous literature search?** • Partly rigorous Search carried out in MEDLINE, EMBASE, CINAHL, and SCOPUS. Search terms included the 3 specific conditions which were the focus of this review. This might have excluded papers with a wider remit (e.g. complex health needs or disability). **Study quality assessed and reported?** • Unclear There does not appear to have been any exclusion on the basis of study quality. However, the framework analysis itself serves as 1 type of quality assessment in that the described models were assessed on the extent to	from assessing them in framework analysis). **Do conclusions match findings?** • Yes **Study quality assessed and reported?** • Yes Authors used a validated scoring system and cite the source for this (Hawker et al. 2002). Each study component (total 8) of the full text paper was given a quality score starting from 1 (very poor) to 4 (good), which generates a maximum potential score of 32. Discrepancies were resolved by consensus. Only 31 out of the 92 articles (34%) were empirical studies and could be fully quality assessed using the tool above. These empirical studies were of variable study design with only a few high-scoring ones ranging from 18–31 out of 32.	• Yes **Are the population groups relevant?** • Yes **Inclusion of relevant health outcomes?** • N/A This was not about outcomes, but about whether service models appeared to integrate good practice for delivery and implementation. **Inclusion of relevant social care outcomes?** • N/A This was not about outcomes, but about whether service models appeared to integrate good practice for delivery and implementation.	concerned that their search strategy might have missed important and relevant studies on transition models for a wider group (e.g. disabled young people, or young people with chronic health conditions). The conclusions might have altered if study selection had employed certain quality criteria for papers. While the focus of this review is not effectiveness per se, some quality criteria for inclusion would have helped the reader understand better what kind of evidence they were building their analysis on. **External validity** • ++

which they fulfilled established criteria for good transitional care and whether they fulfilled criteria for ensuring good uptake of a new service model.			

Study characteristics table

Abbott D, Busby K, Carpenter J (2009) Transition to adulthood for young men with Duchenne muscular dystrophy and their families: final report to the Department of Health (++/++)

Methodology and aims	Sample size	PICO
Methodology • Mixed methods Semi-structured interviews, case studies, qualitative interviews, medical record review, clinical interview survey of parents and carers. **Country** • UK **Study aim** 1. To investigate, from their own perspectives, how the health and well-being of young men living with DMD, and that of their parents, can be maximised, particularly at the transition to adulthood. 2. To consider the potential contribution of the National Service Framework for Long Term Neurological Conditions for this group of people.	• Case studies Young people with Type 1 diabetes (n=46). Carers (n=39). • Survey A total of 234 people responded at least once to the survey.	**Population** • Young people with long-term conditions – Type 1 diabetes • Carers/parents **Sample characteristics** • Age Not reported • Sex Not reported • Ethnicity Not reported **Outcomes** • Continuity of care The study aimed to identify continuity mechanisms in diabetes transition. • Views studies

(p.5)		

Allen D, Channon S, Lowes L, et al. (2011) Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service (+, relevance to this guideline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study Longitudinal (3 time points over 18 months), part of a larger-scale evaluation of transition services. **Country** • UK **Study aim** To examine the experiences of young people and their primary carers during the transition from children's to adults' services, with a focus on the role of primary carer in this period.	**Sample size** Total of 46 young people, 39 mothers.	**Population** • Young people with long-term conditions – Type 1 diabetes. • Carers/parents **Sample characteristics** • Age 14–22, across 5 different services. • Sex 23 young women, 23 young men, 39 mothers. • Ethnicity Not reported. **Outcomes** • Views studies For views studies, our methodology is not to extract specific outcomes. These are reported in the general narrative findings.

Allen D, Cohen D, Hood K, et al. (2012) Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study (+/++)

Methodology and aims	Sample size	PICO

Methodology • Mixed methods Semi-structured interviews, case studies, qualitative interviews, medical record review, clinical interview survey of parents and carers. **Country** • UK **Study aim** ‘To identify the continuity mechanisms central to a smooth transition from child to adult diabetes care, the service components through which these can be achieved and their inter-relations in different contexts’ (p140). The study objectives were to: – develop a typology of diabetes transition models, building on previous research on continuity of care – identify users’/carers’/providers’ experiences of, and preferences for, transition services, the processes and	**Sample size** • Case studies Young people with Type 1 diabetes (n=46). Carers (n=39). • Survey A total of 234 people responded at least once to the survey.	**Population** • Young people with long-term conditions – Type 1 diabetes • Carers/parents **Sample characteristics** • Age Not reported • Sex Not reported • Ethnicity Not reported **Outcomes** • Continuity of care The study aimed to identify continuity mechanisms in diabetes transition. • Views studies

organisational challenges involved and assess costs – identify what works best to promote 'a smooth transition', for whom and in what circumstances' (p141).		

Andemariam B, Owarish-Gross J, Grady J, et al. (2014) Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care (-/+)

Methodology and aims	Sample size	PICO
Methodology • Case-control study Retrospective evaluation study. The study 'retrospectively studies clinical and non-clinical risk factors for an unsuccessful transition' (p697). Risk factor categories included 'patient demographics, transition clinic attendance and disease severity' (p697). **Country** • USA **Study aim** The study aimed to 'evaluate the successes and failures of a new transition program'	**Sample size** 47 patient transitions between 2007 and 2013 through the modified transition process.	**Population** • Young people with long-term conditions: sickle cell disease **Sample characteristics** • Age 16–18 (n=18), 19–20 (n=21), 21+ (n=8). • Sex Male (n=20), female (n=27). • Ethnicity Black (n=41), Hispanic (n=4), White (n=1), Indian (n=1) **Intervention** The study described the intervention as a 'formal combined transition programme'. The transition service was set up between the paediatric medical centre in Connecticut and the sickle cell disease centre at the University of Connecticut Health Center. The intervention used a 3-stage process taken from the former transition process: preparatory, transitional and completion. Both the preparatory and transition stage began at age 16 and the transitional and completion stages were jointly managed by children's and adults' services. Monthly combined transition clinics were held at the children's

(p.697) for young people with sickle cell disease. The study looked at a transition programme in Connecticut after it had been implemented for 5 years.		medical centre. These were attended by parents, patients and staff from both children's and adults' services, including nursing, social work and medical staff. Each patient was expected to attend at least 4 of these combined clinics.

Barn R, Andrew L, Mantovani N, et al. (2006) Review of life after care: the experiences of young people from different ethnic groups (++/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Mixed methods The study used a combination of both quantitative and qualitative methods including: a) a demographic profile questionnaire to capture information on characteristics of participants such as age, gender, ethnicity, length of time in care, employment, etc.; b) semi-structured interview and a focus group to explore in-depth the experiences of young people in areas including preparation for leaving care, experiences after leaving care, experiences with housing, homelessness, education,	**Sample size** For the quantitative questionnaire 261 care leavers in the leaving care teams from across 6 local authority social services departments in England (3 in London and 3 in central and northern England); 116 were minority ethnic young people. Qualitative	**Population** • Care leavers: 261 care leavers from a range of ethnic backgrounds as well as from the white indigenous population were included in the sample. • Social care practitioners: 13 managers and professionals based in local authority leaving care teams were also interviewed. **Sample characteristics** • Age More than 50% of young people were aged between 19 and 20, followed by two-fifths who were between 16 and 18, and only less than a tenth aged 21 or older. • Sex Most of the study respondents (57%) were female. There were gender variation within ethnic groups; e.g. within the Caribbean group male and female distribution was similar (17 and 18 respectively), while within the African group, male numbers were higher than female (18 and 11 respectively). • Sexual orientation Two young men referred to the discrimination they had received as a result of their sexuality (p49). • Ethnicity

employment and so on; c) semi-structured interviews were also used to capture professional views. **Country** • UK, England **Study aim** This paper describes the perceptions, needs and concerns of minority ethnic care leavers in the UK compared to those of their white peers. Key areas explored were the outcomes of young people in education, housing, employment and training. The views of social work professionals (senior managers and practitioners) were also explored, with emphasis on perceived needs and concerns, and support levels.	sample 36 young people selected through purposive sampling (from the main sample of 261) to ensure good representation of minority ethnic numbers and gender balance. Broken down as 16 male, 20 female (11 African Caribbean, 8 African, 3 Asian, 10 mixed parentage and 4 white). The high proportion of teenage mothers in the sample (55), was also reflected in the sample; 13 managers and professionals based in the leaving care teams.	Primary group was care leavers from a minority ethnic background i.e. African, African Caribbean, Asian and mixed parentage. White indigenous care leavers were also part of the sample; 44% of population sample of 261 were of minority ethnic origin with those from mixed parentage being the largest; 62% of the minority ethnic group were from the 3 London sites, compared to 29% for the outer London study sites (p14). • Socioeconomic position Diversity highlighted in terms of ethnicity and socioeconomic circumstances. • In complex/unstable living conditions The nature of the topic being care leavers suggests complex/unstable living conditions. • Other Religion, marital status and parenthood were 3 other areas that were profiled.

Bent N, Tennant A, Swift T, et al. (2002) Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study (+/++)

Methodology and aims	Sample size	PICO
Methodology • Retrospective comparison evaluation (retrospective cohort study) **Country** • UK	**Sample size** n=254 It appears that the comparison areas were Leicester (n=76) and Birmingham (n=59): 135. It appears that the areas providing young adult teams were Leeds (n=74) and Stoke-on-Trent (n=45): 129. A group of 124 health college students were used to contextualise the outcome measures in the main group of interest (total sample of young	**Population** • Young people in the target diagnostic groups of cerebral palsy, spina bifida, traumatic brain injury, or degenerative neuromuscular disease • Young people with or without learning disabilities Ages 17–28, 135 men and 120 women. Communication difficulties: 23% (n=58). **Intervention** Multidisciplinary teams set up to facilitate transition from children's to adults' services, usually including a consultant in rehabilitation medicine, a psychologist, therapists and a social worker. **Outcomes** • Self-efficacy: participation in society measured on the London Handicap Scale • Condition-specific: Nottingham Health Profile subscales: pain, energy, sleep

	people with disabilities).	

Beresford B, Cavet J (2009) Transitions to adult services by disabled young people leaving out of authority residential schools (++, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study Phone interviews with professionals. **Country** • UK **Study aim** The aims of this small scoping project were to identify: differences in practice with regard to transition planning for disabled young people in residential schools compared to young people attending their local special schools; the factors which impact on transition planning and transition outcomes for these young people; key areas for future research and the feasibility of such work.	**Sample size** A total of 38 staff were interviewed including managers and frontline staff working in children's services, Connexions, adults' services and senior strategic managers or commissioners working for the local authority or primary care trust.	**Population** • Young people disabled • Social care practitioners Practitioners and managers working in children's services (social care, education and health), adult social care, and Connexions in 10 local authorities in England and involved in the transitions of young people returning from residential placements in out authority schools. • Health care practitioners • Other • Connexions staff **Sample characteristics** • Other Though not part of the study participants, the focus of the study was disabled young people in 38- or 52-week placements in out authority residential schools, who are leaving school and transferring into adults' services. **Outcomes** • Experience of care • Continuity of care

Beresford B, Moran N, Sloper T, et al. (2013) Transition to adult services and adulthood for young people with autistic spectrum conditions (working paper no. DH 2525) (+/+)

Methodology and aims	Sample size	PICO
Methodology • Mixed methods • Cost analysis **Country** • UK **Study aims** • What appears to be working well and why? Where are the gaps? What do these mean for young people? What can this tell us about policy? • What mechanisms need to be in place in different contexts of the young person's life (e.g. school, college, family, community) to support young people with ASC to achieve positive transitions?	• Qualitative interviews with 68 managers and practitioners Survey of parents and young people across 5 sites: 12.8% (105/818), 6.8% (56/818), 25.2% (28/111), 16.9% (20/118) In-depth interviews with 36 parents. In-depth interviews with 20 young people.	**Population** - Young people disabled - Autistic spectrum conditions, with a special focus on those with high functioning autism and Asperger's syndrome - Young people with learning disabilities - Parents - Managers - Practitioners. **Age** Qualitative interviews with young people with high functioning autism or Asperger's syndrome aged 18–24. Qualitative interviews of parents of young people with autistic spectrum conditions and aged 16–24. **Intervention** The study focused on 5 research sites where multiagency transition systems had been implemented, including specific services for young people with autistic spectrum conditions.

Beresford B, Harper H, Mukherjee S, et al. (2014) Supporting health transitions for young people with life-limiting conditions: researching positive practice (the STEPP project) (+, relevance to this guideline: highly relevant)

Methodology and Aims	Sample size	PICO
Methodology	**Sample size**	**Population**

• Qualitative study **Country** • UK **Study aim** The STEPP project aimed to gather the experience of transition into adults' services for young people with life-limiting conditions, and from the point of view of young people, their parents and professionals. It conducted interviews with these groups across 6 case studies which all represented condition-specific pathways into adult care.	• 28	• Young people with long-term conditions Conditions diagnosed in childhood: congenital and acquired neurological conditions (complex physical and health needs but no significant learning disability), Duchene muscular dystrophy, cystic fibrosis, renal disease (from Table 1, p405 in Beresford and Stuttard 2014). • Healthcare practitioners • Carers/parents **Sample characteristics** • Age: 18–25 • Sex: 18 male, 10 female

Betz C, Lobo M, Nehring, W, et al. (2013) Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition (++/+)

Methodology and aims	Sample size	PICO
Methodology • Systematic review **Country** • Range of countries Ten studies (29%) were conducted in the US (Table 1), and 25 (71%) studies were	**Sample size** • As this is a systematic review, sample size is given as number of studies as opposed to	**Population** • Young people with long-term conditions More specifically described as adults and emerging adults with special healthcare needs (AEA-SHCN). Emerging adulthood refers to the developmental period from late adolescence to early adulthood. Special healthcare needs apply to 'those who have or are at increased risk for a chronic physical, development, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that

conducted internationally, including 14 in the European Union (1 in Belgium, 1 in Germany, 1 in France, 1 in Italy, 3 in the Netherlands, 1 in Norway, 1 in Switzerland, and 5 in the United Kingdom), 7 in Canada, 3 in Australia, and 1 in Hong Kong. **Study aim** • To gather evidence related to the views and experience of adolescents and emerging adults with special healthcare needs (AEA-SHCNs') regarding their healthcare transition (HCT).	number of participants in a study; 35 studies included.	required by children generally' (McPherson et al. 1998, p138). • Young people disabled • Young people with long-term conditions and young people disabled • Young people with mental health problems **Sample characteristics** • Age The diversity of age ranges in the studies made it difficult to quantify and compare. Age groupings could be described as associated with the following stages of AEA-SHCN transition: (a) actual and potential enrolment in transition program: 9 to 21 years of age (3 US studies and 11 international studies); (b) a combination of current and former transition programme enrolees: 14 to 34 years of age (5 US studies [Belair et al. 2011 did not identify age range] and 1 international study; and (c) past enrolees of transition programme: 16 to 28 years of age (3 US studies [Stabile et al. 2005 did not identify AEA ages] and 9 international studies. • Ethnicity Five studies reported the ethnicity of samples studied (Bundock et al. 2011; Latzman et al. 2011; McPherson et al. 2009; Tuchman et al. 2008; Weiner et al. 2011). But generally there was a lack of information about ethnicity. • Socioeconomic position Academic and employment status information was more often apparent in the studies of older adolescents and young adults. • Other Most studies used convenience and purposive samples. Sample information broken down by geographical location, young people's health condition characteristics, study setting and ages of participants. None of the studies reviewed had in their sample AEAs with intellectual and developmental disabilities. No information provided on other sample characteristics such as sex, sexual orientation, etc. Sample information broken down by geographical location, young people's type of health condition, study setting and ages of participants.

Betz C, Smith K, Macias K (2010) Testing the transition preparation training program: a randomized controlled trial (+/+)

Methodology and aims	**Sample size**	**PICO**	**Follow-up**
Methodology • Randomised controlled trial **Country** • USA	**Sample size** Originally 80, but 65 were analysed; 38 were allocated to the control group, 2 withdrew, 1 lost to follow-up, 1 not included in the analysis since not access to the same parent at pre- and post-; 42 were allocated to the treatment group, 3 withdrew (1 moved, 1 dropped out), 7 withdrawn by the principle investigator (2 hospitalised, 5	**Population** • Young people with spina bifida Mean sample age was 16 years, 27 young men (40%) and 39 young women (60%). Most young people in this sample were coded to ‘Latino’ (n=58) (90%), 4 were white, 2 were mixed race and 1 was Asian. Parents’ highest education levels are reported: 18 (28%) elementary school, 6 (9%) middle school, 30 (46%) high school, 7 (11%) college, 3 (5%) graduate school, 1 (1%) ‘other’. **Intervention** A 3-module training programme consisting of 8 sessions delivered over a 2-day workshop. This workshop included the development of a transition plan which focused on the young person’s own goals for the future in relation to health, education, work, community living, housing, recreation and leisure. The plan was developed over the 2 workshop sessions. **Outcomes** • Self-efficacy Role mastery: measured on the Community Life Skills Scale (CLSS) which focuses on: transportation, support services, support-involvement, interest-hobbies and	**Follow-up** • Measures were collected 4 months after the baseline data

	unable to schedule attendance), 1 excluded since not diagnosed with spina bifida.	regularity-organization-routines. Self-care practice: measured on the Denyes Self-Care Practice Instrument (DSCPI-90), focusing on general health behaviours and specific self-care behaviours. Quality of life: subjective wellbeing: measured by parents completing the PARS III tool which covers: peer relations, dependency, hostility, productivity, anxiety-depression, withdrawal. Included in the demographic questionnaire were questions about young people's spina bifida.	

Bhaumik S, Watson J, Barrett M, et al. (2011) Transition for teenagers with intellectual disability: carers' perspectives (+/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Mixed methods Combination of survey and in-depth interviews. **Country** • UK **Study aim** To identify healthcare needs of young people within a local area, their carers' perceptions of the transition process and to make recommendations on how to address unmet needs.	**Sample size** • 79 responded to the survey, 24 of these also participated in in-depth interviews	**Population** • Age 16–19-year-olds • Sex 48 male (60.8%), 31 female (39.2%) • Ethnicity 56 Caucasian (71%) 17 South Asian (21.5%) 4 African heritage (5.1%) 1 mixed (1.3%) 1 other (1.3%) **Outcomes** • Views studies For views studies, our methodology is not to extract specific outcomes. These are reported in the general narrative findings.

Binks J, Barden W, Burke T, et al. (2007) What do we really know about the transition to adult-centred health care? A focus on cerebral palsy and spina bifida (+/+)

Methodology and aims	Sample size	PICO
Methodology • Systematic review **Country** • UK • Austria • Canada • USA **Study aim** In relation to the transition from children's to adults' services for young people with spina bifida and cerebral palsy: to identify barriers associated with the transition process; to identify characteristics that should be included in transition programmes; and to review evidence on transition process and transition outcomes.	**Sample size** • Number of studies (SRs) 150	**Population** • Young people with long-term conditions • Spina Bifida and cerebral palsy

Bloom R, Kuhlthau K, Van Cleave J, et al. (2012) Health care transition for youth with special health care needs (++/++)

Methodology and aims	Sample size	PICO

Methodology • Systematic review **Country** • Range of countries USA (n=7), Germany (n=2), England (n=2), Finland (n=2), Australia (n=1), Canada (n=1) **Study aim** To assess the adult outcomes for young people with special healthcare needs who do not receive a special transition intervention. To identify evidence for interventions, models or strategies which improve outcomes, with a focus on access to adult services.	**Sample size** • Number of studies (SRs) 15	**Population** • Young people with long-term conditions and young people disabled Population defined as 'Youth with special health care needs'. Included studies used the same description (5) or focused specifically on cystic fibrosis (3), developmental disability (2), diabetes (4), and congenital heart defect (1). **Intervention** This review did not focus on a specific type of transition strategy, as long as it was about supporting purposeful and planned transition into adults' services for young people with special healthcare needs. The review focused on identifying outcomes for young people whose transition is not supported within this kind of framework. It also focused on the effectiveness of such strategies in supporting successful transitions, in particular in terms of providing access to adult care. **Outcomes** • Quality of life Quality of life mental health • Experience of care Satisfaction with care quality of care outcomes of care • Continuity of care Access to adult care

Broadhurst S, Yates K, Mullen B (2012) An evaluation of the My Way transition programme (+, relevance to this guideline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study The effectiveness of the My Way transition programme was independently	**Sample size** • 75 young people from the ages of 15–24 were involved	**Population** • Young people with long-term conditions • Young people disabled: 14 young people had a physical disability • Young people long-term conditions and young people disabled: 2 young people had both physical and learning disabilities

evaluated over a 2-year period through interviews with young disabled people, families, professionals and facilitators of MY Way. **Country** • UK **Study aim** This study is an independent evaluation of the effectiveness of My Way approach to transition developed by the MacIntyre Charity. The focus is on the transition of young disabled people into adulthood. The paper also summarises existing research on the outcomes achieved by young disabled and factors that promote best practice for successful transition, as well as cost information, concluding with certain recommendations.		• Care leavers • Young people with learning disabilities: 53 young people in this category, some of whom had profound and complex learning disabilities • Social care practitioners: this group comprised local authority care managers and senior managers • Carers/parents • Other: Connexions personal advisers, providers and facilitators from the My Way transition programme **Sample characteristics** • Age Ages of the sample of young people ranged from 15 to 24; 23 people were under the age of 18, 49 people were aged 18–21 and 3 people were aged 24. • Communication difficulties Four young people had both a learning and sensory disability; 1 young person had a sensory disability. **Intervention** • The My Way transition programme

Burgess C (2007) Staying afloat: effective interventions with young people in South Ayrshire. An evaluation of the impact of social work services and related agencies on outcomes for young people (++/++)

Methodology and aims	**Sample size**	**PICO**
Methodology	**Sample size**	**Population**

- Mixed methods The study was undertaken using both quantitative and qualitative research methods as follows: quantitative data was systematically obtained from 78 case files and a detailed form completed for each young person; qualitative information was also gathered from these case files to allow for a more in-depth analysis of the impact of services as perceived by social workers and other professionals involved with the young person; qualitative data was obtained through 19 face-to-face interviews with young people on their views and experiences of social work services and their current circumstances, and with 7 professional workers from both social work services and other agencies involved in service provision. **Country** • UK **Study aim**	• 78 case files of young people extracted and interviews with 19 young people.	• Care leavers • Young people with mental health problems • Social care practitioners Interviews with key staff from social services and partner agencies were included. • Other The young people all had involvement with social work services. They included those whose involvement was on a voluntary basis and those who had a statutory order, usually a supervision order, placed upon them, i.e. young people who were 'looked-after' and, in some cases, 'accommodated'. Range of circumstances from living at home, placed in foster or residential care in the local area or in residential or secure care (and sometimes in a custodial setting) outside the authority. **Sample characteristics** • Age Study participants from birth up to the age of 26. A total of 78 case files were examined; 3 excluded as incomplete info. Files made available from 5 sources: 1. throughcare support team: 19 young people all currently aged between 16 and 26, the average age being 19 or 20 years; 2. Whitletts area social work centre: 31 young people, 20 of whom were 18–20 years but 11 of whom were just 14 or 15 years – as 8 of these 11 young people had 5 years or more involvement with social work services they were included in the study; 3. Girvan social work team: 16 young people, 8 of whom were 16 or over and 8 just 14 or 15 years but all with at least 5 years involvement with social work services; 4. family centre: 5 family files were studied, including children with a range of ages from 3 months to 9 years (not relevant to our study) (p37); 5. criminal justice team: all over 18 years of age; as information about social work involvement was not comprehensive, it was decided to limit the numbers from this source. For the purposes of this data extraction, the main focus is on the groups (predominantly the second) below: 10–13 years = 17 young people (11 male/ six female);14 years and over = 22 young people (13 male/9 female) (p12).

The overall aim of the study was to outline the range of services offered by social work and related agencies and identify any particular models of intervention or common features within these which appear to have been successful in engaging and working effectively with young people, thereby helping to produce positive outcomes for them. The 2 main strands of the study were as follows: identification of particular patterns and models of social work intervention occurring throughout young people's lives, especially those associated with key life events, such as periods of transition; utilisation of a framework of measurable outcome factors in order to ascertain how effective social work provision has been for young people, taking into account their individual circumstances.		• In complex/unstable living conditions **Focus (qual)** • Views/experiences As reported in the mixed methods tool.

Cadario F, Prodam F, Bellone S, et al. (2009) Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach (-/++)

Methodology and aims	Sample size	PICO	Follow-up
Methodology • This is a retrospective study, comparing outcomes of young people who transitioned before and after the introduction of a transition support intervention **Country** • Italy	**Sample size** 62 Comparison numbers: 32 Intervention number: 30	**Population** • Young people with Type 1 diabetes **Ages** • Mean age 19: 34 young men, 28 young women **Intervention** A transition coordinator worked with the young people during their last year in paediatrics, and continued this work as they moved on to adults' services. An adult endocrinologist was involved in the transition planning. The coordination included a letter to the young people describing the transfer process, and young people were given the option of moving back to paediatrics if they didn't want to continue in adults' services after the transfer. The last clinic at paediatrics was conducted jointly with the adult endocrinologist, and without parents present. At the last clinic the paediatrician also gave a conclusive letter and a programmed file to both the adult endocrinologist and the young person. The paediatrician was then present at the first adult clinic visit. **Comparison intervention** At the last paediatric visit young people were given a letter summarising their clinical history, and a date for an appointment in the adult clinic. **Outcomes**	**Follow-up** • The clinic attendance rates were measured for the 1 year following transition to adult care, but they also report clinic attendance after 3 years

		• Condition-specific Mean HbA1c % in the last year in paediatric services and the first year in adult services. Experience of care: questionnaires asking about their experience if care in paediatrics and their experience of transition. Continuity of care: attendance rates after transfer to adults' services. Time between discharge from paediatrics and first appointment in adult services. Type of care during transition (self-care, GP, specialist care). Number of examinations during transition.	

Care Quality Commission (2014) From the pond into the sea: children's transition to adult health services (++, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • National, regional, local reports/assessments/ evaluations This was a themed review using focus groups, telephone interviews and an online web form. **Country** • UK **Study aim** The aims are not explicit but the report states that CQC began a process of 'themed'	**Sample size** • 58 young people, 124 family members, 437 multidisciplinary team members, 78 commissioners. A total of 100 clinical commissioning groups (CCGs) were approached to help identify young people	**Population** • Young people with long-term conditions Children with complex health needs. There is no standard definition of complex health needs) but in the context of this study, it includes children with physical disabilities, SEN and life-limiting or life-threatening conditions. • Carers/parents 124 family members • Administrators, commissioners, managers 78 commissioners • Other 437 MDT members **Sample characteristics** • Age Young people were aged 14–25. • Communication difficulties

work to look at the transitions arrangements for young people with complex health needs, through various consultation methods that highlight the challenges faced by young people, their families and carers.	(aged 14–25) with complex physical health needs. This information was anonymised and used as the basis for selecting a sample of 19 areas to visit across England. CQC also inspected 23 CQC-registered services that provide care for young people during and after the period of transition to adults' services. These included residential care homes and colleges, short break services, home care services and hospices.	In many cases, young people had communication problems. Numbers were not stated.

Certo N, Mautz D, Smalley K, et al. (2003) Review and discussion of a model for seamless transition to adulthood (-/+)

Methodology and aims	Sample size	PICO
Methodology • Evaluation tracking outcomes of young people who received a particular transition support model It is not clear whether this is a retrospective or prospective evaluation. **Country** • USA **Study aim** To discuss the implementation and audit the outcomes of the Transition Service Integration Model.	• The report provides outcome information for 234 students with significant support needs who were enrolled in the programme during 4 academic years	**Population** • Young people with learning disabilities Young people aged 21 (starting their final year in school), 22 (graduating from school. **Intervention** • Transition Service Integration Model The premise of this model is to integrate the 3 main services which are important to disabled young people with support needs: education, rehabilitation and developmental disabilities. The study was conducted in the US, and the equivalent agencies in the UK would likely be education, occupational therapy, physiotherapy and mental health services. Integration was sought through a) joint funding and b) transition service provision starting in the last year of school, thereby all adults' services referrals and transitions having happened by the end of a young person's last school year. The aim was to secure employment so that young people would go straight from school to work. Similarly, during the last year of school, workers aimed to link young people into community activities which would continue beyond graduation. **Outcomes** • Continuity of care Number of students where 'continuation of services were authorized by rehabilitation and developmental disabilities to start the first service day after school exit' (p9). **Other**… • Employment

Cheak-Zamora N, Xuejing Y, Farmer J, et al. (2013) Disparities in transition planning for youth with autism spectrum disorder (+/+)

Methodology & Aims	Sample Size	PICO

Methodology • Cross-sectional study Analysis of 2005–6 National Survey of Children with Special Health Care Needs. ‘Logistic regression analyses explored whether individual, family, or health system factors were associated with receipt of HCT services for youth with ASD’ (p447). **Country** • USA **Study aim** ‘This study expands our understanding by examining the receipt of HCT services in youth with ASD compared with youth with other special health care needs (OSHCN)’ (p447). ‘This study investigated the following: (1) the prevalence of receiving HCT services among youth with ASD, (2) the difference in prevalence for youth with ASD compared with youth with other special health care needs (OSHCN), (3) how individual, family, and health	**Sample size** • 806 young people with autism	**Population** • Young people with long-term conditions: 806 young people with special health needs **Sample characteristics** • Age Mean Age 14.1 (with ASD), 14.5 (with OSHCN) • Sex With ASD 28.4% male, with OSHCN 56.3% male • Ethnicity Race/ethnicity non-Hispanic - white - (with ASD) 67.0% (with OSHCN) 68.2% non-Hispanic - black - (with ASD) 17.1% (with OSHCN) 15.2%, Hispanic (with ASD) 10.9% (with OSHCN) 10.6% other (with ASD) 5% (with OSHCN) 6%. • Socioeconomic position Poverty level 0–99%, FPL (with ASD) 22.0 (with OSHCN) 17.7 100%–199%, FPL (with ASD) 23.2 (with OSHCN) 22.6 200–399% FPL (with ASD) 30.1(with OSHCN) 30.0 $400% FPL (with ASD) 24.6% (with OSHCN) 29.7%. **Outcomes** • Continuity of care The study looks at access to services for young people with autism and other special health care needs and also how the 2 groups compared in terms of meeting transition outcomes.

system characteristics influence the acquisition of HCT services' (p448).		

Children's Workforce Development Council (2010) Do young people experiencing the transition from children's services to adult services understand the process and what their choices are? (-, relevance to this guidline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study **Country** • UK **Study aim** This study aims to identify progress made locally over the first 2 years of Aiming High for Disabled Children (AHDC), government guidance for disabled children's services in England launched in May 2007. The study looks at the transition experiences of young people and their carers. A particular focus is to explore how planning for transition between North Yorkshire Children's Social Care Disabled Children's	**Sample size** • 9 young people	**Population** • 9 young people with a disability Carers/parents: their role appears to be more to facilitate interviews by prompting and supporting their dependant during discussion. But this is questionable and the author suggests that coercion may have been an issue with some of the young people's responses. **Sample characteristics** • Age Not stated • Sex 4 males and 5 females • Communication difficulties Two young people had severe disabilities which meant that carers had to assist with communication during interviews. • Other No detail provided on profile of disabled young people. **Outcomes** • Views studies For views studies, our methodology is not to extract specific outcomes. These are reported in the general narrative findings.

teams and adult and community services could be improved for disabled teenagers.		

Clarke S, Sloper P, Moran N, et al. (2011) Multi-agency transition services: greater collaboration needed to meet the priorities of young disabled people with complex needs as they move into adulthood (+/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Mixed methods In-depth interviews with service providers and survey with young people and parents in 5 service areas in the UK. **Country** • UK **Study aims** To consider how multiagency transition services meet the priorities and concerns of disabled young people with complex needs.	• 130 managers and staff in 5 transition services; 110 pre-transition and 33 post-transition parents/carers; 73 pre-transition and 24 post-transition young people	**Population** • Young people with long-term conditions and young people disabled Complex health needs and learning difficulties (74% had high levels of learning difficulties). 73 young people completed the pre-transition questionnaire, they were aged 14–22 years. 24 young people completed the post-transition questionnaire, they were aged 18–22 years. In both groups there were young people who completed a version of the questionnaire using symbol-based language. • Social care practitioners Transition workers/team members and their line managers, relevant staff in education, social care and Connexions. Some interviewees worked in schools/colleges attended by young people receiving a transition service. • Healthcare practitioners Relevant staff in health.

		• Carers/parents A total of 143 parents or carers returned the questionnaire; 110 of these were from pre-transition parents or carers, and 33 were post-transition. In both groups the majority of respondents were mothers (>80%). Both groups represented young people with a range of ethnic backgrounds, but both were predominantly white. • Administrators, commissioners, managers Members of steering groups for transition services. **Intervention** This is not an evaluation of a particular intervention, but it did focus on providers and service users of multiagency transition teams in the UK.

Cobb R, Alwell M (2009) Transition planning/coordinating interventions for youth with disabilities: a systematic review (+/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Systematic review **Country** • Not reported	**Sample size** • Number of studies (SRs) A total of 31 studies: of these 8 were between group comparison studies, 7 one group before-after studies (no comparison group), 2 were called 'multiple baseline across subjects and the	**Population** • Young people disabled Sample characteristics • Sex Percentage of male participants reported for each included study, when reported. • Communication difficulties Two studies' samples reported as 'acquired brain injury' and 'traumatic brain injury', and 9 studies' sample characteristics on conditions reported as 'varied' which may have included young people with communication difficulties. **Intervention** •Transition planning and coordinating interventions. **Outcomes** • Self-efficacy Student participation in transition planning. Perceptions of barriers to

	remaining 14 qualitative.	involvement. Vision of the future and self-determined status (outcomes reported here for relevant studies). • Experience of care Perceptions of the outcomes of transition. Perceptions of factors that would promote involvement (outcomes reported here for relevant studies). • Continuity of care Retention in programme (outcomes reported here for relevant studies). • Carers/family members' outcomes Parent participation in transition planning meetings (outcomes reported here for relevant studies).

Commission for Social Care Inspection (2007) Growing up matters: better transition planning for young people with complex needs (-, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study **Country** • UK **Study aim** 'This study examines in detail the experiences of young-people aged 14–19 and their families of transition into adult life. It also examines the perspectives of those who provide and organise care and considers the impact of current organisational and	**Sample size** • Total 22 case studies; 179 interviews with management from children's and adults' social services departments from 52 local authorities; 47 care staff at residential school	**Population** • Young people with long-term conditions • Social care practitioners • Healthcare practitioners • Carers/parents • Administrators, commissioners, managers **Sample characteristics** • Sample size 22 case studies 179 interviews with management from children's and adult social services depts from 52 local authorities. 47 care staff at residential school. **Outcomes** • Views studies For views studies, our methodology is not to extract specific outcomes. These

policy changes' (p3).		are reported in the general narrative findings.

Cowen A, Duffy S, Murray P (2010) Personalised transition: innovations in health, education and support (-, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • National, regional, local reports/assessments/ evaluations **Country** • UK **Study aim** The aim of this report is to describe personalised transition, which is a new way (at the time of publication) of organising support for young disabled people and their families. It enables young people with complex needs to leave school and achieve active citizenship within their communities.	**Sample size** • Not applicable	**Population** • Young people disabled Young people with complex needs. Sample characteristics not provided. • Social care practitioners Sample characteristics not provided. • Healthcare practitioners Sample characteristics not provided. • Other Education professionals. Sample characteristics not provided. **Sample characteristics** • Other Young people with complex needs. **Data extraction** • Intervention Personalised transition – a model to help young people with complex needs to take an active part in organising their care and support during transition from school to community. This model was developed at Talbot Specialist School in Sheffield in 2006 in collaboration with families, schools, Sheffield City Council, NHS Sheffield and the Learning and Skills Council and brought funding into a single pot. **Focus (qual)** • Intervention/programme Personalised transition for young people with complex needs. The main focus of case studies being individual budgets and self-directed support.

Craston M, Thom G, Spivak R (2013) Impact evaluation of the SEND Pathfinder Programme research report (++/+)

Methodology and aims	Sample size	PICO
Methodology • Mixed methods The study employed a survey, qualitative case studies a staff work and satisfaction survey and the cost/expenditure analysis tool. **Country** • UK **Study aim** This study, part of a bigger project evaluating the SEND Pathfinder Programme is the impact evaluation of the programme. It aims to describe and analyse: - experiences, outcomes and distance travelled by the initial cohort of participating families - extent to which working practices have changed for staff/individuals that have worked directly with these families	**Sample size** • 237 individuals	**Population** • Young people disabled A study sample included a mixture of disabilities, conditions and special educational needs. • Young people with long-term conditions and young people disabled **Sample characteristics** • Age A variety of ages. NOTE: this study is not just about young people of transition age: 17% under 5, 17% 17 and over • Sex 70% male **Intervention** • SEND Pathfinder Programme The initial 18 months of the SEND pathfinder programme sought to explore how to reform the statutory SEN assessment and statement framework, as a means of: - better supporting life outcomes for children and young people - giving parents confidence by giving them more control - transferring power to professionals on the frontline and to local communities. The Pathfinder Programme involved the development and delivery of alternative approaches that could enhance or replace the existing system. Each pathfinder was tasked to develop and trial an assessment process; a single, joined up ‘education, health and care plan’ (hereafter referred to as the EHC plan); and personal budgets across education, social care and health, and adults’ services as appropriate for children and young people from birth to

- indicative assessment of the costs of the reforms (p12).		25 years. In addition, the Programme explored how best to utilise and build the skills and resources of families and the voluntary and community sectors (VCS) (p18), and the development of a local service offer. **Outcomes** • Other The study states that it found no 'consistent statistical evidence' that the Pathfinder approach had an impact on parent or child outcomes. The qualitative parts of the study did show impacts. In terms of children making a transition, or gaining new support from a professional or changes in QoL due to respite care.

Crowley R, Wolfe I, Lock K, et al. (2011) Improving the transition between paediatric and adult healthcare: a systematic review (-/++)

Methodology and aims	Sample size	PICO
Methodology • Systematic review **Country** • Not reported **Study aim** To identify and review studies on the effectiveness of transitional care programmes for young people with a long-term conditions or disability who are moving into adults' services. To identify the essential components of	**Sample size** • Number of studies (SRs) They found 10 studies which evaluated transition interventions. Results are only presented for 6 studies which showed a statistically significant difference in	**Population** • Young people with long-term conditions and young people disabled **Sample characteristics** • Age: 11–25 **Intervention** '… approaches to improving the processes and structure of transitional care'; this was defined as 'a health service intervention during the period of transition from paediatric to adult care' (both quotes from p549). **Outcomes** - Self-efficacy - Young people with diabetes: self-management skills, disease specific knowledge

effective programmes.	health outcome from the intervention.	- Condition-specific - Diabetes-related quality of life score: disease-specific biochemical markers (all from studies about young people with diabetes: HbA1c acute complications (diabetic ketoacidosis, hypoglycaemia), chronic complications (hypertension, nephropathy, retinopathy) - Continuity of care - Young people with diabetes: rate of loss to follow-up/clinic attendance rate, rate of screening for complications

Day P, Turner J, Hollows A (2007) Bridging the gap: transition from children's to adults' palliative care, final report (+, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study Case study methodology including some document analysis, interviews and focus groups. **Country** • UK	**Sample size** • 13 individuals	**Population** • Young people with mental health problems and acute mental health problems **Sample characteristics** • Age 15–20 • Gender 6 male, 7 female • Other The sample had a range of diagnoses including self-harm, depression, schizophrenia, OCD, ADHD, autism, eating disorder and post-traumatic stress disorder. **Outcomes** • Views studies For views studies, our methodology is not to extract specific outcomes. These are reported in the general narrative findings.

Donkoh C, Underhill K, Montgomery P (2006) Independent living programmes for improving outcomes for young people leaving the care system (++/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Systematic review **Country** • Range of countries	**Sample size** • Number of studies (SRs) 0 studies	**Population** • Care leavers **Intervention** • This review looks at the effectiveness of independent living programmes Independent living programmes are intended to equip young people exiting the care system with the skills they need to transition into independent living and adulthood. These schemes can offer a wide range of training and assistance including education and employment support and help with personal development and the development of independent living skills. **Outcomes** • Self-efficacy, health outcomes Outcomes of interest were health status, behaviour outcomes (i.e. coping skills, financial skills) and knowledge (knowledge of state benefits systems, accessing community resources and similar.

Doug M, Adi Y, Williams J, et al. (2011) Transition to adult services for children and young people with palliative care needs: a systematic review (+/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Systematic review **Country** • Range of countries USA: 42, UK: 27, Australia: 11, Canada: 8, Denmark: 1, Switzerland: 1, Germany: 1,	**Sample size** • Number of studies (SRs) 92 studies were included in the review, 31 of these were	**Population** • Young people with long-term conditions • Young people with life-threatening conditions or conditions leading to premature death or palliative care needs **Sample characteristics** Age range of studies was 13–24

South Africa: 1 **Study aim** To evaluate the evidence on transition from children's to adults' services for children with palliative care needs, especially focusing on the continuity of care, young people and their families' experiences; and to identify examples of good practice.	classified as empirical studies and subjected to a quality assessment	**Intervention** • Transition from paediatric to adult palliative care. However, studies were sampled primarily on population **Outcomes** • Experience of care 'Experiences of transition and their impact on young people, their families, carers and service providers' (p79). • Continuity of care • Carers/family members' outcomes Impact from their experiences of transition. • Practitioners' outcomes Impact from their experiences of transition. **Focus** • Views/experiences Young people, families and carers, and professionals. Intervention/programme. Transition processes.

Downing J, Gleeson H, Clayton P, et al. (2013) Transition in endocrinology: the challenge of maintaining continuity (+/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Case-control study Retrospective analysis of information about patients after their transition from children's to adults' services. They were all patients at endocrine or adrenal clinics. **Country**	**Sample size** 103 people	**Population** • Young people with long-term conditions • Endocrinology and adrenal clinical patients **Sample characteristics** • Age 18 or younger – 63; 19 years or older – 40 • Sex Male – 48; Female – 55 **Intervention**

• UK **Study aim** ‘This study examined indicators of patient loss to follow-up at initial transfer from paediatric care to identify implications for transitional care practice and research’ (p29).		No distinct intervention but the study looks at young people’s transition from children’s services to the young person’s transition clinic, not adults’ services. **Outcomes** • Continuity of care The study looks at indicators to loss of patients after transition.

Everson-Hock E, Jones R, Guillaume L, et al. (2011) Supporting the transition of looked-after young people to independent living: a systematic review of interventions and adult outcomes (++/-)

Methodology and aims	**Sample size**	**PICO**
Methodology • Systematic review **Country** • Range of countries Six studies from the USA, 1 from the UK.	**Sample size** • Number of studies (SRs) 7 studies	**Population** • Care leavers **Intervention** • This review looks at a range of interventions with the following characteristics: support services to assist and prepare looked-after young people for the transition from foster/residential care to independent living or some form of community care, delivered or commenced during the young people’s time in care. **Outcomes** • Other Educational attainment, employment, substance misuse, criminal and offending behaviour, young parenthood, housing and homelessness, and physical, mental and sexual health. Other outcomes such as their own children being taken into care were considered when reported by the included studies.

Fair C, Albright J, Lawrence A, et al. (2012) ‘The pediatric social worker really shepherds them through the process’: care team members’ roles in transitioning adolescents and young adults with HIV to adult care (++, relevance to this guideline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study **Country** • USA **Study aim** The study aims to analyse interview material gathered from 19 HIV care providers. The professionals were specifically asked about the different roles of providers during transition from paediatric to adult care.	**Sample size** • 19 professionals participated	**Scope population?** • Social care practitioners • Healthcare practitioners **Sample characteristics** • Sex 6 male, 13 female • Ethnicity All Caucasian **Data Extraction** • Intervention No intervention as such, participants were asked to identify the different roles HIV care providers during the transition process. • Follow-up None **Outcomes (quant)** • Practitioners’ outcomes The study analyses the roles of different professionals during the transition process. **Focus (qual)** • Views/experiences

Fegran L, Hall E, Uhrenfeldt L, et al. (2014) Adolescents’ and young adults’ transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis (++/++)

Methodology and aims	Sample size	PICO
Methodology	**Sample size**	**Scope population?**

• Systematic review Qualitative metasynthesis **Country** • Range of countries **Study aim** To synthesise qualitative studies of how adolescents and young adults with chronic disease experience the transition process from paediatric to adult hospital services.	• 368 in sample Number of studies (SRs) 18.	• Young people with long-term conditions • Healthcare practitioners • Carers/parents **Sample characteristics** • Age Studies range from as young as 8 years to oldest in sample at 35 years • Sex Not clear what distribution between male and female is. • Other Only info on age and sex provided. **Outcomes (quant)** • Views studies

Garvey K, Wolpert H, Laffel L, et al. (2013) Health care transition in young adults with type 1 diabetes: barriers to timely establishment of adult diabetes care (++/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Survey The survey was designed to assess transition barriers for young adults with diabetes and transition preparation and satisfaction, and also look at where there might be	**Sample size** • 258 respondents	**Population** • Young people with long-term conditions Diabetes. **Sample characteristics** • Age Average age was 26.7. Young people were average age 19.5 when they transitioned.

gaps in service, self-care and demographics. **Country** • USA **Study aim** 'To examine barriers to health care transition reported by young adults with type 1 diabetes and associations between barriers and prolonged gaps between paediatric and adult diabetes care' (p946).		• Sex 62% female • Ethnicity 92% Caucasian **Outcomes** • Continuity of care Barriers to the timely establishment of adult diabetes care. • Views studies Experiences of transition.

Gilmer T, Ojeda V, Fawley-King K, et al. (2012) Change in mental health service use after offering youth-specific versus adult programs to transition-age youths (+/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Comparison evaluation **Country** • USA **Study aim** To assess the impact on service use when providing	**Sample size** • 2505 patients • Comparison numbers 1574 in adult services group • Intervention number	**Population** • Young people with mental health problems **Sample characteristics** • Age All participants were aged 21. • Sex Intervention group – 50% female, adults' services group – 55% female • Ethnicity

young people-focused services, in comparison to providing adults' services, for young people aged 18–24.	931 in intervention group	Intervention group – 43% non-Latino white, 11% African American, 37% Latino, 9% Asian. Adult group – 49% non-Latino white, 8% African American, 38% Latino, 5% Asian. **Data extraction** • Intervention The study looked at the effects of outpatient programmes designed for transitioning young people using mental health services. The study was set in San Diego, the programme was designed for 18–24-year-olds and staffed by workers who had a level of experience working with young people. The transitions team worked with other professionals involved in the young people's care. The programme focused on independent living skills, educational and vocational services and age-appropriate social skills. This included peer-support provided by young people with mental health services experience. • Comparison intervention The standard outpatient programme provided the usual mental health for adults with mental health issues and substance abuse issues. **Outcomes (quant)** • Condition-specific Inpatient admissions and emergency service visits. • Continuity of care Outpatient visits. • Other Jail service days. **Focus (qual)** • Intervention/programme

Hagner D, Kurtz A, Cloutier H, et al. (2012) Outcomes of a family-centred transition process for students with autism spectrum disorders (-/+)

Methodology and aims	**Sample size**	**PICO**	**Follow-up**
Methodology • RCT This is a trial which used ‘waiting-list control’, so they recruited students and parents, randomly assigned half to the intervention in year 1, and then the other half was the comparison group for that year but then they also received the intervention in year 2. **Country** • US	**Sample size** • Comparison numbers 23 • Intervention number 24 • Sample size 47	**Population** • Young people disabled Young people with autistic spectrum disorders • Carers/parents All young people were recruited along with 1 parent. **Sample characteristics** • Age Range from 16–19 years, with mean 17.7 years in Year 1 (first intervention group) and 17.4 years in the comparison group (which got the intervention in Year 2). • Sex Almost all in the sample were male and only 2 were female. • Ethnicity All students were white. • Communication difficulties This is not reported as a participant characteristic, but when reporting on the findings it transpires that some of the young people needed help with filling in the survey, and some were ‘unable to complete the surveys, and these were those students with the most significant language limitations’. **Intervention** Three components: A: group training sessions for families teaching them about person-centred planning, networking, using adults’ services and how to plan a future beyond high school. B: person-centred planning: facilitators worked with the	**Follow-up** • Outcomes measured 1 year after the start of the intervention

		student and their family to select and invite extended family and community people to 2–5 meetings. Once this group had agreed ideas for transition, staff from their school and adults' services were invited to provide input to the final plan. It was the role of the facilitator to ensure transparent and full participation in the group, especially for the young person. This included further support to the student outside of the planning meetings. C: follow-up assistance: facilitators who were involved in the planning provided 4–6 months' follow-up on the implementation of the plan. **Outcomes** • Transition readiness Students' expectations for adult life, measured by a survey tool that asks about 5 education milestones (high school graduation, further education) and four independence milestones (driver's licence, employment, living situation). • Self-efficacy Self-determination in students, using the Arc Self-Determination Scale, which has been tested for internal consistency and validity. • Carers/family members' outcomes Parents' expectations for their child's adult life measured by the same tool as the young people but completed separately.	

Hamdani Y, Proulx M, Kingsnorth S, et al. (2014) The LIFEspan model of transitional rehabilitative care for youth with disabilities: healthcare professionals' perspectives on service delivery (++, relevance to this guideline: highly relevant)

Methodology and aims	Sample size	PICO

Methodology • Qualitative study **Country** • Canada, Toronto **Study aims** To elicit professionals' views on delivering LIFEspan, a model for delivering coordinated care throughout transition.	**Sample size** • 14 health professionals	**Population** • Young people with long-term conditions and young people disabled Only health professionals were interviewed. However, the service was provided to young people with cerebral palsy and acquired brain injury. • Health care practitioners • Carers/parents No carers or parents were interviewed but the service was aimed specifically at both young people and their carers or parents. **Intervention** The LIFEspan model means that transition preparation starts at the age of 16, so that the young people have two years of preparation before they go through a coordinated transfer to adults' services. LIFEspan is implemented in both paediatric and adults' services. In both paediatric and adults' services teams of professionals work with the young person. Preparation in paediatrics includes explaining about the reduced service provision in adults' services, so as to manage expectations.

Heslop P, Abbott D (2007) School's out: pathways for young people with intellectual disabilities from out-of-area residential schools or colleges (++, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study **Country** • UK **Study aim** Though not explicitly stated in an aim, the study explores the views of parents of young people with ID	**Sample size** • Originally 15 young people, but 2 dropped out. The response rate across the 5 authorities was 39% (range 11–57%). All of the	**Population** • Young people with learning disabilities Despite young people being included in the sample, the primary interest is the views of parents. • Social care practitioners • Carers/parents **Sample characteristics** • Communication difficulties The young people's sample contains some individuals with communication

regarding what factors contributes to a good pathway and outcome from an out-of area residential school or college on to the next phase of their son or daughter's life. Professionals' views are used to supplement this or where they provide background.	young people agreed to the research team talking to their parents about their experiences; parent response rate was 100%. Each of the young people and their parents also nominated professionals they thought helped them in preparing or supporting them through transition. Out of 32 nominations, 27 were eventually included.	difficulties. Effort is made to ensure all groups have been able to participate in the research, despite various levels of communication difficulty. • Other Some learning disabled young people with physical impairments have also been included.

Hiles D, Moss D, Wright J, et al. (2013) Young people's experience of social support during the process of leaving care: a review of the literature (+/++)

Methodology and aims	**Sample size**	**PICO**

Methodology • Systematic review **Country** The review includes a considerable body of international literature and despite the cultural, contextual and policy differences in other countries, there were similar experiences among many of the young people in terms of social support. The review looks at those common experiences, but with an emphasis on those which appear relevant within the UK policy context. Predominantly, papers were from England, followed by USA, Scotland and Australia. UK papers also featured in other categories. **Study aim** The aim of this review is to collate and synthesise research relating to young people's experiences of social support during their transition from care. Key themes were identified, and briefly considered using	**Sample size** • Number of studies included: 47 .	**Population** • Care leavers **Outcomes** • Views studies For views studies, our methodology is not to extract specific outcomes. These are reported in the general narrative findings.

relevant psychological theory and implications for policy, practice and future research were considered.		

Hiles D, Moss D, Thorne L, et al. (2014) ‘So what am I?’ Multiple perspectives on young people’s experience of leaving care (++, relevance to this guideline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study **Country** • UK **Study aim** The study aims to highlight the experiences of care leavers in transition, and the support available, within the context of a highly pressured leaving care system. Implications for policy, practice and future research are also considered.	**Sample size** A total of 6 care leavers formed the main sample; 4 health and social care practitioners were also part of the study.	**Population** • Care leavers • Social care practitioners Total 3 workers in social care: 1 social worker within a care leavers’ service; 1 fostering social worker; 1 community care worker within a young people’s accommodation service. • Healthcare practitioners Healthcare based: a family therapist working with care leavers. **Sample characteristics** • Age 16–22 years. Mean age 18.8 years. • Sex Male only. • Ethnicity All care leavers were white British. • In complex/unstable living conditions **Outcomes** • Views studies For views studies, our methodology is not to extract specific outcomes. These are reported in the general narrative findings.

MHI Probation, HMI Prisons, Care Quality Commission, et al. (2012) Transitions: an inspection of the transition arrangements from youth to adult services in the criminal justice system (++, relevance to this guideline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • National, regional, local reports/assessments/ evaluations Inspection report which involved speaking to young people (those aged under 18) and young adults (those aged 18 and over) about their experiences, as well as inspecting case records. We also held discussions with practitioners and managers from criminal justice agencies, and others, such as health and education, training and employment, who worked in partnership with them to provide interventions. **Country** • UK **Study aim** This inspection was agreed by the Criminal Justice Chief Inspectors' Group, as part of the Joint Inspection	**Sample size** • Interviews with 25 young people and young adults about their experience of the transition process; and inspections of the case records of 128 young people and young adults. In custody – 17 young adults who had transferred from an under-18 establishment. Case records of same 17 also inspected.	**Population** • Young people with mental health problems • Social care practitioners • Healthcare practitioners • Carers/parents • Teachers Education professionals – not specified exactly who. • Other Sample consisted of professionals based in youth offending teams and probation trusts and youth offending institutions. Reference to young people's physical health conditions made in broadest sense with no explanation of conditions. **Sample characteristics** • Other Reference to young people's physical health conditions made in broadest sense with no explanation of conditions. Young people with mental health problems also included, but again no detail. **Outcomes** • Experience of care • Continuity of care

Business Plan 2010–12. Its terms of reference were to assess the quality of work undertaken to promote an effective transition for young people subject to community and custodial sentences, at the age of 18, from youth-based to adult-based provision.		

Huang J, Terrones L, Tompane T, et al. (2014) Preparing adolescents with chronic disease for transition to adult care: a technology program (++/+)

Methodology and aims	Sample size	PICO	Follow-up
Methodology • RCT **Country** • USA	**Sample size** • 81 **Comparison** • 41 **Intervention** • 40	**Population** • Young people with long-term conditions: inflammatory bowel disease, cystic fibrosis, and type 1 diabetes **Sample characteristics** • Age: recruited from 12–20, the sample age ranged from 13–18 • Ethnicity In the intervention group (n=40), 18 young people were Hispanic, 16 were white, and the rest were of other ethnicities. In the control group (n=41), 22 young people were Hispanic, 11 where white and the rest were other ethnicities. **Intervention** MD2Me: this is a transition support intervention delivered over a 2-month period via the web and by texting, to support condition management and skills	**Follow-up** • At 2 and 8 months after baseline

		development, followed by a 6-month review period. It included ‘a texting algorithm for disease assessment and health care team contact’ (p1639). Young people who did not have a mobile phone were provided with one by the study. This was compared with monthly emails or postal materials on general health topics. ‘Usual health care communication portals were available to controls’ (p1641). **Outcomes** • Transition readiness Health literacy assessments: Test of Functional Health Literacy in Adults. The Transition Readiness Assessment Questionnaire (TRAQ) 4.1. • Self-efficacy The Patient Activation Measure. • Quality of life Global health status: the Karnofsky Performance Scale. Paediatric Quality of Life Scale (PedsQL). • Condition-specific Disease status, assessed by condition-specific scales. • Continuity of care Patient-initiated health care communications (frequency and mode of communication contacts between young people and the healthcare system).	

Jordan L, Swerdlow P, Coates T, et al. (2013) Systematic review of transition from adolescent to adult care in patients with sickle cell disease (+/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Systematic review	**Sample size** • Number of	**Population** • Young people with long-term conditions

Country • The review was conducted in the US and by US authors, but country of origin not reported for the included studies. **Study aim** This review aimed ‘to examine the barriers to and approaches for successful transition of patients with SCD [sickle cell disease] from adolescent to adult care’ (from the study abstract).	studies (SRs) 20	Focus on sickle cell disease, but 6 included studies were also about other long-term conditions. **Sample characteristics** • Other Population characteristics for the studies were not reported. **Outcomes** • Continuity of care The main focus of this study is continuity of care, and this is also the main outcome of concern.

Kaehne A (2011) Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems (++, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study **Country** • UK Three local authorities in Wales. **Study aim** The study aim is to investigate how mental health professionals	**Sample size** • 8 staff as follows: 4 based in CAMHS, 3 based in AMHS, 1 based in local authority mental health team	**Population** • Young people with learning disabilities This group were not interviewed, but they were the focus of the study. • Healthcare practitioners Staff in CAMHS (4) and AMHS (3) and 1 member of staff in a local authority mental health team. **Sample characteristics** • Other Young people with intellectual disabilities (subject of study, not sample).

organise transition for young people with intellectual disabilities, what they consider to be the key gaps in services at that critical time for young people, and what they think the main barriers to smooth transitions are.		

Kelly, B (2013) Don’t box me in: disability and transitions to young adult life (++, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study **Country** • UK **Study aim** This study aimed to explore the transitional and early adult life experiences of young adults with learning disabilities through qualitative methods including: semi-structured interviews with young people, families and carers and professionals; case file reading; and biographical narrative techniques (Denzin and Lincoln 2000). The	**Sample size** • 10 learning disabled young people	**Population** • Young people with learning disabilities • Social care practitioners Key workers (all of whom were social workers) for the selected cases from adult learning disability services in 4 of the 5 health and social care trusts in Northern Ireland. This coverage replicated the geographical areas in the first study before the restructuring of trusts. In addition, interviews were undertaken with transition coordinators, team leaders and senior managers (n=10), voluntary sector managers (n=5) and senior personnel at policy and commissioning levels (n=3). • Carers/parents • Administrators, commissioners, managers **Sample characteristics** • Age Ten young people with learning disabilities. Age breakdown below. Male/female total 18–21 2 1 3 22–25 1 3 4 26–29 1 2 3 TOTAL 4 6 10 • Sex Ten young people with learning disabilities – 4 male and 6 female. Gender

study is based on a follow-up study of 10 young adults who were involved in research examining the family support needs of disabled children and their families 10 years earlier when these participants were all aged under 18 and receiving services from their local children's disability social work team.		breakdown by age below. Male/female total 18–21 2 1 3 22–25 1 3 4 26–29 1 2 3 TOTAL 4 6 10 **Outcomes** • Views studies

Kime N, Bagnall AM, Day R. et al. (2013) Systematic review of transition models for young people with long-term conditions: a report for NHS Diabetes (+/++)

Methodology and aims	**Sample Ssze**	**PICO**
Methodology • Systematic review **Country** • Range of countries The review reports the countries of the individual studies included in this review. These were mainly the USA, but also Canada, some western European	**Sample size** • Number of studies (SRs) 16 systematic reviews and 13 individual studies published after the search data parameters for the included reviews.	**Population** • Young people with long-term conditions **Sample characteristics** • Age Studies were included based on young people aged 11 to 25 **Intervention** Models, or components of models, of transition from paediatric to adult services. **Outcomes**

countries, 1 study from the UK and 1 from Hong Kong. This review also included other reviews, but did not specify the individual studies in the included reviews. **Study aim** The review aimed to answer the following questions: 1. What models or components of models are effective in ensuring a successful transition process for young people with long-term conditions? 2. What are the main barriers and facilitating factors in implementing a successful transition programme? 3. What are the key issues for young people with long-term conditions and professionals involved during the transition process? (p1)		• Self-efficacy Secondary outcome: confidence and motivation to self-manage. • Quality of life Primary outcome: wellbeing and quality of life, including psychosocial measures such as self-image and self-esteem. • Condition-specific Secondary outcome: biochemical markers associated with particular long-term conditions such as HbA1c, FEV1. • Experience of care Secondary outcome: patient satisfaction. • Continuity of care Secondary outcome: compliance with treatment. • Views studies Systematic review which looks at outcomes and views.

Kingsnorth S, Lindsay S, Maxwell J, et al. (2010) Implementation of the LIFEspan model of transition care for youth with childhood onset disabilities (overall validity ++, relevance to this guideline: – highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study **Country** • Canada **Study aims** The study aims to understand key factors in this collaborative cross-sector partnership by understanding a process evaluation of stakeholder experiences.	**Sample size** • Total of 18 clinical and non-clinical staff participated in the study They were identified through their involvement in the implementation of the LIFEspan model. The professionals were from multiple disciplines, including medicine, OT, nursing, physiotherapy and others. Managers and senior administration staff were also included.	**Population** The study does not clearly describe how many professionals from different disciplines participated from each site. It states that individuals were at times cross-appointed and occupied more than one role. Participants were clinical service delivery staff, managers or senior administrators, or they were steering committee members. • Healthcare practitioners • Administrators, commissioners, managers **Intervention** 'Two health centres in Toronto, Canada partnered to develop a linked model of care to support transition from paediatric to adult rehabilitation services' (p547). The LIFEspan model draws together 3 stages of care provision to help introduce more continuity into the care process: paediatric services, transfer services and adult services.

Kipps S, Bahu T, Ong K, et al. (2002) Current methods of transfer of young people with Type 1 diabetes to adult services (-/++)

Methodology and aims	Sample size	PICO
Methodology • Comparison evaluation Retrospective chart review/evaluation of	**Sample size** • 229 Comparison numbers	**Population** • Young people with long-term conditions Type 1 Diabetes **Sample characteristics**

outcomes for young people in 4 regions of Oxford (Oxford, Reading, Northampton, Aylesbury), all found to have different strategies for transitional care. **Country** • UK **Study aim** To systematically review outcomes of different transition practices across 4 NHS regions.	1. Transfer from a paediatric clinic to an adult clinic (n=56). 2. Transfer from a paediatric clinic to a young adult clinic held in a diabetes centre at a different hospital (n=67). 3. Transfer from a paediatric clinic to a young adult clinic held in the same hospital; patients were introduced to the adult physician in the paediatric clinic prior to transfer (n=65). 4. Initial move from a paediatric clinic to an adolescent clinic held in the same diabetes centre (run jointly by the paediatrician and adult physician)	• Age Mean age at transfer ranged across the four areas from 13.3 to 22.4 • Sex Of the total sample of 229 young people, 130 were male. This proportion roughly reflected the breakdown per area. **Intervention** Compared 4 different types of transition: 1. transfer from a paediatric clinic to an adult clinic; 2. transfer from a paediatric clinic to a young adult clinic held in a diabetes centre at a different hospital; 3. transfer from a paediatric clinic to a young adult clinic held in the same hospital; patients were introduced to the adult physician in the paediatric clinic prior to transfer; 4. initial move from a paediatric clinic to an adolescent clinic held in the same diabetes centre (run jointly by the paediatrician and adult physician) before transfer to the adult clinic **Outcomes** • Condition-specific HbA1C • Experience of care Young people’s perceptions of their medical care. • Continuity of care Clinic attendance in adult services compared with when in children’s services.

	before transfer to the adult clinic (n=41).	

Kirk S, Fraser C (2013) Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: a qualitative study (++, relevance to thus guideline: highly relevant)

Methodology & Aims	**Sample Size**	**PICO**
Methodology • Qualitative study **Country** • UK **Aims** Study has three aims: (1) To examine how young people with life-limiting conditions and their parents experience transition. (2) To identify families' and hospice staff's perceptions of family support needs during transition. (3) To identify the implications for children's hospices (p342).	**Sample size** • 16 young people and 16 parents participated	**Population** • Young people with life-limiting conditions **Sample characteristics** • Age Total 16 young people aged between 16 and 31. The majority (n=8) aged between 18 and 22. Parents who spoke for their children (12 interviews) children aged between 18 and 31, the majority (n=9) aged between 18 and 22. • Sex Young people – 7 female, 9 male. Parents speaking for young people – 6 male, 6 female. **Outcomes** • Views studies For views studies, our methodology is not to extract specific outcomes. These are reported in the general narrative findings.

Lee Y, Wehmeyer ML, Palmer S, et al. (2011) The effect of student-directed transition planning with a computer-based reading support program on the self-determination of students with disabilities (+/+)

Methodology and aims	Sample size	PICO	Follow-up
Methodology • RCT Randomised at school campus level **Country** • US	**Sample size** • Comparison numbers 82 • Intervention number 86 • Sample size 168	**Population** • Young people disabled Young people with difficulty reading, as identified by their teachers. The participant table indicate that even though this was a requirement 1 student in the control group and 3 in the intervention group were exemplary readers (above grade level) and 34% (n=28) in the control group and 16.3% (n=14) in the intervention group were proficient readers (at grade level). **Sample characteristics** • Age Mean age in the control group was 13.3, mean age in the intervention group was 13.9. • Sex In the control group 70% were young men, and 30% young women. In the intervention group 77% were young men and 23% were young women. • Ethnicity White: control group n=50 (61%), intervention group n=45 (52%), Black: control group n=9 (11%), intervention group n=26 (30%), Hispanic/Latino: control group N=20 (24%), intervention group n=11 (13%), Asian: control group n=2 (2%), intervention group n=3 (4%), Native American/Alaskan native: n=1 (1%) in each group. • Communication difficulties There is a breakdown of the sample based on disabilities, and of these there is a category called ‘speech disorder’ with n=9 (11%) in the comparison	**Follow-up** • Pre-tests were administered before the implementation of the intervention. Post-tests were administered after the implementation of all 10 lessons, or at the end of the semester

		group and n=6 (7%) in the intervention group. **Intervention** ‘Whose Future is it Anyway?’ an organised and planned transition approach which aims to teach students about participating in their own transition. It contains 6 areas, which are covered across 36 sessions: 1) self-awareness and disability awareness; 2) decision-making about transition-related outcomes; 3) identifying and securing community resources to support transition services; 4) writing and evaluating goals and objectives; 5) communicating effectively in small groups; 6) developing skills to become an effective team member, leader or self-advocate. In this study they could only implement 10 sessions which covered self-awareness and disability awareness, communication, decision-making and team membership. Both groups in this study received this short version of Whose Future is it Anyway? In addition, the intervention group received Rocket Reader, a computer software program for students with disabilities. The Rocket Reader changes text into audio format. **Outcomes** • Transition readiness The outcome ‘knowledge about transition planning’ was measured using the WFA Knowledge Test which is a multiple-choice questionnaire about information they had received as part of the person-centred planning. • Self-efficacy Their outcome ‘self-determination’ was assessed using: 1) Arc’s Self-Determination Scale, which assessed students on autonomy, self-regulation, psychological	

		empowerment and self-realisation, all of which correspond to our 'self-efficacy' outcome which is defined in scope as 'young people's ability to undertake the activities they want to, as independently as possible'. 2) AIR Self-Determination Scale which assesses an individual's level of self-determination and then identifies goals and strategies to reach these goals. In addition, they measured 'self-efficacy for educational planning'. While education is out of PICO as an intervention unless it includes a social care or health input, the nature of the scale used to assess this here means that we have included this outcome too: this was a 20-item questionnaire which aimed to measure the degree to which young people believed a) that they knew how to behave in order to participate successfully in planning meetings; b) that if they behaved accordingly they would achieve their desired outcomes.	

Lewis S, Noyes J. (2013) Effective process or dangerous precipice: qualitative comparative embedded case study with young people with epilepsy and their parents during transition from children's to adults' (Internal validity + Relevance to this guidance – Highly Relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study **Country** • UK **Aim** 'The aim of this qualitative comparative embedded	**Sample size** • Total 30 young people and 28 parents were interviewed	**Population** • Young people with long-term conditions Epilepsy **Sample characteristics** • Age Participants appear to be aged between 14–19.

case study was to explore the views of young people with epilepsy (and their parents) about their experience of communication, information and knowledge exchange in two epilepsy services' (p3).		**Outcomes** • Experience of care

Mackie AS, Islam S, Magill Evans J, et al. (2014) Healthcare transition for youth with heart disease: a clinical trial (+/+)

Methodology and aims	Sample size	PICO	Follow-up
Methodology • RCT incl. cluster **Country** • Canada	**Sample size** • 58 individuals were enrolled **Comparison** • 31 received usual care **Intervention** • 27 received intervention	**Population** • Young people with long-term conditions Cardiac disease. **Sample characteristics** • Age Range 15–17. **Intervention** Hour-long, nurse-led sessions with young people preparing to transition. The intervention was one-on-one and designed to inform patients about their condition and treatment. **Outcomes** • Transition readiness: the intervention was designed to improve self-management and advocacy. Outcomes were measured using Transition Readiness Assessment Questionnaire.	**Follow-up** • At 6 months

Marriott A, Townsley R, Ward L et al. (20029) Access to independent advocacy: an evidence review (+/++)

Methodology and aims	**Sample size**	**PICO**	**Follow-up**
Methodology • Systematic review Country • UK • Study aim This is a review which aimed to look at the extent and nature of the evidence on independent advocacy for disabled people who are at risk of losing their choice and control in four situations, one of which included transition from children's to adults' services.	Sample size • Number of studies (SRs) 23	**Population** • Young people long-term conditions and young people disabled • Young people with learning disabilities **Intervention** Independent advocacy, defined as a partnership between a person who is feeling vulnerable or isolated and a member of the community, where this member of the community provides support, information and representation to this person. This means that if the person wants, the advocate can act on their behalf in certain situations. The overall aim of the partnership is to encourage the person to express their needs and wishes.	**Follow-up** • Data extraction Intervention Independent advocacy, defined as a partnership between a person who is feeling vulnerable or isolated and a member of the community, where this member of the community provides support, information and representation to this person. This means that if the person wants, the advocate can act on their behalf in certain situations. The overall aim of the partnership is to encourage the person to express their needs and

			wishes.

Mills J, Cutajar P, Jones J, et al. (2013) Ensuring the successful transition of adolescents to adult services (+, relevance to this guideline: – highly relevant)

Methodology and aims	Sample size	PICO
Methodology • National, regional, local reports/assessments/ evaluations **Country** • UK **Study aim** This article discusses the outcomes of transition to adults' services of children and young people with chronic illnesses or disabilities referred to the department of learning disabilities at Nottinghamshire Healthcare NHS Trust, which covers a population of about 578,000. It aims to collect information on the age of each client at referral. The age at transition.	**Sample size** • The eligible sample was 20 individuals, 14 male and 6 female	**Scope population** • Young people with learning disabilities • Young people with learning disabilities were not study participants, but their case notes were examined. The eligible sample was 20 individuals, 14 male and 6 female. Their ages at referral ranged between 14 and 21 years, with a mean age of 18.02 years. **Sample characteristics** • Age Ages of young people at referral ranged between 14 and 21 years, with a mean age of 18.02 years.

The specialty of each referring organisation. Information communicated in the referral. Whether each of the service users had a named care coordinator. Any problems that arose during referral.		

Milner C (2008) Experiences of health transition for young people with learning difficulties and complex health needs in Northumberland (+, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology - Qualitative study **Country** - UK **Study aim** 'The objective of this audit was to investigate and collate experiences of the transition from children's to adults' health services, for young people in Northumberland who have both learning difficulties and complex health needs and for their families and/or carers' (p5).	**Sample size** - 21 individuals who were passing through transition or who had completed transition	**Population** - Young people with long-term conditions - Young people with learning disabilities **Sample characteristics** - None given **Outcomes** - Views studies

Mitchell F (2012) Self-directed support and disabled young people in transition (part 2) (+, relevance to this guideline: somewhat relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study **Country** • UK **Study aim** 'This paper aims to describe the implementation of self-directed support (SDS) in transitions for disabled children and young people moving from children's to adults' services; it also seeks to describe the use of realistic evaluation as an approach to evaluation of this particular policy implementation' (p223).	**Sample size** • Individual semi structured interviews Total 3 senior managers from social work service. Focus group numbers are not given. It appears there was 1 focus group with 'parents of disabled young people, social workers, social work team managers, managers from the third sector, and a head teacher of a school for children with additional support' (p225).	**Population** • Young people disabled • Social care practitioners • Carers/parents **Sample characteristics** • Other The focus group was undertaken with parents, services users and professionals and the 3 in-depth interviews. **Intervention** A pilot project in a Scottish local authority, which used a programme of self-directed support for disabled young people in transition. **Outcomes** • Views studies The study discusses how self-directed care improves outcomes for young people. There is not much detail on what these outcomes might be. It seems that the study means outcomes as chosen by the young person in question.

Montano C, Young J (2012) Discontinuity in the transition from paediatric to adult health care for patients with attention-deficit/hyperactivity disorder (-/-)

Methodology and aims	Sample size	PICO
Methodology • Systematic review **Country** • USA This is a systematic review, but country origin of included studies are not stated. The review refers to UK studies and US studies, but the findings and analysis are clearly situated within a US context. **Study aim** To evaluate, from the perspectives of healthcare providers, the barriers to continuity of care for young people with ADHD when they transition from children's to adults' services.	**Sample size** • Number of studies (SRs) They say that they found 12 studies in the electronic search and an additional 58 studies from citation searching of these 12. This study views the drop-in medication for ADHD after age 15 as a major problem. Presumably this might be true for some people who want to continue on medication but might be prevented from doing so. But what about those who want to take	**Population** • Young people with mental health problems Focus on ADHD, but included studies of young people with other complex healthcare needs

	more control over their own medication and thereby reject it? What about changes in their lives which might influence their ADHD (e.g. leaving school).	

Munro E, Lushey C, National Care Advisory Service, et al. (2012) Evaluation of the Staying Put: 18 + Family Placement Programme: final report (++/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • A mixed methods approach was used and carried out in 2 phases In Phase 1 (December 2009–April 2010) a mapping exercise and face-to-face interviews with managers responsible for implementing Staying Put in each of the 11 pilot authorities were undertaken to explore: a) how authorities were actually implementing Staying Put (and any	**Sample size** • 32 young people (21 of whom stayed put and 11 who did not stay put)	**Population** • Care leavers Interviews with 32 care leavers (Phase 2). • Social care practitioners Total 14 personal care advisers (Phase 2 telephone interviews), social care practitioners (Phase 2, 5 focus groups). • Carers/parents Interviews with 31 foster carers (Phase 2). • Administrators, commissioners, managers Interviews with managers responsible for implementing Staying Put (Phase 1). • Teachers A specialist teacher from local authority 'L' focus group (Phase 2). **Sample characteristics** • Age • Sex

changes compared to plans submitted to the former DCSF); b) challenges and issues that they were facing implementing Staying Put in practice (see Munro et al. 2010b for the findings). In Phase 2 in-depth work was undertaken in 6 pilot authorities: a) face-to-face interviews with 21 young people who stayed put and 11 who did not stay; b) face-to-face interviews with young people's current or former foster carers (31 interviews); c) telephone interviews with young people's leaving care personal advisers (14 personal advisers responsible for 18 in-depth cases); d) focus groups and verification surveys with social care practitioners (5 focus groups and 15 verification surveys from 5 pilot authorities); e) scrutiny of quarterly returns submitted to the DfE; f) management		Total 16 young women, 12 who stayed put and 4 who did not; 20 young men, 11 who stayed put and 9 who did not. **Outcomes** • Views studies

information system (MIS) data were also sought from all 11 pilot authorities to explore uptake of Staying Put and early outcomes. **Country** • UK **Study aim** The overarching aim of the evaluation was to assess the effectiveness and impact of the Staying Put pilots in meeting the objectives below and promoting positive outcomes for young people making the transition from care to independence. It also sought to determine the unit costs of staying put and roll out of the pilot. The key objectives of the pilot are to: a) enable young people to build on and nurture their attachments to their foster carers, so that they can move to independence at their own pace and be supported to make the transition to adulthood in a more		

gradual way just like other young people who can rely on their own families for this support; b) provide the stability and support necessary for young people to achieve in education, training and employment; and c) give weight to young people's views about the timing of moves to greater independence from their final care placement.		

Munro E, Lushey C, Ward H, et al. (2011) Evaluation of the Right2BCared4 pilots: final report (-/+)

Methodology and aims	Sample size	PICO
Methodology • Comparison evaluation Evaluation with a comparison group. Elements: following a mapping exercise and focus groups with professionals from 11 pilot sites to see which sites could best meet the objectives of the intervention 7 sites were selected to be included in	**Sample size** 180 young people took part in the study 33 people were interviewed • Comparison numbers 51 people (28%) completed the baseline survey 13 (32%) completed the follow up	**Population** • Care leavers • Social care practitioners **Sample characteristics** • Age Intervention sites: baseline age 15 - n=2 age 16 - n=17 age 17 - n=45 age 18 - n=33 age 19+ - n=33 control sites: baseline age 15 - n=1 age 16 - n=5 age 17 - n=23 age 18 - n=7 age 19+ - n=14 intervention sites: follow-up age 15 - n=1 age 16 - n=4 age 17 - n=12 age 18 - n=4 age 19+ - n=7 control sites: follow-up age 15 - n=1 age 16 - n=2 age 17 - n=7 age 18 - n=2 age 19+ - n=1 interview data 16 - intervention - n=4, control - n=2 17 - intervention - n=6, control - n=4 18 - intervention - n=4, control - n=1 19 - intervention - n=4, control - n=1.

the study. Two control sites were also selected to provide a comparison. These services provided ‘standard leaving care practices’ (12). At baseline the study surveyed 184 young people (intervention n=133, control n=51); 41 cases were followed up (intervention n=28, control - n=13), interviews 33 individuals (intervention - n=25, control - n=8), 21 sets of case records were scrutinised (intervention - n=13, control n=8). Interviews with 16 social workers or leaving care personal advisors, 7 IROs and 2 advocates, plus a focus group. Interviews with 6 managers at pilot sites. Focus groups and interviews with social workers and other professionals at intervention and control sites around ‘time spent activity’ for costing purposes. **Country**	survey] Interview Data 8 people were interviewed Intervention number 133 people (72%) completed the baseline survey 28 people (68%) completed the follow up survey Interview Data 25 people were interviewed	• Sex Intervention group: baseline men - 58 (45%) women - 71 (55%) control group: baseline men - 25 (51%) women- 24 (49%) intervention: follow-up men - 6 (21%) women - 22 79% control group: follow-up men - 5 (39%) women - 8 (62%) interview sample men: intervention - n=10, control - n=0 women: intervention - n=15, control - n=8 • Ethnicity Survey data: the sample was majority white both at baseline and follow-up. The control site was also overwhelmingly majority white, again at baseline and follow-up. The largest minority group to take part was ‘Asian or Asian British’ who made up 9% of the intervention group at baseline. ‘Black or Black British’ was the second largest minority group, making up 7% at baseline in the intervention and 6% in the control group. A total of 16% of the survey sample were unaccompanied asylum-seeking children. • Interview data The vast majority of interviewees were white (56% in the intervention group and 100% of the control group). There were 2 individuals who were Asian or Asian British in the intervention group and 2 individuals who were white or white British and 2 who were mixed white and black. • In complex/unstable living conditions The majority of the same in both groups were in care at the time of the study. In the interview data 52% were in care in the intervention group and 63% were in case in the control group. **Intervention** Right2BCared4 was an intervention piloted at local authorities to improve outcomes for young people preparing to exit the care system. The interventions varied from one authority to the next they were based on the following principles: young people should not be expected to leave care until they reach 18 years old; they should have a greater say in the decision-making process preceding their exit from care; and should be properly

• UK **Study aim** The evaluation aims to 'assess the extent to which the Right2BCared4 pilots help care leaver achieve better outcomes' (p11). It looks at factors like: whether the pilots empowered young people to participate in the transition process; better communication between social workers and other professionals and young people; new review mechanisms that ensure that care plans etc. are driven by the needs of the client; more stability in care placements up until the age of 18, less young people living independently pre-18; costs analysis of the intervention compared to standard care leaver's services.		prepared for living independently (p11). **Outcomes** • Transition readiness A key outcome of the study was for professionals to encourage young people to stay in care up until the age of 18, when they legally reach adulthood. The study states that it focuses on encouraging a 'cultural shift in professional attitudes concerning care planning and decision-making for young people aged 16 plus' (p8). • Self-efficacy The study looks at how young people were involved in the transition planning process and how they coped after transition out of care. • Quality of life The study aimed to improve the health and wellbeing of young people preparing for transition. They were also encouraged to take more involvement in the transition planning process Overall young people who received the intervention 'rated their health, emotional wellbeing and confidence highly'.

Nakhla M, Daneman D, To T, et al. (2009) Transition to adult care for youths with diabetes mellitus: findings from a universal health care system (-/++)

Methodology and aims	Sample size	PICO	Follow-up
Methodology - Retrospective comparison evaluations **Country** - Canada	**Sample size** - 1507 The researchers surveyed the type of transfer coordination provided within 34 diabetes centres. They categorised the types of transfer arrangements.	**Population** - Young people with diabetes Age 16, 52% male. Income quintiles are reported, and there was a higher proportion of those in the higher income brackets: 1 (low) n=228 (15.1%) 2 n=251 (16.7%) 3 n=313 (20.8%) 4 n=375 (24.9%) 5 (high) n=323 (21.4%) missing data n=14 (1.1%). **Intervention** The researchers surveyed the type of transfer coordination provided within 34 diabetes centres. They categorised the types of transfer arrangements by whether the young people would continue contact with either allied healthcare team or physician after transfer, theorising that continued contact with at least 1 of these or both would promote continuity of care. Three centres provided a combination of transfer arrangements that the researchers theorised would be conducive to continuity of care during transition: a) change of physician only, so staying with the paediatric health care team; b) no change of team; c) staying with the paediatric physician but changing the allied healthcare team. **Comparison intervention** The comparisons consisted of young people who experienced transfer to adult care as a) a change in physician and allied healthcare team; or b) a change in physician and with no follow-up care from an allied health care team.	**Follow-up** - The outcomes were measured in the 2 years following transfer to adult care

		Outcomes Condition-specific: outcomes in the first 2 years after transfer (aged 18–20). Diabetes melitus-related hospitalisations, attendance at eye care clinics (retinopathy screening visits).	

Nesmith A, Christophersen K, (2014) Smoothing the transition to adulthood: creating ongoing supportive relationships among foster youth (+/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Comparison evaluation Country • USA Study aim To assess the effectiveness of the CORE foster care model, designed to support young people in foster care into adulthood.	**Sample size** • 85 • Comparison numbers 30 • Intervention number 58	**Scope population** • Care leavers **Sample characteristics** • Age Young people were aged 16 at the time of the baseline interview, and aged 17 (intervention group) and 18 (comparison group) at the post-test interview. • Sex Intervention group: 36% female, 64% male, comparison group: 40% female, 60% male **Data extraction** • Intervention The CORE intervention was developed to focus on young people’s own resources in the transition into adulthood. It provides training to young people, foster carers and social workers in order to enhance young people’s ability to establish relationships with other people and drawing on them for support. The emphasis on this training was that adulthood is interdependence rather than independence. In addition, the intervention involves young people in the running of the programme: as educators, coaches and as chairs of their own planning meetings. In addition, foster carers and young people received training on trauma, and how this impacts

		on behaviour and mental health. Again, young people were invited to be involved as trainers on further trauma workshops for new young people coming through. • Comparison intervention Young people who received traditional foster care services, including independent living skills training. **Outcomes (quant)** • Self-efficacy In the form of ability to establish relationships with other, so as to create a supportive network for oneself. This was measured on 2 self-report scales developed for this study: the Relationship Competency Assessment and the Quality Youth Relationship Assessment scales. The RCA was a 23-item scale focusing on motivation, relationship skills and current support. The QYRA asked young people to identify the most important adult in their life. • Experience of care Experience of the CORE programme.

Newman G, Collyer S, Foulis M, et al. (2009) A multi-agency consultation project with young people with support needs at the transition between children's and adult's services (++, relevance to guideline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study **Country** • UK **Study aims** This study explored the transition experiences of 49 young people with various	**Sample size** 49 young people who had been involved in some form of planning for adulthood over the past 3 years, broken down as below: • 23 from category	**Population** • Young people with learning disabilities **Sample characteristics** • Age 49 young people aged 14–25 **Outcomes** • Views study

support needs as they moved from secondary school to adult services.	‘need more choices and chances’ persistent truants • young people with mental health needs • young people with low attainment • young people with offending behaviour • young parents • young people with drug/alcohol problems • young people not in/recently left education, training, employment.	

Noyes, D et a (2004) Changing systems for transition: students, families, and professionals working together (**-**, relevance to guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study	• The study compiled case studies of 4	**Population** • Young people disabled • Social care practitioners

Country • USA **Study aims** To conduct 4 in-depth case studies of students, their families, teachers and adult agency personnel and their experiences of impact of the POTSIP model. The research questions were: How do students with significant disabilities, their families, transition teachers and adult agency staff perceive the transition process 12–24 months after exiting school? Does interagency collaboration and early intervention impact the transition service delivery system from the perspectives of students, families, teachers, and adult agency representatives?	students Each case study included interviews with professionals, young people and their carers, and observations.	• Adult services • Carers/parents • Teachers **Sample characteristics** The young people were aged 23–25 • Communication difficulties The students were identified as having severe disabilities, but this was not specified. **Intervention** Point of Transition Service Integration Project (POTSIP), providing early intervention, shared funding and regular interagency committee meetings to increase service integration during transition.

Paul M, Street C, Wheeler N, et al. (2014) Transition to adult services for young people with mental health needs: a systematic review (++/++)

Methodology and aims	Sample size	PICO
Methodology • Systematic review **Country** • Range of countries The included studies are a mixture of UK and US studies. **Study aim** The study aims to 'systematically review evidence on the effectiveness of different models of CAMHS to AMHS transitional care, service user and staff perspectives and facilitators of/barriers to effective CAMHS-AMHS transition' (p1).	**Sample size** • Number of studies (SRs) 19 studies were identified in the search.	**Population** • Young people with mental health problems **Sample characteristics** • Age The search looked for papers which addressed adolescence, 13–17 years or young adults, 18–29 years. **Intervention** The review aimed to look at the effectiveness of different models of transitional care. The interventions found in the included studies are various. The kind of models which emerged in the search were a protocol or reciprocal agreement approach and transition programme models. **Outcomes** • Quality of life • Condition-specific Styron (2006) used a reduction in symptoms as an outcome, and fewer mental health problems. • Experience of care Styron (2006) evaluated a young adult service which looked at a range of outcomes including satisfaction with care. Experience of transitions was also the focus of David and Butler (2002), Jivanjee et al. (2009) and Jvanjee and Kruzich (2011). • Carers/family members' outcomes Jivanjee et al. (2009) looked at the experiences of families as did Jivanjee and Kruzich (2011). • Practitioners' outcomes Richards and Vostanis (2004) looked at professional opinions of transition

		services, as did papers by Davis et al. (2006, 2005, 2005) and Arnett and Tanner (2005).

Pilnick A, Clegg J, Murphy E, et al. (2011) ‘Just being selfish for my own sake ...’: balancing the views of young adults with intellectual disabilities and their carers in transition planning (overall validity +, relevance to guideline: a bit relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study **Country** • UK **Study aim** The aim is to examine how the process of transition from children’s to adults’ services in ID is managed. Using data from 8 tape-recorded meetings in which transitions were planned and discussed, the authors examine what happens when the views of the parent/carer and the young adult are in apparent conflict. Conversation analysis is used to examine	**Sample size** • Transition staff identified eligible families for participation Of the 44 young people leaving school in the period and supported by specialist staff, 28 took part and 4 declined. It is not clear why the remaining 12 did not respond as this information remained confidential.	**Population** • Young people with learning disabilities **Sample characteristics** • Age Young people aged 18–19. **Outcomes** • Views study.

how professionals manage and negotiate this conflict and how some points of view or courses of action ultimately prevail over others.		

Pole JD, Alibhai SM, Ethier MC, et al. (2013) Adolescents with acute lymphoblastic leukaemia treated at paediatric versus adult hospitals (-/+)

Methodology and aims	Sample size	PICO
Methodology • Retrospective comparison study **Country** • Canada	**Sample size** • 290 Adults' services recipients n=144 (49.7%) Paediatric services recipients n=146 (50.3%)	**Population** • Young people with acute lymphoblastic leukaemia • Age 15–19, female n=86 (29.7%) Proportions of higher income quintiles slightly higher than lower quintiles: 1 lowest n=45 (15.5%), 2 n=58 (20%), 3 n=45 (15.5%), 4 n=66 (22.8%), 5 highest n=64 (22.1%), missing n=12 (4.1%) **Intervention** • Treatment of acute lymphoblastic leukaemia at a paediatric hospital versus treatment of acute lymphoblastic leukaemia at an adult hospital **Outcomes** • Condition-specific Overall survival at 5 years, 'calculated as the time between each patient's date of diagnosis and their date of death or the end of the follow-up period (31 July 2010) or the date last seen' (p802).

Por J, Goldberg B, Lennox V, et al. (2004) Transition of care: health care professionals’ view (+/++)

Methodology and aims	Sample size	PICO
Methodology • Cross-sectional study **Country** • UK **Study aim** • The purpose of this study was to explore the views and needs of healthcare professionals from 1 National Health Service trust regarding the transition of care for adolescents with a chronic condition from children’s to adults’ services and to identify possible ways to improve the current services for this particular group of young adults.	**Sample size** • 40 healthcare professionals.	**Population** • Young people with long-term conditions Adolescents with chronic conditions, such as cystic fibrosis and sickle cell disease were the focus of the study but not part of the study sample. • Healthcare practitioners The sample consisted of 40 healthcare professionals from the children’s department and adult ward-doctors, nurses, psychologists, physiotherapists and pharmacists currently working in the same hospital trust. **Sample characteristics** • Other Adolescents with chronic conditions, such as cystic fibrosis and sickle cell disease were the focus of the study BUT not part of the study sample.

Powers L, Geenen S, Powers J, et al. (2012) My Life: effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education (+/+)

Methodology and aims	**Sample size**	**PICO**	**Follow-up**
Methodology • RCT **Country** This study was conducted in Oregon, US.	**Sample size** • 69 young people were recruited. However, only 61 young people completed the study and are included in the analysis. • Comparison numbers Total of 32 young people were allocated to the control group. • Intervention number Total 29 people were allocated to the intervention group.	**Population** • Care leavers Young people in foster care who also had special educational needs. **Sample characteristics** • Age Ages between 16.5 and 17.5 years, the groups were similar in age. • Sex Overall sample 41% women, 59% male, similar in each group. • Ethnicity The sample was predominately Caucasian at 50.8%, then African American 16.4%, Native American at 9.8%, Hispanic at 8.2%. **Intervention** • Take Charge intervention which is designed to enhance young people’s self-determination as they prepare and go through transition. The intervention uses coaching to help young people identify their	**Follow-up** • Directly after the intervention was finished, and again after 1 year

		goals and mentors them throughout their transition process. **Outcomes** • Transition readiness The study used 'The Transition Planning Assessment' to measure 'youth transition planning knowledge and engagement' (p2183). This tested how far the intervention helped young people to take a leading role in their transition plan. • Self-efficacy Young people's ability to 'achieve self-identified goals' measured on the Arc Self-determination Scale. Young people were asked to describe 'their goals and accomplishments as retrospective indices of their self-directedness and positive self-attribution' (p2183). • Quality of life A quality of life questionnaire was used with young people receiving the intervention.	

Prestidge C, Romann A, Djurdjev O, et al. (2012) Utility and cost of a renal transplant transition clinic (-/++)

Methodology and aims	Sample size	PICO	Follow-up
Methodology • Comparison evaluation **Country** • Canada, British Columbia	**Sample size** • Total sample = 46 One person's data was not available at follow-up. **Comparison** 34 patients did not use the transition clinic, 33 were followed up.	**Population** • Young people with long-term conditions Renal transplant. **Sample characteristics** • Age At transition mean age 17.8 years, comparison age 17.5 years. • Sex: 32 men, 13 women. • Ethnicity: 32 Caucasian, 5 Aboriginal, 6 Asian, 2 other	**Follow-up** • Follow-ups were carried out after 2 years • **Further information** The study reports on health outcomes but not adequately on outcomes of the

	Intervention 12 patients used the transition clinic.	**Intervention** The transition clinic aimed to provide a multidisciplinary approach to transition renal transplant patients. The clinic included a paediatric nephrologist, renal nurse, youth health specialist, renal pharmacist, renal dietician and a social worker. The service emphasised enhancing patients' condition knowledge and self-management skills. **Outcomes** • Transition readiness • Condition-specific: the study measures the death rate in patients who did or did not receive the transition clinic service. The study also measure 'graft loss' or 'graft malfunction' relating to problems with the transplant.	multidisciplinary service, which included a social work element. Measurement of other outcomes would be useful in tracing a link between the positive medical outcomes within the group who received the intervention and their enhanced knowledge, quality of life and self-efficiency skills.

Price C, Corbett S, Lewis-Barned N, et al. (2011) Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes (+, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study **Country** • UK **Study aim** 'The purpose of this study is to evaluate one [transition] model in diabetes, the "Transition Pathway" via interviews	**Sample size** • 11 individuals	**Population** • Young people with long-term conditions Diabetes. **Sample characteristics** • Age • Young people aged between 16–18. **Outcomes**

with young people who have experienced it first-hand' (p852). Aims were: 1. 'To evaluate the transition pathway (TP) in diabetes using qualitative methods in order to explore the experiences and suggestions of the young people concerned.' 2. 'To understand these in the context of theory regarding the psychosocial developmental tasks of adolescence' (p854).		• Views study

Reid GI, Shaw K, Southwood T, et al. (2004) Prevalence and correlates of successful transfer from paediatric to adult health care among a cohort of young adults with complex congenital heart defects (+/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Cross-sectional study **Country** • Canada **Study aim** To find out how many young people with	**Sample size** • Potentially eligible young people in the database were 891 428 were excluded, a further 63 were unable to be	**Population** • Young people with long-term conditions Complex congenital heart defects. **Sample characteristics** • Age: 19–21 **Outcomes**

congenital heart defects have a successful transfer from children's to adults' services, and consider the factors that contributed to this transfer.	contacted, a further 40 were excluded after contact, resulting in a final sample of 390, and 234 agreed to participation and fully completed the study's measure.	• Continuity of care The outcome of interest was 'successful transition to adult care' defined as 'the patient having attended at least 1 appointment of any type ... at a CACH centre' (p e198).

Richards M, Vostanis P (2004) Interprofessional perspectives on transitional mental health services for young people aged 16–19 years (++, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study **Country** • UK **Study aim** The aim was to establish themes of mental health service needs for young people aged 16–19 years, as perceived by professionals from all agencies involved in their care, i.e. mental health, education, social and non-	**Sample size** • 39 participants (18 managers and 21 practitioners) were recruited from 22 statutory and 5 non-statutory services across a health district	**Population** • Social care practitioners Social services and learning disability services. • Healthcare practitioners CAMHS, AMHS and other specialist mental health services. • Other Education (e.g. educational psychology), non-statutory agencies (e.g. family service unit), young offenders team. **Sample characteristics** • Age Though not part of the sample, the study focus was young people aged 16–19 years.

statutory agencies.		

Sebastian S, Jenkins, H, McCartney S, et al. (2012) The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists (+/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Cross-sectional study **Country** • UK **Study aim** To identify, from the perspective of health professionals, the needs of young people with inflammatory bowel disease and barriers to their successful transition into adults' services.	**Sample size** • 729 adult gastroenterologists There was a 49% response rate in which 17 responses were deemed invalid: n=341. • 132 paediatric gastroenterologists There was a 62% response rate: n=82.	**Population** • Healthcare practitioners UK adult and paediatric gastroenterologists, with an interest in inflammatory bowel disease.

Shaw K, Southwood T, McDonagh J (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey (+/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Survey	**Sample size** • Of 1670	**Population** • Social care practitioners

Country • UK **Study aim** To assess the needs of young people with juvenile idiopathic arthritis according to professionals, and to examine how these needs might be addressed by a transitional care programme.	questionnaires, 478 (29%) were completed and returned, and used in the analysis	• Healthcare practitioners Professionals in rheumatology and from psychosocial organisations including psychologists, social workers, youth workers and regional contacts (young arthritis care). Also included members of the National Association for the Education of Sick Children, and vocational organisations. • Teachers

Shaw K, Watanabe A, Rankin E, et al. (2014) Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility (+/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Cross-sectional study The study used questionnaires to assess clinics transitional procedures and also to gather information of satisfaction among patients. **Country** • UK **Study aim** • The study aimed to examine how far a	**Sample size** • 23 clinics and 457 patients participated, 326 in paediatric care 131 in adult care	**Population** • Young people with long-term conditions **Sample characteristics** • Age The patients were transferred from paediatric care at 17 (median). Those who had transitioned into adult care were aged 19 (median). • Sex Paediatric care 57.7%, female adult care 59.5% • Ethnicity Paediatric care 73%, white/European adult care 74% • In complex/unstable living conditions In education/employment, paediatric care 89.3%, Adult care 84% **Data extraction** • Intervention

paediatric and nearby adult facility have mainstreamed transitional care guidance into practice. The study aims to ascertain how far they were adhering to national guidelines, and which transnational models in clinics were most satisfactory to patients.		The study looked at satisfaction among patients in a number of adult and paediatric clinics. The study also looked at which transition models had been implemented. The study requested data from lead clinicians on the transition model employed at their clinic. The study sought to identify if the clinic met national guidance for 'transition and youth friendly services which included 100 criteria relating to topics such as accessibility, health promotion, confidentiality, appropriate environments, staff training and whether transitional care provision was holistic' (p664). **Outcomes (quant)** • Experience of care • Other Different models of transitional care.

Shropshire Parent and Carer Council (2011) Transition Parent Consultation Findings (-, relevance to guideline: somewhat relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study **Country** • UK **Study aim** 'To produce a report on families experiences of transition in Shropshire...The aim of the project was to gain a view on transition from the perspectives of parents and carers of young people with additional needs,	**Sample size** • 10 interviews 9 in-depth questionnaires	**Population** • Young people with learning disabilities • Young people disabled **Sample characteristics** • Age Young people aged 12–20. • Sex 12 male, 7 female. **Outcomes** • Views studies

provide feedback on the draft transition booklet and to make recommendations to public sector services to improve service delivery to meet the needs of parents, carers and young people during transition'. (p.3)		

Singh S, Paul M, Islam Z, et al. (2010) Transition from CAMHS to adult mental health services (TRACK): a study of service organisation, policies, process and user and carer perspectives (++, relevance to this guideline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Mixed methods This study used a whole range of methods: 1. audit of transition policies and procedures in 6 mental health trusts; 2. a case note survey of referrals from CAMHS to AMHS over 1 year, this was retrospective data collection; 3. qualitative interviews with people working in health and social care agencies; 4.	**Sample size** • 11 individuals	**Population** • Young people with mental health problems • Social care practitioners • Healthcare practitioners • Administrators, commissioners, managers **Sample characteristics** • Sex 6 male, 5 female • Ethnicity Case note review: the majority ethnic group was White (31%), followed by Black (23%), although no ethnicity was recorded for a large portion of the sample (27%). Ethnicity information on potential referrals which were not actual referrals: 'White (n=8), Black (n=4), not recorded (n=2), Asian (n=1), and mixed/other (n=1). Ethnicity information on referrals refused by service user: 'ethnicity was mixed between White (n=4), Black (n=3), Asian (n=2),

qualitative interviews with young people, carers and mental health professionals. **Country** • UK **Study aim** 'The TRACK study aimed to identify factors that facilitate or impede effective transition of patients from CAMHS to adult services, and make recommendations about the configuration and delivery of services that will promote good continuity of care' (from study abstract).		not recorded (n=2) and Mixed/Other (n=1)'. Ethnicity information on referrals not made due to no need for further service: 'ethnicity was not recorded in most cases; the others were White (n=3) and Black (n=1)' (information on p56). **Outcomes** • Experience of care Experiences of mental health services and transition. • Views studies

Sloper P, Beecham, J, Clarke S, et al. (2011) Models of multi-agency services for transition to adult services for disabled young people and those with complex health needs: impact and costs (+/++)

Methodology and aims	**Sample size**	**PICO**
Methodology • Mixed methods Evidence was gathered from 4 different sources. 1) A national survey to identify existing multi-	Sample size • Stage 1 Survey of transition services: 50 services completed the detailed questionnaire	**Population** • Young people with long-term conditions • Young people disabled • Social care practitioners • Healthcare practitioners • Carers/parents **Intervention**

agency transitions services. 2) Interviews with staff and management at 5 case study sites. 3) A survey of patients and the parents of patients receiving care from transition services from one of the 5 case study sites. 4) Qualitative interviews with a sample of parents and young people who had completed the transfer into adult services 5) Analysis of the costs involved in the multi-agency services. **Country** • UK All case studies and interviews were conducted in England. **Study aims** The study aimed to provide evidence on 'what works in developing and implementing multi-agency co-ordinated transition services for disabled young people and those with	• Stage 2 Case studies: 5 services took part in a case study to investigate processes and outcomes. Stage 2 included in-depth interviews with managers and practitioners; 130 interviews were carried out. • Stage 3 Survey of young people and parents: 143 parents completed questionnaires; 97 young people completed questionnaires. • Stage 4 Interviews with parents and young people: 6 interviews were conducted.	There is no individual intervention discussed in this study. The approaches to multiagency transition services are various. What each service shares is that it is draws health, social care, education and other services together into a multiagency approach to providing a care for young people in transition. **Outcomes** This is a wide ranging study but its main outcomes are looked at in relation to satisfaction and testimony from service users and carers. The study looks at positive outcomes in the experiences of parents and young people and also negative outcomes like unmet needs. Crucially for the implementation question, the paper looks at the organisation and implementation of the services and the factors which helped and hindered this process.

complex needs' (pvii). Further aims with specific relation to implementation include; 'To compare the implementation and operation of different models of transition services' (pvii).		

Social Care Institute For Excellence (2011) Case study: Y-Talk counselling and therapy service, Sheffield YMCA (-/-)

Methodology and aims	**Sample size**	**PICO**
Methodology • Mixed methods Missed methods case study/evaluation. **Country** • UK **Study aim** • The study is a case study of the Y-Talk intervention: 'Y-Talk aims to provide an accessible and young person friendly counselling and therapy service. This is delivered in partnership with other organisations from places that young people already go, such as schools and youth and	**Sample size** • Sample size Data was collected from 600 young people But the reports states that 101 people completed the pre-service form and 33 have also completed the review forms.	**Population** • Young people with mental health problems Mental health issues and emotional issues. **Sample characteristics** • Age 46% 16–19. • Sex 42% male, 58% female. • Ethnicity Ethnicity was not always recorded but where it was 20% were black or ethnic minority. **Intervention** 'Y-Talk counselling and therapy service is a third sector service for 16–25 year olds who require emotional and mental health support. The service is based in Sheffield and provided in the city centre and outreach centres, including schools and community settings' (p1). **Outcomes (quant)**

community centres. There is a diverse team of counsellors and therapists which helps the service to reach out and provide support to young people from many different backgrounds' (p1).		• Transition readiness One set is strategic and is about helping to bridge the gap: between accessible universal services and specialist statutory services to help provide a smoother care pathway, especially for vulnerable groups; between children's and adults' mental health services by providing age-appropriate transitional help and trying to influence commissioning to address the particular needs of 16–25-year-olds (p5). Other outcomes: aim 1 – to increase the self-esteem and wellbeing of young people using the service; aim 2 – to increase young people's resilience and ability to cope when things are difficult by improving their ability to express their feelings appropriately, discuss their problems and gain support from others; aim 3 – to enable young people using the service to participate and make a positive contribution.

Stein M, Morris M (2009) Increasing the number of care leavers in 'settled, safe accommodation': research review 3 (+/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Systematic review **Country** • UK **Study aim** The study aims to provide evidence that will help service providers improve services for care leavers and outcomes for children, young people and families.	**Sample size** • Number of studies (SRs) The review draws from 98 studies.	**Population** • Care leavers Care leavers who had been cared for a medium to long period. Some care leavers who had been in care for a short time. Young people preparing to leave care or have left care. • Social care practitioners 25 studies includes social care professionals. • Healthcare practitioners 25 studies look at practitioners views including health professionals. • Carers/parents Total 10 studies looked at foster parents, carers and birth parent experiences. **Sample characteristics** • Age

The review focuses on young people leaving care and a need for them to enter ‘settled, safe accommodation’. The review looks at evidence which shows that accommodation should be suitable for each person in relation to their needs, that accommodation is approved by the responsible authority, and that it takes account of the young person’s wishes and needs.		Care leavers were aged between 13 and 25. • Sexual orientation Total 3 studies take into account the sexual orientation of young care leavers. • Ethnicity Total 27 studies include black and ethnic minority young people and 8 include asylum-seekers. **Intervention** The interventions that the review looks at are: independent living programmes and the leaving care service **Outcomes** • Self-efficacy Health and life skills are listed as outcomes of Independent living schemes.

Swift K, Hall C, Marimuttu V, et al. (2013) Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): a qualitative analysis of their experiences (++, relevance to this guideline: highly relevant)

Methodology and aims	**Sample size**	**PICO**
Methodology • Qualitative study – semi-structured interviews **Country** • UK **Study aim** ‘The aim of the study is to explore the experiences of young people with ADHD during transition to CAMHS	**Sample size** • Total 10 individuals	**Population** • Young people with mental health problems, specifically ADHD **Sample characteristics** • Age Between 17 years and 18.5 years. • Sexual orientation 8 male 2 female. • Ethnicity

to AMHS' (p2).		All participants were white, British. **Outcomes** • Views study

Swift K, Sayal K, Hollis C (2013) ADHD and transitions to adult mental health services: a scoping review (++/+)

Methodology and aims	**Sample size**	**PICO**
Methodology • Systematic review **Country** • Range of countries The review looks at papers which are UK and US based. **Study aim** The study aimed to describe literature which looks at the process of transition for young people with ADHD and to review current literature and policies surrounding ADHD and transitions.	**Sample size** • Number of studies (SRs) The review looked at 23 papers.	**Population** • Young people with mental health problems Young people with ADHD. **Intervention** The studies found by the review team do not present much in the way of models for evaluation. One paper refers to the Life Transition Model, another reports on a transition clinic in Yorkshire. The review also looks at two longitudinal studies and a case not review. **Outcomes** • Other The review's aim is to identify literature addressing transition for young people with ADHD, as such it contains a broad summary of the included studies messages and does not focus on outcomes.

Tierney S, Deaton C, Jones A, et al. (2013) Liminality and transfer to adult services: a qualitative investigation involving young people with cystic fibrosis (++, relevance to this guideline: highly relevant)

Methodology and aims	Sample size	PICO
Methodology • Qualitative study **Country** • UK **Study aim** To explore the experiences of transition from children's to adults' services among young people with cystic fibrosis.	**Sample size** • 19	**Population** • Young people with long-term conditions Young people with cystic fibrosis who had transitioned within 12 months of the interview taking place. About half (10) had transitioned within a month of being interviewed, the remaining had transitioned within 3–12 months. **Sample characteristics** • Age 17–19 years. • Sex 2 male, 7 female. • Other Young people were recruited in an adult clinic for cystic fibrosis which does not have an adolescent clinic and is not located in the same hospital as paediatric clinics. **Outcomes** • Views study

van Staa A, Loes, van AH, Jedeloo S (2011) Readiness to transfer to adult care of adolescents with chronic conditions: exploration of associated factors (+/+)

Methodology and aims	Sample size	PICO
Methodology • Cross-sectional study	Sample size • 3, 648 formed the	**Population** • Young people with long-term conditions

Country • Holland Study aim To explore associations between adolescents' perception of their readiness to transfer to adult care and sociodemographic and disease-related characteristics, effect of the condition, self-management ability, and attitude toward transition.	study population	Described as young people with chronic conditions. **Sample characteristics** • Age 12–15 (61.3%), 16–19 (38.7%) • Sex 56.2% female, 43.8% male • Ethnicity Dutch surname 86.7%, non-Dutch surname 13.3% **Outcomes (quant)** • Transition readiness The study compared the patients' perceptions of their readiness to transition and their socioeconomic level and disease status, as well as their skills related to transition and attitude towards transfer to adults' services.

Walleghem N, MacDonald C, Dean H, et al. (2009) Building connections: The Maestro Project. The evolution of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes (+/+)

Methodology and aims	**Sample size**	**PICO**	**Follow-up**
Methodology • Retrospective cohort evaluation **Country** • Canada	**Sample size** • 165 patients Total 64 patients in younger group, 101 patients in older group.	**Population** • Young people with diabetes Ages: people in the younger group were aged 18 and people in the older group (already transferred) were aged 19–25. **Intervention** The Maestro Project is a systems navigator model designed to assist young adults with Type 1 diabetes. The Maestro is an administrative project manager, it 'maintains telephone and email contact with young	**Follow-up** • Across 5 years

		adults to provide support and help identify barriers to accessing health care services' (p2). The model works with other community services to support patients, has a website, produces newsletter, holds drop-in groups and hosts educational events. **Outcomes** • Self-efficacy One element of the intervention is condition education to help patients understand and manage their conditions. • Condition-specific Medical outcomes were looked at in terms of complications related to the condition and hospital admission. • Experience of care Participants were interviewed about their expectations of transition to adults' services. They were also asked about whether there was a need for service provided by Maestro. Response rates to the survey were poor.	

Watson R, Parr J, Joyce C, et al. (2011) Models of transitional care for young people with complex health needs: a scoping review (-/++)

Methodology and aims	Sample size	PICO
Methodology • Systematic review This was a conceptual review which explored models of transitional care, not effectiveness of	**Sample size** • Total 19 papers covering 18 service models	**Population** • Young people long-term conditions and young people disabled Young people with diabetes, autistic spectrum disorders or cerebral palsy.

interventions. **Country** • UK, Australia, Canada, Italy, US, Spain, Denmark **Study aim** To explore successful models of care for young people with complex health needs when they move from children's to adults' services. Three conditions were used as exemplars: cerebral palsy, autism spectrum disorders and diabetes.		