NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

DRAFT GUIDELINE

Transition from children's to adults' services

Draft for consultation, September 2015

Contents

Introduction

The Department of Health [and/or Department for Education] asked NICE to produce this guideline on Transition from children's to adults' services (see the scope).

Young people with ongoing or long-term health or social care needs may be required to transition into adult services. Transition is defined as a purposeful and planned process of supporting young people to move from children's to adults' services (Transition: getting it right for young people, DfES & DH). The preparation and planning around moving on into adult services can be an uncertain time for young people with health or social care needs. There is evidence of service gaps where there is a lack of appropriate services for young people to transition into and evidence that young people may fail to engage with services without proper support (Watson 2005, Singh 2009).

Transition takes place at a pivotal time in the life of a young person, part of wider cultural and developmental changes that lead them into adulthood; Individuals may be experiencing several transitions simultaneously (McDonagh and Viner 2006). There is evidence that transition services in health and social care are inconsistent, patchy and varied depending on the condition. A loss of continuity in care can be a disruptive experience, particularly during adolescence, when young people are at an enhanced risk of psychosocial problems (Patten and Viner 2007). Some groups are seen as at particular risk of falling into service gaps: Young people with complex and multiple needs (Crowley et al. 2011), child and adolescent mental health service users (Singh et al. 2010), young people with palliative care needs and life limiting conditions (Children and Young People's Health Outcomes Forum 2012) and young people leaving residential care (Beresford and Cavet 2009)

There is a good deal of policy and guidance around the support of young people passing through transition and agreed principles in good transitional care. But there is evidence that these principles are often not reflected in practice (Beresford and Cavet 2009, Clarke et al. 2011, Gordon 2012, Singh 2010, Hovish et al. 2012). Poorly managed transitions can result in

disengagement with services and deteriorating health (Watson 2005, Singh 2009).

The Department of Health commissioned NICE to develop an evidence based guideline to improve practice and outcomes for young people using health and social care services and their families and carers. The guideline was developed by a Guideline Committee following a detailed review of the evidence. The guideline focuses on young people, passing through transition to adult services with health and/or social care needs. The guideline will cover young people up to the age of 25 who expect to go through a planned service transition. The guideline does not cover young people who are not using children's health or social care services, or young people entering adult services who have not used children's health and social care services. This is because the guideline focuses on transition from children's to adults'.

The views of young people experiencing transition, as well as parents and health and social care providers were a key source of evidence in the development of these recommendations. The guideline considers how young people can be comprehensively prepared for transition through the adequate provision of information, services geared towards young people, person centred planning, adequately trained professionals both in children and adult services and support for parents and carers.

This guideline has been developed in the context of new legislation, policy and guidance affecting health and social care services, most notably the Care Act 2014. This guideline has some recommendations driven by the requirements of the Care Act, but also a focus on what 'what works' in terms of how to fulfil those statutory duties and how to best deliver support to young people moving on into adult services.

For information on how NICE guidelines are developed, see Developing NICE Guidelines: The Manual (2014)

Context

Legislation, policy and guidance

This guideline has been developed in the context of a new and rapidly evolving landscape of guidance and legislation, most notably the Care Act (2014), which has a significant impact on individuals with care and support needs moving from children's to adults' support services. The majority of the Care Act took effect in April 2015, with specific financial provisions coming into force from 2020.

Despite previous guidance,[1] which has highlighted that all young people with health and mental health needs are at risk during transition, and that those with neurological disorders and disabilities are the least well served, there has been a failure to result in any significant change. Based upon this growing need to support young people with a wide range of conditions (and multiple conditions), the Care Act now places a duty on local authorities to not only consider the 'physical, mental and emotional wellbeing of the individual needing care', but to also build the system around each individual person – i.e. what care they each need and want.

In conjunction with the Children and Families Act (2014), the Care Act places a duty on local authorities to promote better choice and control over care and support for young people and families (rather than requiring them simply to provide services). The Children and Families Act introduces a system of support which extends from birth to 25, while the Care Act deals with adult social care for anyone over the age of 18. Both pieces of legislation ensure that people aged 18-25 will be entitled to support, placing the same emphasis on outcomes, personalisation and the integration of services. The acts are also aligned with a range of other policies and guidance relating to transitional care.[2] The importance of joined-up working, and the integration of services is

[1] Such as: Transition: getting it right for young people (2006) and Transition: moving on well (2008).
[2] For example: Department for Children, Schools and Families / Department of Health (2007) A transition guide for all services; and, Commissioning Panel for Mental Health (2012) Guidance for commissioners of mental health services for young people making the transition from child to adult mental health services.

prioritised so that people do not 'get lost' in the system during these critical periods.

The requirement of services to operate in response to need and to provide continuity is also reflected in statutory guidance such as the Department of Health (2010) Implementing fulfilling and rewarding lives, which emphasises transition as being a process – rather than an event or 'single point of switch over' (i.e. a transfer). The guidance thus sets out that young people with autism (and their families and carers) should always be at the heart of their transition planning (in line with the principles set out in Equity and Excellence: Liberating the NHS of "no decision about me without me"), and that professionals involved in this process have received appropriate training so that they may adjust their behaviour to reflect the needs of the young person concerned.

The Children and Families Act has also introduced new rights to improve how young carers and their families are identified and supported. From April 2015, all young carers will be entitled to an assessment of their needs from the local authority, which works alongside measures in the Care Act for assessing adults to enable a 'whole-family approach' to providing care and support.

While the Care Act and other legislation describes what organisations must do, this guideline is focused on 'what works' in terms of how they fulfil those duties to support young people moving from children's to adults' support services.

Current practice

Transition to adulthood is a time when young people and their families are thinking about their hopes for the future for the future. If people are likely to have care and support needs when they are 18, they need information and advice so that they can make the necessary plans. Despite this, there is evidence that the transition process is variable, with previous good practice guidance not always being implemented.[3] The lack of information, support and services available to meet the complex needs of young people and their

[3] CQC (2014) From the pond into the sea

families can be confusing, creating additional hurdles at what can be an already difficult time. This is particularly important to address given that young people's experience of transition is as important as their transition outcomes.

The reasons for discontinuities between children's to adults' support services are numerous and have been identified clearly by young people and their families. For example, there is evidence of service gaps for some young people, particularly those leaving specialist residential schools to move back to their community, those with palliative care needs,[4] and young people with mental health needs.

A study of young people's transitions from CAMHS to AMHS has in fact found that two thirds of teenagers are either 'lost' from or interrupted in their care during this time,[5] which is likely to have serious consequences, especially if needs are unmet. Moreover, those that do make a transition can still experience poorer quality of care. For example, research such as the SDO TRACK[6] study has shown that only 4% of young people experienced their 'ideal' transition from CAMHS to AMHS. In many areas, CAMHS is designed to meet the needs of a wide range of disorders and problems such as Attention Deficit and Hyper Activity Disorder (ADHD) or Autistic Spectrum Disorder (ASD), whereas AMHS tend to offer services only to those suffering severe and enduring illnesses such as psychosis or severe depression. The consequence of such different service provision is that young people in receipt of a service from CAMHS may find that on reaching adulthood, their condition and presentation does not change, yet adult mental health services are not configured to support them.

In addition to this, there is evidence to show that disabled young people face more challenges than their non-disabled peers during their transition from children's to adults' services. For example, a disabled young person may move from paediatric to adult health services at 16, before moving from

[4] Children and Young People's Health Outcomes Forum (2012)
[5] Singh et al., (2010) Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study
[6] Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK Study): A study of protocols in Greater London, Singh et al., (2008)

children's to adults' social care at 18 – meaning that transitions are likely to occur independently, and disabled young people and their families may have to repeatedly tell their story to numerous professionals across a fragmented system of health and social care.[7]

There are also increasing numbers of young people who have a range of physical, sensory and cognitive impairments, many of whom also have continuing health care needs associated with their impairments. Whilst it is acknowledged that they all require a combination of health and support services in order to access a good quality of life, many professionals find it a complex matter to meet both the underlying and variable needs of these individuals. This is thought to be, partly, a result of divisions and inadequate liaisons between health and social services.[8]

Despite this, there are examples of good practice that mirror guidance in this area such as: good communication with young people, their families and each other, and providing good information about what to expect.[9] Moreover, a good transition requires not just the efforts of children's services, but should also involve adult services in the process.[10]

Involvement and choice

Research has found that only 54% of young people preparing for transition and their families felt they had been involved as much as they wanted to be.[11] Furthermore, there is evidence that children's services and transition teams do not consistently provide preparation or training for young people and their

[7] Department of Health (2007) A transition guide for all services
[8] Transition to adulthood for young disabled people with 'complex health and support needs' (JRF, 1999)
[9] See: Department for Children, Schools and Families / Department of Health (2007) A transition guide for all services; and, Commissioning Panel for Mental Health (2012) Guidance for commissioners of mental health services for young people making the transition from child to adult mental health services.
[10] Fegran et al., (2013) Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: A qualitative metasynthesis
[11] For example: Department for Children, Schools and Families / Department of Health (2007) A transition guide for all services; and, Commissioning Panel for Mental Health (2012) Guidance for commissioners of mental health services for young people making the transition from child to adult mental health services.

families for the differences they are likely to face when transferring to adult services, with support plans additionally not reflecting young people's wishes.

While this guideline focuses on transition between services, it will be implemented in the context of young people's developmental transition. The timing and nature of developmental transition can vary from one young person to the next, making it critical that those providing care and support understand the young person's needs and preferences. While there are some person-centred models in use,[12] there is a lack of consensus about best practice methods for person-centred planning involving young people in transition (Hudson, 2003).[13] Services supporting the transition planning process will therefore need to be flexible in their response to applying the lessons from this guideline about 'what works'.

[12] For discussion of examples, see: Essential Lifestyle Planning, Making Action Plans and Planning Alternative Tomorrows with Hope

[13] Hudson (2003) From adolescence to young adulthood: the partnership challenge for learning disability services in England

Person-centred care

This guideline offers best practice advice on the care of young people with health or social care needs making a transition from children's to adults' services.

Patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution for England – all NICE guidance is written to reflect these. Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If the patient is under 16, their family or carers should also be given information and support to help the child or young person to make decisions about their treatment. Healthcare professionals should follow the Department of Health's advice on consent. If someone does not have capacity to make decisions, healthcare professionals should follow the code of practice that accompanies the Mental Capacity Act and the supplementary code of practice on deprivation of liberty safeguards.

NICE has produced guidance on the components of good patient experience in adult NHS services. All healthcare professionals should follow the recommendations in Patient experience in adult NHS services.

NICE has also produced guidance on the components of good service user experience. All health and social care providers working with people using adult NHS mental health services should follow the recommendations in Service user experience in adult mental health.

Recommendation wording

The Guideline Committee makes recommendations based on an evaluation of the evidence, taking into account the quality of the evidence and cost effectiveness.

In general, recommendations that an action 'must' or 'must not' be taken are usually included only if there is a legal duty (for example, to comply with the Care Act or health and safety regulations), or if the consequences of not following it could be extremely serious or life threatening.

Recommendations for actions that should (or should not) be taken use directive language such as 'agree', ‘offer’ 'assess', 'record’ and ‘ensure'.

Recommendations for which the quality of the evidence is poorer, or where there is a closer balance between benefits and risks, use 'consider'.

1 Recommendations

The wording used in the recommendations in this guideline (for example words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation). See 'recommendation wording' for details.

1.1 Overarching principles

1.1.1 Involve young people and carers in all aspects of service design, delivery and evaluation related to transition by:

- considering co-producing transition policies and strategies with them
- asking them whether the services helped them achieve agreed outcomes
- considering co-producing, planning and piloting materials and tools
- feeding back to them about the effect their involvement has had.

1.1.2 Use person-centred approaches to ensure that transition support:

- takes full account of the young person’s views and needs
- is strengths-based and focuses on what is positive and possible for the young person rather than on a pre-determined set of transition options
- identifies the support available to the young person, which includes but is not limited to their family or carers
- is developmentally appropriate, taking into account their maturity, cognitive abilities, needs in respect of long-term conditions, social and personal circumstances and psychological status
- treats the young person as an equal partner in the process

- supports the young person to make decisions and builds their confidence to direct their own care and support over time
- fully involves the young person in terms of the way it is planned, implemented and reviewed
- addresses all relevant outcomes, including those related to employment, community inclusion, health and wellbeing including emotional health, and independent living
- involves agreeing goals with the young person
- includes review of the transition plan with the young person at least annually or more often if their needs change.

1.1.3 Health and social care service managers should work together in an integrated way, involving colleagues in education to ensure a smooth and gradual transition for young people moving from children's to adults' services[14]. This could involve, for example, developing:

- a joint mission statement or vision for transition
- jointly agreed and shared transition protocols, information-sharing protocols and approaches to practice.

1.1.4 Service managers in both adults and children's services, across health and social care, should proactively identify and plan for young people in their locality with transition support needs.

1.1.5 Every service involved in supporting a young person should take responsibility for sharing safeguarding information with other organisations.

[14] For young people with education health and care (EHC) plans (see the gov.uk guide), local authorities and health commissioners **must** work together in an integrated way, as set out in the Children and Families Act 2014.

1.2 Transition planning

Named worker

1.2.1 Help the young person to identify a single named worker to coordinate their transition care and support. The named worker could be supported by an administrator.

1.2.2 The named worker:

- could be, for example, a nurse, youth worker or another health or social care practitioner, depending on the young person's needs
- should be someone with whom the young person has a meaningful relationship
- should initially be someone in children's or young people's services but should hand over their responsibilities to someone in adult services when appropriate.

1.2.3 The named worker should:

- be the link between the young person and the various practitioners involved in their support
- help the young person navigate services
- support the young person's family, if appropriate
- act as a representative for the young person, if required (that is to say, someone who can provide advice, support or advocate for them)
- proactively engage primary care in transition planning and direct the young person to other sources of support and advice, for example peer advocacy support groups provided by voluntary and community sector services
- think about ways to help the young person to get to appointments, if needed
- provide advice and information

- ensure that the young person is offered support, as appropriate, with the following aspects of transition (which may include directing them to other services):
  - employment
  - community inclusion
  - health and wellbeing, including emotional health and independent living.

1.2.4 The named worker should support the young person for:

- the time defined in relevant legislation, or
- a minimum of 6 months before and after transfer (the exact length of time should be negotiated with the young person).

Timing and review

1.2.5 Start transition planning early for young people in out-of-authority placements.

1.2.6 For groups not covered by legislation, health, social care and education, practitioners should start planning for adulthood from year 9 (age 13 or 14) at the latest[15]. For those entering the service close to transition age, planning should start immediately.

1.2.7 Ensure the transition planning is developmentally appropriate and takes into account each young person's capabilities, needs and hopes for the future. The point of transfer should not be based on a rigid age threshold.

1.2.8 Hold an annual meeting to review transition planning, or sooner if needed[16]. This should:

[15] For young people with education, health and care (EHC) plans, this **must** happen from year 9, as set out in the Children and Families Act 2014. For young people leaving care, this **must** happen from age 15-and-a-half.

[16] For young people with a child in need plan, an Education, Health and Care (EHC) plan or a care and support plan, local authorities **must** carry out a review, as set out in the Children Act 1989, the Children and Families Act 2014 and the Care Act 2014.

- involve all practitioners providing support to the young person and their family or carers
- inform a transition plan that is linked to other plans the young person has in respect of their care and support.

Involving young people

1.2.9 Offer young people help to become involved in their transition planning. This may be through:

- peer support
- coaching and mentoring
- advocacy
- the use of mobile technology.

1.2.10 Service managers should ensure a range of tools are available to help young people communicate effectively with practitioners. These may include, for example, communication passports, communication boards, 1-page profiles and digital communication tools.

Building independence

1.2.11 Consider opportunities for young people to have peer support and mentoring during transition from children's to adults' services.

1.2.12 Include support for young people to develop and sustain social, leisure and recreational networks in the transition plan. Put young people in touch with peer support groups if they want such contacts. This may be provided by voluntary- and community-sector organisations, such as specific support groups or charities.

1.2.13 Include information and signposting to alternative non-statutory services in transition planning. This may be particularly important for people who do not meet the criteria for statutory adult services.

1.2.14 Everyone working in health, social care and education should support all young people who continue to receive support from

social services into adulthood. The support should help them to build autonomy in respect of their:

- employment
- community inclusion
- health and wellbeing, including emotional health
- independent living.

1.2.15 For young people with disabilities in education, the named worker should liaise with education practitioners to ensure comprehensive student-focused transition planning is provided. This should involve peer advocacy, and friends and mentors as active participants.

1.2.16 If the young person has long-term conditions, ensure they are helped to manage their own condition as part of the overall package of transition support. This should include an assessment of the young person's ability to manage their condition, self-confidence and readiness to move to adult services.

1.2.17 For detailed recommendations on supporting looked-after children moving to independent living see 'Preparing for independence' in NICE's guideline on looked-after children.

Involving parents and carers

1.2.18 Ask the young person how they would like their parents or carers to be involved throughout their transition, including when they have moved to adult services.

1.2.19 Discuss the transition with the young person's parents or carers to understand their expectations about transition, recognising that the young person's preferences about their parents' involvement may be different and should be respected..

1.2.20 Help young people develop confidence in working with adult services by giving them the chance to raise concerns and queries separately from their parents.

1.2.21 Adult services should take into account the individual needs and wishes of the young person when involving parents or carers in assessment, planning and support[17].

1.3 Support before transfer

1.3.1 Service managers should ensure that a named worker from the nominated adult service meets the young person before they transfer from children's services.

1.3.2 Service managers should ensure that there is a contingency plan in place for how to provide consistent transition support if the named worker leaves their position.

1.3.3 Consider working in collaboration with the young person to create a personal folder that moves with the young person when they transfer from children's to adults' services. This folder should be in the young person's preferred format. The folder could contain:

- a 1-page profile
- information about their health condition
- history of care interventions
- preferences about parent and carer involvement
- emergency care plans
- unplanned admissions
- their strengths, achievements, hopes for the future and goals.

1.3.4 All services should provide young people and their families or carers with information about what to expect from services and what support is available for them. This information should:

- be in an accessible format, depending on the needs and preferences of the young person (this could include, for example, written information, computer-based reading

[17] For young people with an EHC plan or a care and support plan, this **must** happen, as set out in the Children and Families Act 2014 and the Care Act 2014.

programmes, audio and braille formats for people with disabilities)

- describe the transition process
- describe what support is available before and after transfer
- describe where they can get advice about benefits and what financial support they are entitled to.

Support from the named worker

1.3.5 Consider ways to help the young person become familiar with adult services. This could be through the use of young adult support teams, joint or overlapping appointments, or visits to the adult service with someone from children's services.

1.3.6 Support young people to visit adult services they may potentially use, so they can see what they are like first-hand and can make informed choices.

1.3.7 If a young person is eligible for adult social care services, the named worker:

- must make sure the young person is given information about different mechanisms for managing their care and support, such as personal budgets
- should give the young person the opportunity to test out different mechanisms for managing their care, in order to build their confidence in taking ownership of this over time. This should be done using a stepped approach.

1.3.8 If a young person is not eligible for statutory adult care and support services, make sure that they are given information about alternative support.

1.3.9 If a young person does not meet the criteria for specialist adult health services, involve the GP in their transition planning.

1.4 Support after transfer

1.4.1 If a young person has moved to adult services and does not attend meetings or appointments or engage with services, adult health and social care should:

- follow up the young person
- involve other relevant professionals, including the GP
- try to contact the young person and their family.

1.4.2 If, after assessment, the young person does not engage with health and social care services, the relevant provider should refer back to the named worker with clear guidance on re-referral (if applicable).

1.4.3 If a young person does not engage with adult services and has been referred back to the named worker, the named worker should review the person-centred care and support plan with the young person to identify:

- how to help them use the service, or
- an alternative way to meet their support needs.

1.4.4 Ensure that the young person sees the same healthcare practitioner for the first 2 attended appointments after transition.

1.4.5 Ensure that the young person sees the same social worker throughout the assessment and planning process and until the first review of their care and support plan has been completed.

1.5 Training and development for staff

1.5.1 Local authorities, local education and training boards and NHS trusts should ensure that everyone working with young people in transition up to the age of 25, in children's and adult services, understands:

- young people's communication needs

- young people's development (biological, cognitive, psychological, psychosocial, sexual, social)
- the legal context and framework related to supporting young people through transition, including consent and safeguarding
- special educational needs and disabilities
- how to involve carers and families in a supportive, professional way.

1.5.2 Give all staff delivering direct care training that involves face-to-face interaction with young people, for example through shadowing.

1.5.3 Consider training or advice for staff not directly providing care. This could include, for example, listening to young people's views and experiences through e-learning or case study videos, or through case-based discussion.

1.6 Supporting infrastructure

Ownership

1.6.1 Each health and social care organisation, in both children's and adult services, should nominate:

- 1 senior executive to be accountable for transition strategies and policies
- 1 operational champion to be accountable for transitions.

1.6.2 The senior executive should be responsible for championing transitions at a strategic level.

1.6.3 The operational-level champion should be responsible for:

- liaising with the strategic-level champion
- implementing, monitoring and reviewing the effectiveness of transition strategy.

Developing transition services

1.6.4 Local authorities should ensure there is independent advocacy available to support all young people after they transfer to adult care[18].

1.6.5 Consider establishing local, integrated youth forums for transition to provide feedback on existing service quality and to highlight any gaps. These forums should meet regularly and should involve people with a range of care and support needs, such as those with physical and mental health needs, learning disabilities and people who use social care services.

1.6.6 Ensure that data from education, health and care plans are used to inform service planning.

1.6.7 Carry out a gap analysis to identify and respond to the needs of young people who have been receiving support from children's services, including child and adolescent mental health services (CAMHS), but who are not able to get support from adult services.

1.6.8 In undertaking the gap analysis:

- include young people who don't meet eligibility criteria for support from adult services and those for whom services are not available for another reason
- pay particular attention to young people:
  - with neurodevelopmental disorders
  - with cerebral palsy
  - with challenging behaviour, or
  - who are being supported with palliative care.

1.6.9 Jointly plan services for all young people making a transition from children's to adults' services[19].

[18] This is in addition their statutory duty to provide advocacy under the Care Act 2014.

1.6.10 Consider:

- developing pooled budgets across health and social care services
- developing pooled budgets across children's and adult services
- incentivising adult services to invest in transitions, for example through the best practice tariffs, existing NHS transition CQUINs or similar mechanisms.

Developmentally- appropriate service provision

1.6.11 Service managers should ensure there are developmentally appropriate services for both children and adults to support transition. This could include, for example:

- running joint clinics where young people can meet their consultant from children's services and a new consultant from adult services, before they transfer to adult services
- pairing a practitioner from children's services with one from adult services to encourage communication before, during and after the transfer.

Terms used in this guideline

Named worker

The named worker is one of the people from among the group of workers providing care and support designated to take a coordinating role. This could be, for example, a nurse, youth worker or another health and social care practitioner.

Transition

'Transition is a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young

[19] For young people with EHC plans, local authorities and health commissioners **must** jointly commission services, as per the Children & Families Act 2014.

adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.'[20]

Transfer

'Transfer is the termination of care by a children's healthcare provider and its re-establishment with an adult provider, that is, more of an event or transaction between service'.[21]

Learning disability

'A learning disability is defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.'[22]

Pooled budget

This is 'an arrangement where two or more partners make financial contributions to a single fund to achieve specified and mutually agreed aims. It is a single budget, managed by a single host with a formal partnership or joint funding agreement that sets out aims, accountabilities and responsibilities.'[23]

Person-centred

Seeing the person receiving care as an individual and an equal partner who can make choices about their own care and support.

[20] Blum R, Garell D, Hadgman C et al. Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adol Health 1993: 14; 570-6.
[21] Moli P, Ford T, Kramer T. et al. (2013) Transfers and transitions between child and adult mental health services. Journal of Adolescent Health 51: 213-219
[22] NICE (2015) NG11 Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges
[23] Communities and Local Government (2009) Guidance to local areas in England on pooling and aligning budgets, p8

2 Research recommendations

The Guideline Committee has made the following research recommendations in response to gaps and uncertainties in the evidence identified from the evidence reviews. The Guideline Committee selected the key research recommendations that they think will have the greatest impact on people's care and support.

2.1 Transition support for young adults

What approaches to providing transition support for those who move from child to adult services are effective and/or cost-effective?

Why this is important

Many transition policies exist and there are well-established local models for supporting and improving transition. These models are usually context- and service-specific and very few have been tested for their clinical and cost effectiveness. There is much evidence about the nature and magnitude of the problems of transition from children's to adults' services but very little on what works. Research should focus in particular on transition interventions in adult services and on young adults receiving a combination of different services.

2.2 The role of families in supporting young adults discharged from children's services

What is the most effective way of helping families to support young people who have been discharged from children's services (whether or not they meet criteria for adult services)?

Why this is important

Families and carers often feel left out once the young person moves to adult services, which can cause them considerable distress and uncertainty. The young person may themselves ask for their family not to be involved and so families also undergo a 'transition' in their involvement in the care of the young person. Alternatively, the young person may want their family involved after their move to adult services. We need to understand how best to support

and help families and carers through the transition period. A very important sub-group in this regard is young people with long-term conditions who are leaving care, and who are therefore less likely to have consistent and long-term support from parents or carers. How can foster carers, social workers or personal advisers in leaving care services best support young people transitioning from children's to adults' healthcare services?

2.3 The role of primary care in supporting young people discharged from children's services

What are the most effective ways for primary care services to be involved in planning, implementing and following-up young people in transition (whether or not they meet criteria for adult services)?

Why this is important

Some young people leaving children's services will lose some services previously available to them (for example physiotherapy) even when their needs for these services remain unchanged. Other young people will not be considered eligible for adult services. Young people in care who are placed outside of their local authority are likely to both change providers and GPs during transition. We did not identify any studies researching the role of primary care during transition for any of these groups.

2.4 The consequences and costs of poor transition

What are the consequences and the costs of young people with ongoing needs not making a transition into adult services, or being poorly supported through the process?

Why this is important

Many young people with ongoing needs fall through the transition gap or disengage with services at this point. Their outcomes remain unknown and are a serious cause for concern. We need longitudinal studies on the consequences of poor or no transition and the costs of unmet need as a result of poor transition.

2.5 Support to carers and practitioners to help young people's independence

What is the most effective way to help carers and practitioners support young people's independence?

Why this is important

An identified barrier to planned and purposeful transitions into adult services is supporting adults holding young people back. Both parents and practitioners may prefer young people to stay on longer in children's services and not feel able to support their transfer on to adult services.

2.6 Supporting young people to manage their conditions

What is the relationship between transition and subsequent self-management?

Why this is important

Self-management is part of being independent, and so is a part of developmental transition to adulthood. The most effective models of self-management and whether these are generic or disease-specific still need to be established. Some transition programmes include training in self-management, others do not. While growing independence is part of the transition into adulthood, personalised healthcare and helping people self-manage tends to be variable. Further research is needed to understand how self-management training and planning can be built into transition planning and preparation for young people.

2.7 Transition in special groups: young offenders institutions

What is the most effective way of supporting young offenders transitioning from children's to adults' health and social care services?

Why this is important

Young offenders tend to be vulnerable, with multiple problems. There are concerns that they tend to undergo particularly poor transitions into adult

services. There is a lack of evidence for this group, despite documented high need and poor outcomes.

2.8 Transition in special groups: looked-after young people

What is the most effective way of supporting care leavers in transitioning from children's to adults' health services?

Why this is important

The role of birth parents in the management of childhood-onset long-term physical and mental health conditions is essential at many levels and continues throughout transition. For young people in local authority care, even if they have had a stable placement or social worker during their time in children's services, transition is a period when their social care support is likely to change. The status of the health service user changes at age 18, when the primary receiver of information is the young person, not their social worker or foster carer. There is a need for research on how health and social care services can better collaborate with the young person during transition, respecting their need for privacy but also opening up for inter-agency communication when this is agreed by the young person.

Outcome measures

What indicators are most important for evaluating transition effectiveness?

Why this is important

Although there are outcome tools for measuring transition readiness, there is a lack of understanding of what a 'good' transition actually means to young people, their carers and service providers. Studies use many different outcomes, including clinic attendance, biomedical markers, transition readiness, communication levels with service providers, service satisfaction and measures on disability scales. It is not clear which of these are most important when measuring transition success.

2.9 Training

What are the effects of different approaches to transition training for practitioners on outcomes for young people?

Why this is important

We were unable to identify any effectiveness studies on transition training, yet this is identified as a need by several expert witnesses as well as in the literature. Committee members thought research in this area could help to inform practice, in particular to provide more information about how agencies can collaborate to develop and share learning about transition more effectively.

3 Evidence review and recommendations

When this guideline was started, we used the methods and processes described in the Social Care Guidance Manual (2013). From January 2015 we used the methods and processes in Developing NICE Guidelines: The Manual (2014).Where non-standard methods were used or there were deviations from the manual, and for more information on how this guideline was developed, see Appendix A.

For this guideline we conducted one comprehensive search which encompassed all questions. This search was not limited by study design and included a whole range of terms to cover all populations across health and social care included in the guideline scope. Further detail on this search is provided in Appendix A. All search hits (N=17,735) were imported into Eppi-Reviewer, which is an electronic software developed to support systematic reviews (Thomas et al., 2010) A de-duplication tool removed 2,803 study entries as duplicates, leaving us 14,932 studies which were manually screened in regards to the guideline scope. All studies which fitted within the scope (N=3,424) were screened according to their relevance to the review questions.

Included studies (N=90) were rated for internal and external validity using ++/+/- (meaning good, moderate, and low). Where there are two ratings (for example +/-), the first rating applies to internal validity (the rigorousness of the findings based on methodology and execution of the study). The second rating concerns external validity (the relevance of the study to our guideline scope).

The quality of economic evaluations are described on the basis of their limitations and therefore applicability in answering whether the intervention is cost-effective from the NHS and personal social services perspective, described as having very serious, potentially serious, or minor limitations, accompanied with further detail. Methodological appraisal detailing the limitations of these studies is fully described in Appendix C1.

The critical appraisal of each study considered characteristics of the study's design, and the rigorousness of execution. For our questions about the effectiveness of interventions we have only included studies with one or more comparison groups. For our questions on service users' views, or other aspects of transitional practice, we have included a wider range of study designs. We have, as a minimum, only included studies that provide a detailed methods section on how the study was conducted, and studies which ask questions aligned with one or more of our review questions.

Our evidence tables (Appendix B) provide details on each included study: information about the study's focus and context, design and findings, as well as details on our critical appraisal which underpins our overall quality ratings.

The evidence is here presented under the following headings:

- The effectiveness of interventions or programmes to improve transition from children's to adults' services
- Implementation of programmes to improve transition strategies and practice in transition from children's to adults' services
- Young people and their carers' views and experiences of transitioning from children's to adults' services
- Factors that help or hinder purposeful and planned transitions from children's to adults' services
- The role of adult services
- Managing transitions for young people who receive a range of different services across health and social care

Each of these correspond to one question, or in the case of effectiveness and views, to a group of similar review questions which were addressed together.

3.1 The effectiveness of interventions or programmes to improve transitions from children's to adults' services

Review questions

Three review questions asked about the effectiveness of interventions or programmes. 'Interventions' and 'programmes' included models and frameworks, as well as particular initiatives or services, implemented in order to support young people in advance of their transfer to adult services, at the time of the transfer, and after the transfer. We included initiatives which focused on one, two, or all of these stages which in total make up a 'transition'. Also included here were interventions for parents to support their young adult, and training programmes for staff to help them improve their practice for people being transitioned from children's to adults' services.

The three review questions were:

- What is the effectiveness of support models and frameworks to improve transition from children's to adults' services? These models include early transition planning, joint working or protocols between children's and adult services, and signposting young people to, or offering them support from, the voluntary and community sector.
- What is the effectiveness of interventions designed to improve transition from children's to adults' services? These interventions include any specific intervention which is there to support transition, for example named workers, transition clinics or information evenings, provided by any agency, statutory or voluntary.
- What transition training is available for health and social care professionals in children's and adult services? What is the effectiveness of transition training?

Searching for studies

Electronic databases in the research fields of health, social care, and social science were searched using a range of controlled indexing and free-text

search terms based on the population 'young people' and process 'transition'. No filter was used for study design, and one overall search was conducted to address all review questions given the broad nature of the topic and the diverse populations affected by the issues In addition, a range of websites of relevant organisations were searched too, for grey literature. The search captured both journal articles and other publications of empirical research. The search was restricted to studies published from 1995 onwards. A detailed description of the full search, including all search terms and sources, is provided in Appendix A.

Study inclusion criteria and selection

To be included for these questions, studies had to constitute at least one comparison group, or be a systematic review. Studies had to be conducted in the UK or elsewhere in Europe, Australia, New Zealand, USA or Canada.

The review for these questions focused on the outcomes listed in the guideline protocol (see Appendix A). Outcomes were included for both young adults and their carers, and covered:

- Transition readiness, as measured by a transition readiness scale
- Self-efficacy, defined as a young person's ability to undertake the activities they want to, as independently as possible
- Quality of life, including both health-related and social care-related indicators
- Condition-specific outcomes, including physical and mental health outcomes
- Experience of care, for example, accessibility and acceptability of services
- Condition-specific outcomes, including physical and mental health outcomes
- Experience of care, for example, accessibility and acceptability of services
- Continuity of care, both in terms of reduced or improved continuity

A total of 276 studies were initially coded as being about the effectiveness of models or interventions, and another 21 were coded as being about the effectiveness of training. All these records were then further examined and

further duplicates were removed. Remaining records were re-examined in regards to their focus, whether they had used a comparison group, and whether they had measured any of the outcomes listed above. A total of 239 studies were excluded in this process, primarily due to being duplicate records (N=33) and the lack of a comparison group (N=99).

Included studies

A total of 36 studies were deemed eligible for inclusion to address our questions on effectiveness, although none of these evaluated the effectiveness of training. Some studies were forthcoming (N=14) and their results may be available at the time of publishing this guideline. An additional study was identified at a later stage when screening our 'second opinion' studies. This left a final inclusion of 24 studies of which 11 were systematic reviews and 13 were individual evaluations. As can be gleaned from the summary tables below, these studies spanned a very wide range of populations and interventions. Most of the individual studies were small and of varying quality. See Appendix A for more detailed information about inclusion criteria.

Table 1 Summary of included systematic reviews for effectiveness questions

Author	Sample	Review focus
Bloom (2012)	15 studies	To assess the adult outcomes for young people with special health care 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.
Cobb (2009)	31 studies	To review the effectiveness of transition planning interventions for disabled young people, with a primary focus on education.
Crowley (2011)	10 studies	To review evidence of effect from transitional care programmes for young people with long-term conditions and disability.
Donkoh (2006)	0 studies	To review the effectiveness of Independent Living Programmes for young people exiting the care system.
Doug (2011)	92 studies of which 31 were quality assessed	To evaluate the evidence on transition from children to adult services for children with palliative care needs.
Everson-Hock	7 studies	To review interventions with the following characteristics: Support services to assist and prepare looked after young people for the

(2011)		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.
Kime (2013)	16 systematic reviews and 13 individual studies	To address the questions: • What models or components of models are effective in ensuring a successful transition process for young people with long-term conditions? • What are the main barriers and facilitating factors in implementing a successful transition programme? • What are the key issues for young people with long-term conditions and professionals involved during the transition
Morris (2009)	98 studies.	To review research on how to settle young people leaving care in safe accommodation.
Paul (2014)	19 studies	To review evidence on the effectiveness of different models of CAMHS to AMHS transitional care, service user and staff perspectives and facilitators of/barriers to transition.
Swift (2013)	23 papers.	To describe literature on the process of transition for young people with ADHD.
Watson (2011)	19 papers covering 18 service models.	To review 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.

Table 2 Summary of included individual studies for effectiveness questions

Author	Sample	Population, intervention, outcomes
Bent (2002) UK	Retrospective 2 'young adult team' areas with (N=74) and (N=45) 2 comparison areas with (N=76) and (N=59)	Population: Cerebral palsy, Spina Bifida, traumatic brain injury, degenerative neuromuscular disease, aged 17-28. Intervention: 'Young adult team' are multidisciplinary and set up to facilitate transition from children's to adults' services, including a consultant in rehabilitation medicine, a psychologist, therapists and a social worker. Comparison: Ad-hoc transition support. Outcomes: Participation in society, Nottingham health profile subscales of pain, energy, sleep.
Betz (2010) USA	Prospective Originally 80, 65 were analysed. 38 comparison, 42 intervention	Population: Spina Bifida, mean age 16. Intervention: 3-module training programme of 8 sessions delivered in a 2-day workshop focused on their transition plan. Comparison: Treatment as usual Outcomes: Community life skills, general health behaviours and specific self-care behaviours, subjective well-being, Spina Bifida.
Cadario (2009)	Retrospective 30 in the intervention,	Population: Type 1 diabetes, mean age 19 Intervention: Transition co-ordinator in the last year in paediatrics and after move to adult services. Adult

Italy	compared with 62 patients transitioned before the change in service.	endocrinologist involved in transition planning. Last clinic at paediatrics conducted jointly with the adult endocrinologist. Paediatrician present at the first adult clinic visit. Comparison: Letter summarising medical history and date for appointment in adult services. Outcomes: Mean HbA1c %, experience if care, attendance rates, time between discharge from paediatrics and first appointment in adult services, type of care during transition, number of examinations during transition.
Gilmer (2012) USA	Quasi-experimental modelling 931 in intervention group, 1,574 in adult services group	Population: Mental health problems, aged 21. Intervention: Outpatient programme for transitioning young people, focusing on independent living skills, educational and vocational services, and age-appropriate social skills. Comparison: The standard service for adults with mental health and substance abuse concerns. Outcomes: Inpatient admissions and emergency service visits, outpatient visits
Hagner (2012) USA	Prospective 23 in intervention group, 24 in comparison group	Population: Autistic spectrum disorders aged 16-19 and their carers/parents. Intervention: Group training sessions for families on person-centred planning, networking, and using adult services. Person-centred planning and group meetings with family members and service staff. Facilitators involved in the planning provided 4-6 months follow-up on the implementation of the plan. Comparison: Delayed intervention Outcomes: Students' expectations for adult life, self-determination, parents' expectations for their child's adult life.
Huang (2014) USA	Prospective 41 in comparison group, 40 in the intervention group	Population: Inflammatory bowel disease, Cystic Fibrosis, and Type 1 Diabetes, aged 12-20 Intervention: MD2Me delivered over a 2-month period via the web and by texting, to support condition management and skills development during transition. Young people provided with mobile phones for contact with clinical staff via text messaging. Comparison: Mailed health information materials Outcomes: Health literacy, self-efficacy, quality of life, disease status, patient-initiated health care communications.
Lee (2011) USA	Prospective 82 in the intervention group, 86 in the comparison group	Population: Disabilities and reading difficulties, mean age of 13.3 in comparison group, 13.9 in intervention. Intervention: Student-focused transition planning with Rocket Reader, a computer software programme for students with disabilities Comparison: Student-focused transition planning without Rocket Reader Outcomes: Knowledge about transition planning, self-determination.
Mackie (2014)	Prospective 27 in	Population: Cardiac disease, aged 15-17 Intervention: One hour long, nurse-led sessions to prepare

Canada	intervention group, 31 in comparison group (usual care)	people for transition to adult services. The intervention was one-to-one and informed people about their condition and treatment Comparison: Usual care Outcomes: Transition readiness
Munro (2011) UK	Prospective 13 in comparison group, 28 in the intervention group	Population: Leaving care, aged 15-19 Intervention: Right2BCared4 with local variations but based on the principles: Young people should not be expected to leave care until they reach 18 years old, should have a greater say in the decision making process preceding their exit from care, should be prepared for living independently Comparison: Service as usual. Outcomes: Young people's involvement in the transition planning and coping after care, young people's self-reported health and well-being.
Nakhla 2009	Retrospective 34 diabetes centres.	Population: young people with diabetes mellitus, aged 16-20. Intervention: Continued contact with allied health team or physician after transfer to adult services. Comparison: No contact with allied health team or physician after transfer to adult services. Outcomes: Diabetes Mellitus-related hospitalisations and Attendance at eye care clinics (retinopathy screening visits)
Nesmith (2014) USA	Prospective 58 in the intervention group, 30 in the comparison group	Population: Leaving foster care, aged 14-19. Intervention: 12-15 weekly meetings over a meal, social worker/psychologist and young person discussed relationship skills. Training of young people to coach others, and to lead their own transition meetings. Social workers, foster carers and young people trained on the impact of trauma. Comparison: Transition as usual. Outcomes: Relationship competency and relationship quality, experience of the intervention.
Powers (2012) USA	Prospective 32 in the comparison group, 29 in the intervention group.	Population: Leaving foster care and special educational needs, aged 16.5 - 17.5 Intervention: Take Charge intervention, which uses coaching to help young people identify their goals and mentors them throughout their transition process. Comparison: Foster care independent living programme Outcomes: Transition readiness, self-determination, quality of life.
Prestidge (2012) Canada	Retrospective 12 people in the intervention group, 33 in the comparison group	Population: Renal transplant, mean age 17.8 in intervention, 17.5 in comparison. Intervention: Transition clinic providing 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. Comparison: No transition clinic.

		Outcomes: Transition readiness, death rate, graft loss or graft malfunction.

Narrative summary of the evidence

Considering the wide range of study design, interventions and population groups, we have grouped the studies by the lead sector agency, using the following categories: social care, education, mental health, physical health.

Social care

All studies about social care transitions focused on the support of young people transitioning out of care. We found three systematic reviews:

- Donkoh C, Underhill K, Montgomery P (2006) Independent living programmes for improving outcomes for young people leaving the care system. Cochrane Database of Systematic Reviews. : CD005558-NaN. (++/+)
- Everson-Hock ES, Jones R, Guillaume L, Clapton J, Duenas A, Goyder E, Chilcott J, Cooke J, Payne N, Sheppard L M; Swann C (2011) Supporting the transition of looked-after young people to independent living: a systematic review of interventions and adult outcomes. Child: Care, Health & Development 37: 767-780. (++/-)
- Morris M, Stein M (2009) Increasing the number of care leavers in 'settled, safe accommodation': research review 3. (+/+)

These systematic reviews were of high or good internal validity. The external validity ratings for these three reviews reflect that their outcomes were not in our outcome list, as they focused on housing, education and employment. In addition, the reviews found few high quality studies evaluating transitional planning and support for care leavers, and all concluded that more research is needed on the effectiveness of specific approaches. Independent living programmes are emerging as a promising intervention. Independent living programmes is an overall approach rather than a specific intervention. Underlying principles are that young people should be provided with specific preparation for independent living before moving out of care, that young

people's housing, education, employment and health needs are addressed in their transition plan, and that young people themselves are involved in the planning. One review (Morris and Stein 2009 +/+) found that independent living programmes have a positive impact on young people's life skills (self-efficacy) and health. Everson-Hock et al (2011 ++/-) found two studies of no effect on mental health and one study of positive effect on mental health from independent living programmes.

In addition to the three reviews we found three individual studies:

- Munro ER, Lushey C, Ward H, Soper J, McDermid S, Holmes L, Beckhelling J, Perren K, National Care Advisory Service, Department for Education (2011) Evaluation of the Right2BCared4 pilots: final report. Loughborough: Loughborough University. (-/+)
- Nesmith A, Christophersen K (2014) Smoothing the transition to adulthood: creating ongoing supportive relationships among foster youth. Children and Youth Services Review 34: 1-8. (+/+)
- Powers L E; Geenen S, Powers J, Pommier-Satya S, Turner A, Dalton L D, Drummond D, Swank P, Res Consortium Increase; Success (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. Children and Youth Services Review 34: 2179-2187. (+/+)

Munro et al (2011 -/+) evaluated a UK pilot where care leavers in intervention group local authorities were encouraged to stay in care until the age of 18, had a greater say in decisions regarding their care leaving plan, and received a considered and planned approach to transitioning out of care, including preparation for living independently. These principles were implemented differently across authorities. Common features across were pathway planning, the use of independent reviewing officers or advocates, the option of returning to care after having first left, and transition support from professionals, carers and families. Unfortunately the comparison authorities appeared to have implemented similar initiatives, which undermines the study design.

Nesmith and Christophersen (2014 +/+) evaluated a US intervention called CORE, developed to support care leavers as they move out of services. The intervention is multi-modal and provides training for everyone involved, and encourages young people to lead their own transition planning meetings. This study recruited young people from two foster care agencies, and compared their outcomes with young people from a similar agency, serving a comparable population. Young people receiving the CORE intervention appeared slightly more satisfied with their care than those receiving the usual foster care (independent living skills training). Young people's relationship competencies decreased in the comparison group but remained the same in the intervention group. There was little difference between the groups in terms of their motivation for developing relationships with supportive adults, relationship-building skills, or in the identification of their most important supportive adult.

Powers et al (2012 +/+) was a small US evaluation of ‘Take Charge’, consisting of weekly coaching sessions to enhance self-determination and participation in transition planning, combined with quarterly workshops with adult mentors who have previously transitioned out of foster care. The young people in this evaluation were in foster care, and had learning disabilities, and a quarter of the sample received disabilities services. This was a randomised controlled trial rated + on internal validity. This study found a statistically significant impact on self-determination at follow-up, supporting the intervention: ES=1.09 (p=.0069). However, the groups differed at baseline on this variable, with the intervention group scoring lower, and it is not clear how they adjusted for covariance. This study found a clear improvement in the intervention group in terms of quality of life (ES=0.77, p=0.0008). The average number of independent living activities also increased and favoured the intervention group (ES=0.58, p=.0034). The authors also found positive effects from the intervention on the outcomes ‘use of transition services’. They found no difference between the groups on ‘identification of transition goals’ and ‘transition planning’.

Education

Studies addressing the effectiveness of programmes to support the transition out of children's services for young people with disabilities fell within two main categories. Some studies focused on interventions to support their transition from paediatric to adult health care. These studies would usually focus on particular conditions which cause disability. Other studies focused on disabled young people's educational transitions. While purely educational transitions are outside of the scope for this guideline, we did find some studies where the transition planning was led by education but included other health and social care. For these studies, we focused on their findings in terms of the relevant outcomes to this guideline.

We found one review which focused on transition planning and co-ordinating interventions for young people with disabilities, with an education focus:

- Cobb R, Alwell M (2009) Transition planning/coordinating interventions for youth with disabilities: A systematic review. Career Development for Exceptional Individuals. 32: 70-81. (+/+)

'Student-focused planning' in this review was defined as there being efforts made to make students feel heard and valued at meetings". The review's findings on student-focused planning is underpinned by three small comparison studies. What strengthens their results is that they were similar (non-significant heterogeneity). The authors pooled the effects of these three studies on the outcome 'participation in planning meetings' and found an effect size of g=1.47 (z=5.1, p<.001). So this indicates that the young people receiving 'student-focused planning' were more likely to participate in their planning meetings than those that did not. Note that this measure relates to what is called a proxy outcome. This means that the outcome 'participation in planning meetings' is not a direct measure of people's transitions being planned and purposeful.

We found two individual evaluations:

- Hagner D, Kurtz A, Cloutier H, Arakelian C, Brucker D L; May J (2012) Outcomes of a family-centered transition process for students with autism spectrum disorders. Focus on Autism and Other Developmental Disabilities. 27: 42-50. (-/+)
- Lee Y, Wehmeyer ML; Palmer SB; Williams-Diehm K, Davies DK, Stock SE (2011) The effect of student-directed transition planning with a computer-based reading support program on the self-determination of students with disabilities. The Journal of Special Education. 45: 104-117. (+/+)

Both of these studies were randomised controlled trials. Hagner et al (2012 -/++) had a small sample size (N=47) and large numbers of missing variables. Lee et al (2011 +/+) was a well conducted study, but there is missing information about follow-up and some lack of clarity in terms of numbers. Both were US studies.

The intervention evaluated by Hagner et al (2012 -/+) consisted of group training sessions for families, person-centred planning, and follow-up assistance on the implementation of the plan. The training sessions focused on person-centred planning, networking, adult services and planning for after high school. Person-centred planning involved a facilitator working with the families, inviting people in their community to be involved in the planning. Once the extended group had agreed a plan, professionals (including from adult services) were invited to provide input into the final plan. The outcome they measured which was of relevance to our scope was 'self-determination' (using the Arc Self-Determination Scale). This study concluded that because students receiving the intervention improved more on this scale than those not receiving the intervention, it was effective. However, when calculating the difference between the mean scores at the end of the study, this is not statistically significant (d^{24} = 0.67, CI: -0.047 – 1.386).

Lee et al (2011 +/+) evaluated a computer-based booster 'Rocket Reader' to a student-directed transition planning instruction curriculum called 'Whose Future Is It Anyway?' So this study took as an assumption that the student-

[24] Hedges *g*

directed planning was effective, and then evaluated whether it would be even more effective when using the Rocket Reader. While 'Whose Future Is It Anyway' is a comprehensive transition training approach, in this study they implemented it over 10 sessions, covering self-awareness, disability awareness, communication, decision-making and team-membership. This was delivered to two different groups of students. In addition, one of the groups used the Rocket Reader to provide this curriculum. The Rocket Reader is a software programme which changes text into audio format. The study concluded that this technology significantly impacted positively on students' 'self-determination'. However, this is not entirely clear from the data. The authors say that they conducted further analyses on the individual variables within the Arc Self-Determination Scale, and after adjusting for covariates (differences between the two groups at baseline) found a statistically significant effect on the self-regulation score (stated as F (1, 163) = 12.47, p<.01, this is equivalent to a Cohen's d=0.548).

Mental health

We found two systematic reviews which focused on transition from CAMHS to AMHS:

- Paul et al (2014) Transition to adult services for young people with mental health needs: A systematic review. Clinical Child Psychology and Psychiatry. (++/++)
- Swift et al (2013) ADHD and transitions to adult mental health services: a scoping review. Child: Care, Health and Development. (+/++)

Paul et al (2014 ++/++) searched for "evidence on the effectiveness of different models of CAMHS-AMHS transitional care" (p1). In addition, they searched for studies which had collected young people, families and professionals' views on transition, and research on barriers and facilitators to "effective CAMHS-AMHS transition". This was a comprehensive and sound review which fitted very well with our scope. We here focus on their findings relevant to our effectiveness questions only. This review is included on other guideline questions so will be re-presented with other questions.

Paul et al (2014 ++/++) found three studies which addressed their question on the effectiveness of transitional care, all from the US. All three studies evaluated transitional support which included input from AMHS. All studies found positive impact from the programmes, but the reviewers conclude that there is not enough evidence to support a particular approach to transition.

Swift et al (2013+/++) is a 'scoping' review, which means that they employed systematic review methods to identify literature on a broad topic, in this case young people with ADHD and transition into adult services. The authors primarily sought to identify any study on this topic, rather than address a specific question from the start. The internal validity rating of '+'reflects this overarching aim of the review, since they did not quality appraise included studies. This review did not find any studies relevant to our effectiveness questions.

In addition to the two reviews we found one study by Gilmer et al (2012 +/+) which considered service contact, emergency admissions and jail service days in two samples following the introduction of young people-specific services for those aged 18-24:

- Gilmer et al (2014) Change in mental health service use after offering youth-specific versus adult programs to transition-age youths. Psychiatric Services, 63(6): 592-596 (+/+)

This study is primarily an advanced audit, in that they did not examine actual service need, and so the overall outcome of 'service use' is indicative rather than a direct outcome. It does not tell us whether the change in service provision enhanced young people's transition, and we cannot infer whether the higher usage of services in one group is a positive outcome or not. This study is therefore of limited use and has not been included in the evidence statement. Do note, however, that this study was included in the systematic review by Paul et al (2014 ++/++) described above.

Physical health

The majority of included studies were conducted with a focus on the transition of people from paediatric hospital departments to adult clinics. We found 5 systematic reviews:

- Bloom R, Kuhlthau K, Van Cleave J, Knapp A, Newacheck P, Perrin M (2012) Health Care Transition for Youth With Special Health Care Needs. Journal of Adolescent Health. 51: 213-220 (++/+)
- Crowley R, Wolfe I, Lock K, McKee M (2011) Improving the transition between paediatric and adult healthcare: a systematic review. Archives of Disease in Childhood. 96: 548-554. (–/++)
- Kime N, Bagnall A-M, Day R (2013) Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes. UK: NHS Diabetes. (+/++)
- Doug M, Adi Y, Williams J, Paul M, Kelly D, Petchey, R, Carter, YH (2011) Transition to adult services for children and young people with palliative care needs: a systematic review. Archives of Diseases in Childhood. 96(1): 78-84IS. (+/++)
- Watson R, Parr J, Joyce C, May C, Le Couteur A (2011) Models of transitional care for young people with complex health needs: a scoping review. Child: care, health and development. 37: 780-791. (-/++)

These five reviews concurred in terms of recommending ‘transition clinics’ as a promising intervention. The studies included by Crowley et al (2011 -/++) analysed the impact of various combinations of condition-specific or general training, transition co-ordinator and transition clinics (joint paediatric and adult services clinics, and/or separate young adult clinics), and across these studies there were statistically significant impact found on condition-specific outcomes. All these studies were about young people with diabetes. The outcomes for which these interventions appeared to have a positive effect were all related to this condition: HbA1c, acute complications (diabetic ketoacidosis, hypoglycaemia), chronic complications (hypertension, nephropathy, retinopathy), and rate of screening complications. Listed here are outcomes supported by two included studies or more. Bloom et al (2012

++/+) also found evidence in support of transition clinics (with professionals from adult services), particularly in relation to young people and their families' experiences of transition and transfer. This was supported by two comparison studies and two studies of pre-post design. One study included by Bloom et al (2012 ++/+) found evidence of impact on condition-specific outcomes and one did not.

Kime et al (2013 +/++) focused on transition into adult services for young people with long-term conditions, and Doug et al (2011 +/++) focused on the same type of transition for young people with palliative care needs. The findings of these two reviews concurred on advising that no intervention or model is emerging as being most successful, but that principles for good practice include co-ordination and planning, for example by a transition co-ordinator, and written and verbal communication. In addition, Kime et al (2013 +/++) concluded that transition planning and interventions should be young person-centred and age-appropriate, include collaboration between paediatric and adult services, and across agencies (multi-agency), include self-management training for young people, transition training of professionals, and come with enhanced resources. Doug et al (2011 +/++) further concluded that transition plans should be life, not illness plans. Both reviews emphasise that these conclusions are based on low-quality evidence. For example, Doug et al (2011 +/++) did not find any studies which addressed 'palliative care' as an overall concept, nor any long-term outcome data on effectiveness for specific models.

In addition, we identified three RCTs:

- Betz CL, Smith K, Macias K (2010) Testing the transition preparation training program: A randomized controlled trial. International Journal Of Child And Adolescent Health. 3: 595-607 (+/+)
- Huang JS, Terrones L, Tompane T, Dillon L, Pian M, Gottschalk M, Norman GJ, Bartholomew LK (2014) Preparing Adolescents With Chronic Disease for Transition to Adult Care: A Technology Program. Pediatrics. 133(6): e1639 (++/+)

- Mackie AS, Islam S, Magill-Evans J, Rankin KN, Robert C, Schuh M, Nicholas D, Vonder Muhll I, McCrindle BW, Yasui Y, Rempel GR (2014) Healthcare transition for youth with heart disease: a clinical trial. Heart. 128: doi:10.1136/heartjnl-2014-305748 (+/+)

These studies evaluated very different kinds of transition interventions for young people. Betz et al (2010, +/+) measured the impact of a training course for young people with Spina Bifida to facilitate the development of their healthcare transition plan. This study measured the impact of this on outcomes relevant to self-efficacy, quality of life and Spina Bifida management. It found no impact on any of the outcomes measured.

Mackie et al (2014, +/+) evaluated the impact of a one hour-long nurse-led intervention designed to inform young cardiac patients aged 15-17 about their condition and treatment. At 6 months after the intervention there was no significant impact on self-management. 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.

Huang et al (2014, ++/+) evaluated the impact of the transition programme MD2Me, which was a 2-month intervention where young people with a long-term condition received web and text-based information about their condition management in addition to the option of contacting their health team directly, via a text algorithm. 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 is the normalised score 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 health care 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 early transition preparation.

We identified four retrospective cohort studies with comparison groups:

- Bent N, Tennant A, Swift T, Posnett J, Scuffham P, Chamberlain M A; (2002) Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study. Lancet. 360: 1280-1286. (+/++)
- Cadario F, Prodam F, Bellone S, Binotti M, Trada M, Allochis G, Baldelli R, Esposito S, Bona G, Aimaretti G (2009) Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: A hospital-based approach. Clinical Endocrinology. 71(3): 346-350. (-/++)
- Nakhla M, Daneman D, Paradis G, Guttman A (2009) Transition to adult care for youths with diabetes mellitus: findings from a Universal Health Care System. Pediatrics. 124 (63): e1134-e1141. (-/++)
- Prestidge C, Romann A, Djurdjev O, Matsuda-Abedini M (2012) Utility and cost of a renal transplant transition clinic. Pediatric Nephrology. 27(2): 295-302 (-/++)

Due to their designs, these studies are more prone to bias in their findings, and their findings therefore need to be treated with caution. While the three interventions evaluated by these studies had some similarities in the form of team support at the time of transition, they were still heterogeneous in terms of their components, conditions and outcomes.

Bent et al (2002 +/++) retrospectively collected functionality outcomes (pain, energy, sleep) and participation in society, comparing young people who received transition support from a young adult team with those in areas where this was not provided. The Young Adult Team model provides multi-agency support for transition from children's to adults' services. The study found a

relationship between function and participation. After adjusting for this, they found that those who lived in areas where young adult team were provided were 2.54 times more likely to participate, than those who lived in areas without such teams (95% CI 1.30-4.98).

Economic evidence

Bent et al (2002 +/++) is a UK study that also conducted an economic evaluation. It was rated as having good applicability with minor limitations with respect to economic methodological quality.

The results were presented as a cost-consequence analysis (presenting changes in costs alongside changes in outcomes).

The perspective of the analysis is that of the NHS and social care services, although it is limited to community services and does not measure changes in acute healthcare services and respite social care services. It is not clear why they are not measured and the authors do not provide any rationale.

The results indicate that the intervention improves outcomes with no differences in costs to the NHS and social care services from the perspective of community services. Findings of no difference in costs depends on the assumption that the use of acute and respite care services is similar between groups.

The authors report costs using 1999 prices. Mean intervention costs are presented using low and high estimates although it is not clear how those low and high estimates were derived but it is likely based on the varying team size. Mean intervention costs per person (for the six-month period) ranged from £28 to £57 at one site and between £44 and £88 in another site. Mean cost associated with use of community health and social care services was similar between intervention and control groups (and was not statistically different) but it was marginally lower for the intervention group (£650 vs. £798 over a six-month period).

The evaluation is limited to some extent by the absence of baseline measurements of costs and effects and that there was no bootstrapping of

cost estimates. Bootstrapping is a method to estimate uncertainty associated with cost estimates (using a probability distribution). Even though the authors did not undertake bootstrapping methods they did undertake sensitivity analyses on intervention costs. They doubled the duration of team meetings (from one to two hours per week) and found that this did not change the finding that the intervention was still marginally cost-savings compared to the comparison group.

Please refer to the economic appendices C for more detail (critical appraisal table for economic quality, the evidence table for data extraction and the economic report).

Cadario et al (2009 -/++) considered outcomes from a structured transition support intervention and compared them with the cohort of patients who were transferred in the years before this intervention was implemented. The intervention consisted of a transition support co-ordinator who worked with young people in the last year of children's services, during transfer to adult services, and after transfer. An adult endocrinologist was involved in the transition planning. The co-ordination 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. Before the introduction of this system, young people were given a letter in advance of their transfer, summarising their clinical history, and a date for an appointment in the adult clinic.

The researchers present differences in the two groups on all measured values but did not calculate effect sizes. When in adult services, the groups differed on mean HbA1c, with the transition support group having an improved measure compared with no change for the non-transition group. The mean HbA1c remained better in the transition group after one year in adult services. Three 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.

Nakhla et al (2009, -/++) surveyed the type of transfer co-ordination provided within 34 diabetes centres. They categorised the types of transfer arrangements by whether the young people would continue contact with either allied health care team or physician after transfer, theorising that continued contact with at least one of these or both would promote continuity of care. The comparisons therefore consisted of young people who experienced transfer to adult care as a) a change in physician and allied health care team, or b) a change in physician and with no follow-up care from an allied health care team. There were 15 centres which provided a) (N=945, 63%), and 1 that provided b) (N=61, 4%).

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% v 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 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.

Prestidge et al (2012, -/++) evaluated the impact of a transition clinic for renal transplant young people. This transition 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. 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 were 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 depending 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 adult services was supported by a detailed letter from the transition nephrologist, and a verbal handover by the nurse specialist, social worker and dietician. In addition, the team tried to refer young people to adult transplant experts which were likely to be a good match.

In the 6 years preceding the introduction of a multidisciplinary team the hospital saw a total number of deaths or graft loss 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.

Prestidge et al (2012, -/++) is a non-UK (Canadian) study that also conducted an economic evaluation. It was rated as having good applicability to the UK with some limitations with respect to economic methodological quality.

The economic analysis is an outcome-based model where differences in costs are estimated based the difference in the proportion of individuals with key clinical outcomes: those needing dialysis and transplants. Only direct costs associated with dialysis and transplants are included and cost data are not taken from the study directly but rather from the wider literature. The economic analysis is limited in that it takes a very limited healthcare perspective and does not measure all-important changes in health and social care service use. However, this type of analysis may be appropriate given that the aims of the study are to reduce adverse health consequences. However, it

is likely that the analysis underestimates cost-savings to the healthcare sector as individuals with dialysis or kidney transplant are likely to have greater healthcare needs and may have higher use of healthcare services than those without dialysis or kidney transplant.

Apart from limitations in the study design, the intervention is associated with improvements in outcomes for reduced cost (inclusive of program costs). Lower costs are driven by costly adverse events.

Average intervention costs were estimated on two years participation (Canadian $6,650 per person). Inclusive of intervention costs, the total costs per person for the intervention group ranged between $11,380 and $34,312 versus the control group, between $17,127 and $38,909. The price year of costs is unclear but may be 2010/2011.

It is not possible to say whether the intervention is or is not cost-effective in the UK setting, as it would require further analysis to take into account differences in institutional context and unit costs.

However, insofar as the intervention reduces adverse clinical outcomes that are costly, there is potential for the intervention to be cost-savings and cost-effective.

Gaps in the evidence

It is clear from the narrative summary that although there is a lot of literature on transition from children's to adults' services, there are very few rigorous evaluations that assess the effectiveness of interventions to support young people in advance of, during and after transfer. This is also reflected in the systematic reviews identified, and it is the case across all the main sectors considered here; social care, education, mental and physical health.

For this reason, several expert witnesses were invited to present on their experiences. Appendix D contains a full account of these. Referenced here are the expert witness accounts that addressed our questions on effectiveness, organised by lead sector agency.

Education

- Julie Pointer, transition development manager, Surrey Short Breaks for Disabled Children

This expert stated that transition planning needs to be person-centred, and for young people with disabilities this needs to take into account their social needs as well as services. She emphasised in particular, plans for employment, housing, relationships, and health. To facilitate a system that responds to person-centred planning, young people's plans need to feed into commissioning processes for local services.

Mental health

- Helen Crimlisk, consultant psychiatrist, Sheffield Health and Social Care Foundation Trust

This expert reported on the effectiveness of having a joint commissioning strategy for young people with senior clinicians from CAMHS and adult services, and young people themselves. They have a joint transition protocol which has been agreed by all and which sets out transition standards including preparation for transition.

This Foundation Trust piloted having transition clinics where CAMHS and adult practitioners attended handover clinics with the young person in transition, but this was not found to be the most effective way of addressing the needs of those in most need of support during this period.

Physical health

- Robert Carr, consultant haematologist at Guy's & St Thomas' Hospital Foundation Trust

This expert reported on their experiences of setting up a teenage and young adult multidisciplinary team for young patients with cancer, aged 16-24. His experience is primarily based on delivering this service to young people diagnosed at this point in their lives. The single most effective intervention of this team has been a Facebook page for peer support, administered by the

lead nurse on the team. Another effective way of providing support to young adults has been direct texting contact with the lead nurse.

- Janet McDonagh, Senior Lecturer in Paediatric and Adolescent Rheumatology, University of Manchester

This expert emphasised the importance of a named worker, a transitional care co-ordinator, as well as how transitional care needs to be embedded in all practice and not seen as an addition to existing care. A core component of transitional care is the focus on young people's resilience and how to build this up in preparation for transfer to adult services. She promoted the notion of developmentally appropriate care, which focuses on delivering care that is person-centred and takes into account the capacity of the patient according to their maturity and development. There needs to clear communication which emphasises who is responsible and for what. She also emphasised the importance of engagement from adult services, as well as children's.

- Peter Winocour, consultant physician, East and North Hertfordshire NHS Trust

This expert stated that following the NHS Diabetes Transition document (2013) has led to improved condition-specific outcomes and clinic attendance. A dedicated young adult clinic for those coming through from children's services has been found to be effective in engaging young adults in their own care, but supported by planned transition while in children's services, and continued engagement from adult services. He reported that a pilot in Newham had found use of text messaging improved treatment planning and condition-specific outcomes.

Evidence statements

ES no.	Evidence Statement
ES1	Effectiveness of transition support models for young people leaving care: For this population, there is evidence from two reviews (one of moderate and one of good quality) that independent living programmes, where care leavers are supported to remain in foster care for longer, can improve the transition into adult life (Everson-Hock et al, 2011, ++/+, Morris and Stein, 2009, +/+). This was supported by a low-quality evaluation (Munro et al, 2011, -/+). There is evidence from one small

	study of good quality (Powers et al, 2012, +/+) that a combination of coaching and mentoring can improve young people's quality of life, and uncertain evidence that this intervention did not impact on their engagement in the transition planning. There is evidence from one US study of good quality (Nesmith and Christophersen 2014 +/+) that a combination of training for all parties, and young people's leadership of their own transition planning meetings, can increase young people's satisfaction of the transition process.
ES2	Effectiveness of transition support models for young people with disabilities, when the transition lead is within education: For this population in this setting, there is evidence from one good quality systematic review that student-focused planning increases their participation in planning meetings by a moderate degree (Cobb and Alwell, 2009, +/+). There is evidence from one small study of low quality (Hagner et al, 2012, -/+) that student-focused planning does not impact students' self-determination. There is evidence from one study of good quality that a particular type of reading technology (Rocket Reader) can have a small impact on students 'self-determination' in advance of transition (Lee et al, 2011, +/+).
ES3	Effectiveness of transition support models for young people in transition from CAMHS to AMHS: This evidence statement is based on findings from two reviews (one of moderate and one of good quality) about transition from CAMHS to AMHS (Paul et al, 2014, ++/++, Swift et al, 2013, +/++). Neither review found evidence on the effectiveness of transition support in regards to particular diagnoses. One high quality review (Paul et al 2014 ++/++) identified three studies relevant to questions about the effectiveness of transition planning or support. All three studies evaluated packages of care which included input from AMHS, and all three studies found positive impact from these programmes, but due to study quality and design the reviewers were unable to provide a conclusion. The evidence from these reviews therefore indicate a clear need for further research on the effectiveness of providing purposeful and planned transition from CAMHS to AMHS.
ES4	Effectiveness of transition clinics for young people in transition from paediatric to adult health services: We found mixed quality evidence from four systematic reviews (Bloom et al, 2012, ++/+, Crowley et al, 2011, -/++, Kime et al, 2013, +/++, Doug et al, 2011, +/++) and from one individual study (Prestidge et al, 2012, -/++) that transition clinics can improve condition-specific outcomes for young people transitioning from paediatric to adult services. The transition clinics that were evaluated by these studies were either set within paediatric services but including adult team members, or set in adult services but focusing on young adults only. Some were in combination with training or the provision of a transition co-ordinator. It is important to note that some studies evaluating transition clinics have not found any impact on condition-specific outcomes, and so this is an area of uncertainty. There is mixed quality evidence from four systematic reviews (Bloom et al, 2012, ++/+, Crowley et al, 2011, -/++, Kime et al, 2013, +/++, Doug et al, 2011, +/++) that principles of good practice include co-ordination and planning, for example by a transition co-ordinator, and written and verbal communication. This was supported by one individual randomised study

	(Huang et al, 2014, ++/+) and four retrospective comparison studies (Bent et al 2002 +/++, Cadario et al 2009 -/++, Nakhla et al 2009 -/++, Prestidge et al, 2012, -/++). There is evidence from one good quality systematic review (Kime et al, 2013, +/++) that transition planning should be person-centred, include collaboration between paediatric and adult services and include self-management training for young people. It is, however, worth noting that two good quality RCTs (Betz et al, 2010, +/+, Mackie et al, 2014, +/+) found no impact from one-off training interventions.
ES5	Effectiveness of communication technologies to support transition between paediatrics and adult services There is evidence from one good quality study (Huang et al, 2014, ++/+) that a combination of web-based instruction and text-based reminders can improve self-management of a long-term conditions during transition into adult services.
ES6	Cost-effectiveness of services to support transition from children's to adults' services There is limited evidence from one UK study (Bent et al 2002 +/++) with good applicability and minor limitations in economic methodological quality that multidisciplinary services rather than 'ad-hoc' services is marginally cost-saving and can improve participation in society and reduce activity limitations for individuals with physical disabilities who have multiple service needs. However, the analysis only measures community health and social care services and does not measure in acute or respite social care services. Therefore, cost-savings depends on the assumption that there are no differences between groups in utilisation of those services. There is very limited evidence from one non-UK study (Prestidge et al 2012, -/++) with good applicability and some limitations in economic methodological quality that transition clinics compared to 'standard' services for individuals with renal failure has the potential to be cost saving and cost-effective from a health care perspective. This depends on the assumption that the intervention is able to prevent costly adverse events related to dialysis and renal transplant.

3.2 The role of adult services

Review questions

One question focused on adult services. The objective of this question was to identify how adult services can be more involved in the transition from children's services, and how changes can be made to make adult services more young people friendly: before, during and after transfer.

The review question was:

- How can adult services support effective transition for young people in transition?

Searching for studies

Electronic databases in the research fields of health, social care, and social science were searched using a range of controlled indexing and free-text search terms based on the population 'young people' and process 'transition'. No filter was used for study design, and one overall search was conducted to address all review questions. In addition, a range of websites of relevant organisations were searched too, for grey literature. The search captured both journal articles and other publications of empirical research. The search was restricted to studies published from 1995 onwards. A detailed description of the full search, including all search terms and sources, is provided in Appendix A.

Study inclusion criteria and selection

To be included for this question studies had to be conducted in the UK, Europe, Australia, New Zealand, the USA or Canada. Our protocol (see Appendix A) stated that we would include prospective comparison studies as well as process evaluations, but due to lack of relevant studies we included all studies which fit with our review question.

Included studies

We screened the papers (titles and abstracts) identified in the search outputs and retrieved full texts for those that were clearly about the role of adult services in transition planning or care, or about how adult services could be more involved in any aspect of transition of young people from children's to adults' services. Our focus for this question was on identifying high quality and if possible, contextually relevant evidence (UK studies) on adult service role in transition. See Appendix A for more detailed information about inclusion criteria.

After the second stage of screening, 29 papers were coded to this question. Three of these were excluded because they were duplicates. A further 16 were excluded on the grounds that they were descriptive pieces, not research

studies. We then categorised the papers according to sector. Some papers were excluded because they presented their findings in a short conference abstract and were too brief to quality assess. Some papers were about problems in adult services, rather than what adult services can do in terms of transition. Further information about this process is detailed in APPENDIX A.

We found 3 papers which addressed our question, although not all of these are of equal 'fit' to our focus on what adult services can do to improve transitions. The studies are of variable quality and encompass a whole range of study designs. They all focus on physical health care settings.

Table 3 Summary of included studies for the question about the role of adult services

Author	Aim	Design	Respondent groups
Fair (2012) USA	To analyse interview material gathered from HIV care providers, about their roles in transitioning young people into adult services	Qualitative study Interviews with 19 practitioners	Health and social care practitioners in children's and adult HIV services
Shaw (2014) UK	To examine how far a paediatric and nearby adult facility have mainstreamed transitional care guidance into their practice.	Cross-sectional study using questionnaires 23 clinics participated. 457 patients participated, 326 in paediatric care and 131 in adult care.	YP with long-term conditions The study looked at satisfaction among patients in a number of adult and paediatric clinics.

Table 4 Summary of included individual studies for outcome evaluation

Author	Sample	Population, intervention, outcomes
Walleghe m (2009) Canada	Pre-post evaluation design 2 cohorts of participants in the Maestro Project: an	Population: Young adults with Type 1 Diabetes. Intervention: Maestro navigator model. The Maestro navigator focuses on improving communication between different settings which provide care to young people coming through from children's services. Initiatives aimed at young people included a website and book with information about transition, and social evenings.

	older group,19-25 years with (N =164); and a younger group,18 years of age with (N =84)	Comparison: No comparison (pre-post evaluation). Outcomes: To consider outcomes from the model over time, and identify barriers to care for young adults in adult services. To assess how adult services can respond to the needs of young people transitioning from paediatric care. Includes self-reported outcomes from patient questionnaire and audit of clinic records.

Narrative summary of the evidence

The three included studies were reviewed to address our question on how adult services can support effective transition for young people coming through from children's services. These were:

- Fair C, Albright J, Lawrence A, Gatto A (2012) "The paediatric social worker really shepherds them through the process": Care team members' roles in transitioning adolescents and young adults with HIV to adult care. Vulnerable Children and Youth Studies Vol. 7, No. 4, December 2012, 338–346 (+)
- Shaw KL, Watanabe A, Rankin E, McDonagh JE (2014) Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility. Child: Care, Health And Development. Vol. 40, No. 5, 663-70 (+/++)
- Walleghem N, Macdonald CA, Dean HJ. 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. Canadian Journal of Diabetes Canadian Journal of Diabetes. Vol. 31 No.8.1529–1530 (+/+)

Fair et al (2012 ++) explored the roles of different care team members in teams who provide multi-disciplinary care for young people with HIV. Nineteen care providers from both adult and paediatric teams were interviewed. This study illustrates how professionals in adult clinics participate in transitional care for young people and what adult services need to improve upon when working with young people in transition. This study also references social care roles.

The interview data indicated 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 carers to adjust to a reduced role in an adult medical setting. Adult medical staff were responsible for 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. While the findings from this small qualitative study are not generalisable, they illustrate the importance of adult services in transitional care.

Shaw KL et al (2014 +/++) assessed satisfaction rates among patients in a number of adult and paediatric clinics, in conjunction with transition models used in these clinics. The study found that more clinics within adult hospitals than children's had a transitions programme in place. The most common service model was a combined transition clinic with both paediatric and adult clinical staff present. Only a small number of clinics reported that their transition programme could be described as 'holistic' in that they addressed "medical, psychosocial and vocational issues" (p666). This study found that more adult hospitals were adhering to national guidelines on transitional care. There were higher satisfaction scores among parents of patients who received transitional care than those who did not, and satisfaction appeared to increase with stronger adherence to transition guidance.

We identified one evaluation of a transition model which included a consideration of adult services role (Walleghen et al 2009 +/+). The Maestro project is designed to assist young adults with type 1 diabetes. The Maestro is a patient navigator. This is a position filled by someone who is not a health professional and whom does not provide medical advice or education; rather, this role "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. This study

was deemed relevant because it focuses on an intervention which continues after transition has been made into adult service, and which can help young people remain engaged with services after they have aged out of paediatric care. Key findings were:

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. The individuals who received the Maestro intervention after they had transferred into adult services were helped to reconnect with adult services if they had dropped out. While 60% had visited a clinician at least once in the year before the intervention this increased to 70% following the intervention.

This suggests that adult service need to continue supportive intervention during and following transition to keep patients engaged in services.

In addition to the individual studies found for this question, some of the evidence identified for effectiveness questions was also relevant here. As stated in the narrative summary on effectiveness, transition clinics are emerging as a promising intervention. Transition clinics should include professionals from adult services, or can be led within adult services as a specialist clinic for young adults who have recently transferred (for example, as in the Maestro project).

Gaps in the evidence

While we found evidence that adult services play a crucial role in sustaining the effects of transition-focused initiatives provided in children's services, there is limited evidence about how, specifically, adult services should be working to support effective transition for young people. Some evidence also indicate that adults' services role needs to be active in advance of the transfer.

For this reason, expert witnesses were invited to present on their experiences. Appendix D contains a full account of these. Referenced here are the expert witness accounts that addressed this question.

- Helen Crimlisk, consultant psychiatrist, Sheffield Health and Social Care Foundation Trust

This expert from adult mental health services has succeeded in engaging adult services in transition by a joint commissioning strategy for young people with senior clinicians from CAMHS and adult services, and young people themselves. A joint transition protocol has been agreed by all and which sets out transition standards including preparation for transition.

While the joint commissioning strategy and protocol was reported to be essential in involving adult services, it was clear from the witness statement that individual commitment helped secure this.

- Peter Winocour, consultant physician, East and North Hertfordshire NHS Trust

This expert referred to local audits which have shown that the time of and after transfer to adult services is a major pressure point. He referred to anecdotal evidence that flexibility in transfer to young adult services helps the process. He further stated that young adult care requires the same level of commitment from adult services (and the same resources) as those made available to the transition services. Although there is significant variation in how joint services operate the major challenge is in the care of those aged > 19 at the time of transfer. All adult services should have at least 1 lead consultant and DSN to support transition and ensure continuity in a young adult service after transfer.

Evidence statements

ES no.	Evidence Statement
ES7	How can adult services support effective transition for young people in transition? There were no high quality studies identified by our search that had direct relevance to social care and mental health interventions and adult services, despite the criteria to including non-UK studies. There is a lack of robust evaluation of interventions in adult services aimed at young people in transition. As with other questions in this topic, there is a lack of robust research that responds to our question especially in relation to social care and mental health services, but the expertise of the Guideline Committee can respond to these gaps with examples of

	practice from their experience and/or invitation of expert witnesses.

3.3 Implementation of programmes to improve transition strategies and practice

Review question

One question focused on the implementation of transition practices and guidelines, recognising that there appears to be much consensus on what ought to happen but often a lack of good practice following that. The objective for this question was therefore to assess research on what hinder implementation, and what works to enhance uptake and implementation of transition guidelines.

The review question was:

- What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services?

Searching for studies

Electronic databases in the research fields of health, social care, and social science were searched using a range of controlled indexing and free-text search terms based on the population 'young people' and process 'transition'. No filter was used for study design, and one overall search was conducted to address all review questions. In addition, a range of websites of relevant organisations were searched too, for grey literature. The search captured both journal articles and other publications of empirical research. The search was restricted to studies published from 1995 onwards. A detailed description of the full search, including all search terms and sources, is provided in Appendix A.

Study inclusion criteria and selection

For this question, we included a broader set of study designs than we did for the effectiveness questions. Studies had to be conducted in the UK or elsewhere in Europe, Australia, New Zealand, USA or Canada. As well as

systematic reviews and comparison evaluations, we also included studies which had evaluated implementation processes in a mixed methods study design.

After the second stage of screening, 45 papers were coded to this question, 1 of these was excluded because it was a duplicate. A further 24 were excluded on the grounds that they were descriptive pieces, not research studies, 10 papers were excluded because they had incomplete records or presented their findings in a short conference abstract too brief to properly assess. We then categorised the papers according to sector. Seven studies excluded at full-text stage due to lack of relevance to the review question or duplication.

Included studies

Only 3 studies were identified as being relevant to this question. One of these was a comprehensive systematic review, which was also identified for the questions on effectiveness. Of the two included primary studies, one did not strictly meet our inclusion criteria on study design but was included due to the lack of evidence for this question. See Appendix A for more detailed information about inclusion criteria.

Table 5 Summary of included systematic review for the implementation question

Author	Sample	Review focus
Kime (2013)	16 systematic reviews and 13 individual studies	To address the questions: What models or components of models are effective in ensuring a successful transition process for young people with long-term conditions? What are the main barriers and facilitating factors in implementing a successful transition programme? What are the key issues for young people with long-term conditions and professionals involved during the transition?

Table 6 Summary of included individual studies for the implementation question

Author	Study	Implementation
Kingsnorth (2010)	Qualitative interviews with: 18 clinical and non-clinical staff	Evaluation based at two health centres in Toronto, Canada, which together

	from multiple disciplines, including medicine, OT, nursing, physiotherapy, managers and senior administration.	developed a model of care to support transition from children's to adults' rehabilitation services. This model of care, called the LIFEspan model, draws together three stages of care provision to help introduce more continuity into the care process; paediatric services, transfer services and adult services.
Sloper (2011)	Mixed methods design: Survey of 50 transition services Case Studies of 5 services. In depth interviews with managers and practitioners (N=130). Survey of 97 young people and 134 parents. 6 interviews with parents and young people.	Focus on transition services for disabled young people and their families. The included services provided a range of multi-agency transition services co-ordinating health, social care, education and other services. The study considered 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.

Narrative summary of the evidence

We found one systematic review which addressed our question about factors that help or hinder implementation of effective transition strategies and practice in children's and adult services. This review focused primarily on health care settings:

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

The findings of this review focused on existing barriers to the implementation of transition strategies and less on ways to facilitate implementation. Key themes around barriers to successful transition strategies were grouped into service and provider issues, parental issues and young person issues. This narrative summary draws on the findings concerning service and provider issues.

Drawing on nine previous reviews and individual studies this systematic review 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 of these sources highlighted poor communication between professionals and organisations (particularly communication between adult and paediatric devices) and a lack of collaborative and integrated working as major factors that hinder implementation. A strong concern raised by Kime et al (2013 +/++) is the significant difference between children's and adult care. Children's services are found to be more holistic, supportive and flexible while adult services expect more independence from patients, and professionals had larger caseloads and had therefore less time for patients.

Two individual studies were included:

- Sloper, P. 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 (+/++)
- Kingsnorth, S. et al (2010) Implementation of the LIFE span model of transition care for youth with childhood onset disabilities (++)

Sloper et al (2011 +/++) was a broad mixed-methods study with five different strands of research. The most relevant information for our question on implementation was under ‘reflections on experience of multi-agency transition services’ (p.61). These findings drew on a survey and series of in-depth interviews with practitioners and managers working in multi-disciplinary transition services in the UK. Overall, the study identified 5 factors that hinder implementation of multi-agency transition working: 1) Lack of partnership working 2) Lack of resources and funding 3) High levels of need 4) Lack of services 5) Lack of a distinct transition team.

Working well in partnership was most often identified as a facilitator to the multi-agency 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. Another concern was accountability in terms of people taking responsibility for their work and also a continuity of working across the project.

The study by Kingsnorth, S. et al (2010 ++) was a qualitative arm of a larger evaluation on the LIFEspan model, a well-documented approach to transition care. This approach involved the pairing of two health centres in Toronto, Canada to provide a linked model of care that draws together and co-locates paediatric, transition and adult services. The study used interviews with key professionals involved in the services to describe the factors which helped and hindered its implementation.

The study identified the following factors which contributed to the successful implementation of the LIFEspan model:

- Leadership
- Effective communication
- Organisational parity and equity between organisations in the partnership
- Compatibility - Both organisations shared mission statements, values and mandates and were located near one another

The study identified the following barriers to the implementation of the LIFEspan model:

- Policies and procedures, challenges associated with different policies and procedures in the organisations
- The information management systems at the joined organisations were not linked. Sharing patient information was described as a considerable challenge
- Building an expert team, problems with filling some of the roles needed in the partnership, notably the nurse practitioner role. This role needed extra training and so was not properly embedded in the service for some time.
- Turnover in the team affected team working
- Delineation of roles, in particular challenges in delineating between multidisciplinary working and interdisciplinary working.

All of the identified research primarily identified factors that hinder implementation of guidelines and models to support purposeful and planned

transitions from children's to adults' services. This provides challenges for writing evidence statements on what good practice look like.

Gaps in the evidence

It is clear from the lack of relevant studies to this question that there is considerable gaps in our research knowledge on factors that can facilitate implementation of transition policies and guidelines.

For this reason, several expert witnesses were invited to present on their experiences. APPENDIX D contains a full account of these. Referenced here are the expert witness accounts that addressed our question on implementation, organised by lead sector agency.

Education

- Julie Pointer, transition development manager, Surrey Short Breaks for Disabled Children

The new Education, Health and Care Plan, under the Children and Families Act 2014, is a promising way of supporting disabled young people preparing for adulthood.

Physical health

- Robert Carr, consultant haematologist at Guy's & St Thomas' Hospital Foundation Trust

This expert reported on their experiences of setting up a teenage and young adult multidisciplinary team for young patients with cancer, aged 16-24. They have found that the benefits of this service are difficult to quantify, but strongly supported by the experiences of their patients as well as colleagues in adult services. Funding is a concern for transition services, in spite numerous guidelines outlining transitional care as essential.

- Janet McDonagh, Senior Lecturer in Paediatric and Adolescent Rheumatology, University of Manchester

This expert emphasised how individual champions of transitional care are still important in the implementation of guidelines and practices and therefore need to be supported in this work. Unmet training needs across staff in children's and adult services is another factor that hinder implementation of existing guidelines.

- Peter Winocour, consultant physician, East and North Hertfordshire NHS Trust

This expert stated that one factor that supports implementation of transition guidelines is a single integrated database information system, and another is the use of the best practice tariff. He further stated that a fully resourced multi-disciplinary team appears critical to implementation, including a named worker to support transition care and the actual transfer of care. Local audits have shown that a major pressure point is after or at the time of transfer to adult services. There is anecdotal evidence that flexibility in transfer to young adult services helps the process. He further referred to a recent survey confirming a major challenge in the access to training.

Evidence statements

ES8	Factors that help the implementation of effective transition strategies and practice in children's and adult services One good quality systematic review (Kime et al, 2013, +/++) and two individual studies (one of good quality, Kingsnorth et al, 2010, ++; and, one of moderate quality, Sloper et al, 2011, +/++) found that clarity of roles, and clear communication between organisations, paired with strong leadership, contributed to the successful implementation of transition protocols and practice, and similarly that the lack of this can hinder it. The qualitative study (Kingsnorth et al, 2010, ++) further found that this was enhanced by an emphasis on equity between all organisations involved, and that this needed to be implemented in terms of all organisations being involved in hosting meetings, co-branding, shared accountability and mission statements. There is evidence from the survey (Sloper et al, 2011, +/++) that the involvement of young people and carers can help with implementation of transition strategies and approaches, and this study also suggested that there should be a dedicated transition team.
ES9	Factors that prevent the implementation of effective transition strategies and practice in children's and adult services There is evidence from one moderate quality study (Sloper et al, 2011, +/++) that the lack of joint funding streams and lack of services can hinder successful implementation of transition strategies. There is evidence from one good quality qualitative study (Kingsnorth et al, 2010,

	++) that barriers to implementation are different information sharing protocols across different agencies and sectors, lack of staff expertise in how to support transitions, high staff turnover and difficulties in establishing new roles when there is no previous experience. There is evidence from one moderate quality systematic review (Kime et al, 2013, +/++) that professionals in children's services may hinder young people's transition into adult services because they are concerned about the different culture and provision there.

3.4 Managing transitions for young people who receive a range of different services across health and social care

Review question

One question focused on the transition of young people using multiple services. The objective of this question was to consider how transition from children's to adults' services might be best supported for those using more than one type of service, for example those who use both health and social care services.

The review question was:

- How can the transition process (including preparing the young person, making the transfer and supporting them after the move) best be managed for those receiving a combination of different services?

Searching for studies

Electronic databases in the research fields of health, social care, and social science were searched using a range of controlled indexing and free-text search terms based on the population 'young people' and process 'transition'. No filter was used for study design, and one overall search was conducted to address all review questions. In addition, a range of websites of relevant organisations were searched too, for grey literature. The search captured both journal articles and other publications of empirical research. The search was restricted to studies published from 1995 onwards. A detailed description of the full search, including all search terms and sources, is provided in Appendix A.

Study inclusion criteria and selection

For this question we included studies conducted in the UK, Europe, Australia, New Zealand, the USA and Canada. We included any kind of study design as long as information was provided on the sample characteristics, data collection and analysis.

All studies identified as relevant to this question during the second screening were re-screened to identify duplicates and to consider each title and abstract in detail before ordering the full texts of all potentially relevant studies. In addition, studies coded to the views questions were also screened during this time, and all studies from that group which were coded to ‘multiple’ services were also considered for this question in case there were some evaluations which had been missed during the previous screen.

This meant that we had 42 studies of which 15 were excluded on the basis of their methods, one was forthcoming, four were duplicates and three were not relevant to this topic, leaving 19 studies for which full-text reports were ordered. Of these, full-text was missing for 9 of them and 3 were moved to be used for the questions about young people and carers' views. This meant that 7 studies were initially included for this question. A further study was added at a later stage when we screened our 'second opinion' studies, resulting in a total of 8 studies.

Included studies

The critical appraisal of studies relevant to this question was challenging as the concept of 'best' is not objective.. Some studies can shed light on whether particular models for managed transitions for this group result in changed transition-related outcomes. Arguably, studies asking about stakeholders’ views on service models they have experienced will also be relevant here, but a whole range of different studies were considered within this group. Some of these lacked a methods section and so we were not able to appraise them. Some of these were asking people across a very wide geographical area, and so it was not clear exactly what kinds of models they were providing views on. Furthermore, when our question can be addressed by different study designs,

this make it harder to rate the internal validity of these studies. See Appendix A for more detailed information about inclusion criteria.

It is worth noting that most of the 8 included studies did not measure outcomes, but collected qualitative evidence on aspects of services. Many of the studies focused primarily on education and education/employment concerns, but they were included due to their focus also being on the input from social care and/or health to the transition planning. The review team has been inclusive rather than exclusive in this regard. This highlights the difficulty in systematic reviewing of broad questions and in relation to a very broad population with multiple needs.

Table 7 Summary of systematic reviews included for the question about how to support transition for those using a combination of different services

Author	Sample	Review focus
Watson (2011)	19 papers covering 18 service models.	To review 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.
Marriott (2009)	23 papers	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.

Table 8 Summary of outcome evaluation included for the question about how to support transition for those using a combination of different services

Author	Sample	Population, intervention, outcomes
Certo (2003) USA	Evaluation tracking outcomes of young people who received a particular transition support model. It is not clear	Population: with learning disabilities, 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 three main services which are important to disabled young people with support needs: education, rehabilitation and developmental disabilities. Integration was

	whether this is a retrospective or prospective evaluation. Outcome information for 234 students enrolled in the programme during four academic years.	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. Outcomes: Continuity of care, employment rates after transition

Table 9 Summary of mixed methods studies included for the question about how to support transition for those using a combination of different services

Author	Aim	Design	Respondent groups
Beresford (2013) UK	The study focused on 5 research sites where multi-agency transition systems had been implemented, including specific services for young people with autistic spectrum conditions.	Mixed methods Cost analysis Qualitative interviews with 68 managers and practitioners. Survey of parents and young people across 5 sites Pre-transition parents=12.8% (105/818), Pre-transition young people = 6.8% (56/818), Post-transition parents = 25.2% (28/111), Post-transition young people = 16.9% (20/118) Qualitative interviews with 36 parents. Qualitative interviews with 20 young people.	Young people with Autistic spectrum conditions Parents Managers and practitioners.
Burgess (2007) UK	To outline the range of services offered by social work and related agencies and identify any	Mixed methods Quantitative and qualitative data from 78 case files Qualitative interviews	Care leavers Young people with mental health problems Social care practitioners Staff from partner

	particular models of intervention or common features within these which appear to have been successful in engaging and working effectively with young people.	with 19 young people Qualitative interviews with seven professional workers	agencies
Sloper (2011) UK	To research good practice in developing and implementing multi-agency transition services for people leaving children's services and entering into adult provision.	Mixed methods National survey to identify existing multi-agency transitions services. Interviews with 130 managers and staff at 5 case study sites Survey of young people and parents of young people. 143 parents and 97 young people completed questionnaires Qualitative interviews with a small sample of parents and young people in six families who had transferred to adult services Cost analysis of the multi-agency services	YP with long-term conditions YP disabled Social care practitioners Health care practitioners Carers/parents

Table 10 Summary of qualitative studies included for the question about how to support transition for those using a combination of different services

Author	Aim	Design	Respondent groups
Hamdani (2014) Canada	To elicit professionals' views on delivering LIFEspan, a model for delivering co-ordinated care throughout transition.	Qualitative study 14 practitioners	Interviews with health professionals working with young people in transition to adult services and who have a long-term condition
Noyes (2004)	How do students	Qualitative case	Disabled young people

USA	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?	studies of four students. Each case study included interviews with professionals, young people and their carers, and observations.	aged 23-25 Social care practitioners Adult services Carers/parents Teachers Point Of Transition Service Integration Project (POTSIP), providing early intervention, shared funding and regular interagency committee meetings to increase service integration during transition.

Narrative summary of the evidence

We identified two systematic reviews relevant to the question on how to best deliver services to young people who use a range of different services.

- Watson R, Parr J, Joyce C, May C, Le Couteur A (2011) Models of transitional care for young people with complex health needs: a scoping review. Child: care, health and development. 37: 780-791. (-/++)
- Marriott A, Townsley R, Ward L (2009) Access to independent advocacy: an evidence review. Office for Disability Issues, Great Britain. Norah Fry Research Centre, University of Bristol, UK. CLA Print. (+/++)

The review by Watson et al (2011 -/++) searched for studies on transition models for three conditions: cystic fibrosis, autistic spectrum conditions and diabetes. Of 18 identified transition models, 14 were for diabetes, 4 for cystic fibrosis and none for autistic spectrum conditions. The models were largely embedded within health and the papers were largely descriptive with little evaluative insight into the different models. The authors therefore used a particular type of analysis (using Normalization Process Theory as framework) to consider whether the models included aspects of service delivery.

The review by Marrott et al (2009 +/++) 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. The authors concluded that independent advocacy might help with young disabled people's self-development in terms of self-esteem and confidence. One study suggested that available options for adulthood are 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. Two studies suggested that independent advocacy can have an impact on employment outcomes for young people with disabilities.

We found one outcome evaluation relevant to our question:

- Certo N Mautz, D. Smalley, K. Wade, H. Luecking, Rich. Pum; (2003) Review and Discussion of a Model for Seamless Transition to Adulthood. Education and Training in Developmental Disabilities. 38: 3-17 (-/+)

This US study made efforts to track the outcomes for young people during four years of delivery of the Transition Service Integration Model (Certo 2003 -/++). This model secured joint funding across agencies which were described as ‘education’ and ‘rehabilitation and developmental disabilities’. The joint funding meant that the transition support could start at the beginning of young people’s last year in school during which they stayed with their existing services but receiving transition support in parallel, gradually moving into adult services. The aim was that once they left school and children’s services, they would already have been enrolled and settled into adult services, and there would be a work or educational placement ready for them to start immediately. The main outcome measure for this study was post-education employment or education and so this study is of limited relevance to our scope. It was included due to the multi-agency element of the intervention.

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 three 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 four 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.

We identified three studies which used a mixed methods approach to consider a whole range of questions related to how young people were transitioned into adult services:

- 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. Stirling: University of Stirling. (++/++)
- Beresford B, Moran, N. Sloper, T. Cusworth, L. Mitchell, W. Spi; (2013) Transition to adult services and adulthood for young people with autistic spectrum conditions (Working paper no DH 2525) (+/+)
- Sloper P, Beecham J, Clarke S, Franklin A, Moran N (2011) Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and Costs. University of York: Social Policy Research Unit. (+/++)

Burgess (2007 ++/++) conducted a mixed methods study of social services and other agencies' provision for children and young people with complex needs. They found that in the local area where the research was done, there was good communication between the main agencies which helped strengthen joint developmental and planning work. The different agencies shared aim and ethos of working in an integrated way with an agenda for improving services. Most of the staff interviewed said main strength of the work with young people was in the positive relationships they developed with them. Main gaps in services were in mental health.

The study by Sloper et al (2011 +/++) focused on transition for young disabled people with complex needs, and led to the second one by Beresford et al (2013 +/+) which focused specifically on transition for young people with autistic spectrum conditions, and with an additional emphasis on those with high functioning autism and Asperger's Syndrome. These two studies were similar in design, in that they conducted a combination of different interviews with stakeholders across five transition services (research sites). Some of the areas were the same for both studies, and some differed.

Sloper et al (2011 +/++) reported high levels of unmet needs in their sample, and it can be concluded from their study that transition for young people using a combination of different services can best be managed by addressing these needs by providing:

- Information about the transition process in multiple formats
- Support for young people to participate in leisure and social life
- Help with benefits and finances in the preparation for transition
- Help with future housing options
- Help with planning for future education and employment
- Training for independent living skills
- Focus on young people's developing sexuality
- Overall help with planning for the future.

It is worth noting that in terms of housing and benefits, there were reports that this can be a particularly tricky concern for families where an important part of their income is related to caring responsibilities and housing of the young person, which would then reduce if the young person was to move into an independent living scheme or other housing.

Beresford et al (2013) found that young people with high functioning autism or Asperger's Syndrome often fell through service gaps during transition, often because they were not eligible for adult services at the time of transition. The study queried why mental health support was also often discontinued during this period, when the stresses of change and uncertainty was likely to increase rather than reduce their needs for mental health support.

Practitioners argued that this group would only need a very low-level of support to improve their situation considerably. This study also found that there was a need for services to provide help with planning for education and employment, and that there was a lack of understanding of autistic spectrum conditions in many services. High levels of unmet needs were again found in terms of information, and both young people and practitioners emphasised the usefulness of experiential information (visits and meetings).

We found two qualitative studies relevant to this question:

- Hamdani Y Proulx, M. Kingsnorth, S. Lindsay, S. Maxwell, J. (2014) The LIFEspan model of transitional rehabilitative care for youth with disabilities: healthcare professionals' perspectives on service delivery. Journal of pediatric rehabilitation medicine. 7: 79-91 (++)
- Noyes D Sax, C; (2004) Changing Systems for Transition: Students, Families, and Professionals Working Together. Education and Training in Developmental Disabilities. 39: 35-44 (-)

Hamdan et al (2014) collected professionals' views on the LIFEspan model which introduces transition when young people are aged 16, and works across paediatric and adult hospitals to co-ordinate the transition. The LIFEspan model centred on preparation for transition rather than describing how to co-ordinate transition support across several services. This model was also based on a step-by-step approach to transition, where the preparation included both young people and their parents, and focused on self-management and condition-knowledge as well as preparing for the change in service provision. The professionals spoke about the problems concerning confidentiality and information sharing, and the problems with not having a shared information system. Although they tried had to collaborate with colleagues in social care and education, there continued to be barriers to this.

Noyes et al (2004 -) compiled case studies of four young people who had received integrated transition support from the Point of Transition Service Integration Project POTSIP), which provided early intervention from shared funding streams and regular interagency committee meetings during

transition. This study focused on how this model was experienced by all stakeholders.

The POTSIP model was similar to the Transition Service Integration Model evaluated by Certo (2003) and described above. This study also concluded that it was good to plan that young people would be settled in adult services by the time they left school, and that this was instigated at the beginning of their last year in school and implemented gradually throughout. The shared funding helped young people participate in more activities, and the employment support was highly valued. At the same time, there were still problems with collaboration across agencies and the absence of one overall plan holding all information in regards to a young person's long-term goals and hopes for the future.

Gaps in the evidence

This question about those receiving a combination of different services primarily relate to young people with disabilities, who are receiving social care, specialist health care, and are in special education. Considering the limitations of the research evidence identified, we put this question to one of our expert witnesses.

- Julie Pointer, transition development manager, Surrey Short Breaks for Disabled Children

This expert witness emphasised the importance of a person centred approach, with co-ordination between all relevant services. This is supported by the Code of Practice deriving from the SEND reforms under the Children and Families Act 2014. The preparing for adulthood section of the code (section 8) talks about how this should happen, starting with a person centred transition review from year 9. The Code is very much focussed on outcomes for young people that support them to think about what is positive and possible for their futures. The key life outcomes for young people with SEND are:

- Employment

- Somewhere to live
- Friends, relationships and being part of your community
- Good health

Each local area has a legal responsibility to publish a Local Offer laying out what support and services are available for young people with SEND and in particular with an emphasis on inclusion and allowing young people to lead ordinary lives.

It is important that local areas consider information captured in individual young people's plans can influence their local commissioning strategy.

Evidence statements

ES no.	Evidence Statement
ES10	Paucity of research into the provision of transition support for people supported by a combination of services Overall, there is a need for further research to understand how best to provide transition support for those receiving a combination of different services. We have found six studies which are very different in design and focus, and none of which directly address our question.
ES11	Planning support for young people support by a combination of services There is evidence from three moderate quality mixed methods studies (Beresford et al, 2013, +, Burgess, 2007, +/+, Sloper et al, 2011, +) and one good quality qualitative study (Hamdani et al, 2014, ++) that person-centred planning can be a good way of managing the transition into adult services for those using a combination of different services.
ES12	YP with learning difficulties supported by a combination of services There is evidence from one poor quality US evaluation (Certo et al, 2003, -/+) and one qualitative case study (Noyes et al, 2004, -/++), that for young people with learning disabilities transition planning should be jointly funded across sectors (mental health, social care and education), that the planning should start at the beginning of young people's last year in school/college, with gradual transfer to adult services, and have an emphasis on providing young people with employment or further education immediately after leaving school. Elements of these recommendations are supported by other studies, with two moderate quality mixed methods studies (Beresford et al, 2013, +, Sloper et al, 2011, +) supporting the emphasis on long-term planning when transitioning young people with disabilities or high functioning autism or Asperger's Syndrome, and in particular in relation to education and employment. Findings from one good quality qualitative study (Hamdani et al, 2014, ++/++) also supported joint funding arrangements across sectors and institutions, and the early start for planning the transfer into adult services.
ES13	Information at point of transition There is evidence from two good quality mixed methods studies

	(Beresford et al, 2014, +, Sloper et al 2011, +), that young people who receive multi-agency transition support need good quality information, and that this should be provided in different formats, including experiential information where young people can visit potential services or meet providers. These two studies also found that financial advice should be considered as part of the pre-transition training, and for some families transition could coincide with a loss in income from benefits.
ES14	Remit of transition support There is evidence from two good quality mixed methods studies (Beresford et al, 2014, +, Sloper et al, 2011, +) that transition support for young people using a combination of different services should go beyond service transition and include considerations of developmental transitions and participation in social life, such as relationships and leisure activities. This might include, for example, facilitating social interaction with other young people undergoing similar experiences, given that there is evidence from one good quality mixed methods study (Beresford et al, 2014, +) that for high-functioning young people small levels of support can make a big difference (for example opportunities to meet others with the same condition).
ES15	Support for young people who do not meet criteria for adult services There is evidence from one good quality mixed methods study (Beresford et al, 2014, +) that community mental health services are important during transition for young people transitioning out of children's services who do not meet the eligibility criteria for adult services.

3.5 Young people and their carers' views and experiences

Review questions

Two review questions asked about young people and their carers' experiences of transitions, and in particular what works well in terms of support during this period.

The two review questions were:

- What are young people's experiences of transitions? What works well?
- What are the experiences of families and carers and in respect of young people's transitions? What works well?

Searching for studies

Electronic databases in the research fields of health, social care, and social science were searched using a range of controlled indexing and free-text

search terms based on the population 'young people' and process 'transition'. No filter was used for study design, and one overall search was conducted to address all review questions. In addition, a range of websites of relevant organisations were searched too, for grey literature. The search captured both journal articles and other publications of empirical research. The search was restricted to studies published from 1995 onwards. A detailed description of the full search, including all search terms and sources, is provided in Appendix A.

Study inclusion criteria and selection

After the 2nd screening of studies, 462 records had been coded to the ‘views’ category, although not all individual studies. For this category we had already stipulated in the protocol that we would only include UK studies and this reduced the number considerably. In addition, we decided to only include studies published in 2006 and after. We felt that this was a suitable cut-off point due a number of relevant policy documents published around that time, including the National Service Framework for Children (2004) and the Care Matters Green Paper (2006). Importantly, this cut-off year helped us navigate among a large number of studies.

For the studies on young people transitioning in health care settings we identified two recent high quality reviews by Fegran et al (2014 ++/++) and Betz et al (2013 ++/+) which aligned well with our own review questions. We therefore included individual studies published after the review by Fegran et al (2014) and we found 6.

We found one recent and good quality systematic review on the views and experiences of care leavers (Hiles et al 2014 +/++), which was complemented by three individual studies. We found 9 studies on the views and experiences of young people with learning difficulties and their families, and 3 studies on young people’s views on transitioning from child and adolescent mental health services to adult mental health services.

The studies included to these questions were mainly qualitative studies of experiences and views across a range of sectors from education to health and

social care; different personal backgrounds of young people and families and various ages. Some were mixed-methods studies in which the views were collected qualitatively and in response to a sub-objective.

Included studies

A total of 24 studies were included that captures people's views on transition. These were primarily reviewed in terms of what people had experienced as working well, and what has not worked well. Considering the large amount of studies for this question, we have grouped them by sector and conditions or situation, and only individual studies are presented in the tables. See Appendix A for more detailed information about inclusion criteria.

Included studies conducted within a physical health care setting (N=8)

Two systematic reviews were found:

Betz et al (2013) Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. Nursing Outlook

Fegran et al (2014) Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. Int J Nurs Studies

These were updated with individual studies published at a later date. These individual studies are organised by the condition in focus:

Table 11: views studies - diabetes (N=2)

Allen (2011) UK	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.	Qualitative study Longitudinal (3 time points over 18 months), part of a larger-scale evaluation of transition services.	Young people with diabetes aged 14-22 and their carers/parents, across five different services, 23 young women, 23 young men, 39 mothers
Price (2011) UK	To evaluate the 'Transition Pathway'	Qualitative study Semi-structured interviews will 11	11 young people aged 16-18, with diabetes.

		individuals.	

Table 12: views studies - cystic fibrosis:

Tierney (2013) UK	To explore the experiences of transition from children's to adults' services among young people with cystic fibrosis.	Qualitative study Semi-structured interviews with 19 individuals.	19 young people with cystic fibrosis, aged 17-19, transitioned within 12 months of the interview taking place.

Table 13: Views studies – epilepsy:

Lewis (2013) UK	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' (p.3)	Qualitative comparative embedded case study.	30 young people with epilepsy aged 14-19. 28 parents were interviewed.

Table 14: Views studies – life-limiting conditions:

Beresford (2014) UK	To gather the experience of transition into adult services for young people with life-limiting conditions, and from the point of view of young people, their parents and professionals.	Qualitative study In-depth interviews across six case studies which all represented condition-specific pathways into adult care.	Young people aged 18-25 with conditions diagnosed in childhood: Congenital and acquired neurological conditions, Duchenne muscular dystrophy, cystic fibrosis, renal disease Health care practitioners Carers/parents
Kirk (2013) UK	To examine how young people with life-limiting conditions and their parents	Qualitative study In-depth/ rich study with participants in one hospice setting,	16 young people aged between 16 and 31 with life-limiting

	experience transition. To identify families' and hospice staff's perceptions of family support needs during transition. To identify the implications for children's hospices.	not clear from the reporting whether N was 39 or 35. Sample of young people were not at end-of-life stage and represented a range of health conditions.	conditions. 16 parents speaking on behalf of their children. Seven members of staff.

Included studies conducted within a mental health care setting (N=3)

The studies which had researched the experiences of young people with mental health care needs included one study which did not focus on any particular condition (Singh et al 2010), one focusing on those with acute mental health care needs (Day et al 2007), and one focusing on young people with ADHD (Swift et al 2013). Due to the small number of studies within 'mental health' we have not organised the table further.

Table 15: Views studies - mental health

Day (2007) UK	To examine transition arrangements for young people with acute mental health problems.	Qualitative case study This study used a variety of data collection methods, including a focus group with three young women and interviews with young people, parents, key workers and GPs.	13 young people with acute mental health problems aged 15-20 years: self- harm, depression, schizophrenia, OCD, ADHD, autism, eating disorder and post- traumatic stress disorder.
Singh (2010) UK	To identify factors that facilitate or impede effective transition of patients from CAMHS to adult services	Mixed methods study This review drew on their qualitative interviews with young people and carers/parents	YP with mental health problems (N=11) and parents/carers (N=6)
Swift et al (2013) UK	To explore the transition experiences of young people with ADHD	Qualitative study Semi-structured interviews with young people diagnosed with ADHD and accessing CAMHS clinics.	10 young people with ADHD aged 17-18 years

Included studies conducted with care leavers N=4

We identified 4 studies which had explored care leavers' views on transitioning out of care, including one systematic review:

Hiles et al (2013) Young people's experience of social support during the process of leaving care: a review of the literature. Ch & Youth Serv Rev

We included 3 individual studies, presented in the table below.

Table 16: Views studies - care leavers

Barn (2006) UK	To look at the post-care experiences of young people from different minority ethnic backgrounds, including white care leavers.	Mixed methods a) a demographic profile questionnaire b) semi-structured interview and a focus group c) Semi-structured interviews	261 care leavers from a range of ethnic backgrounds as well as from the white population 13 managers and workers in local authority Leaving Care Teams
Hiles (2014) UK	To highlight the experiences of care leavers in transition, and the support available.	Qualitative study This pilot study and includes the views of care leavers and professionals drawn from separate focus groups.	Six care leavers aged 16-22 Four health and social care practitioners
Munro (2012) UK	To evaluate the impact of the Staying Put pilots and promoting positive outcomes for young people making the transition from care to independence.	Mixed methods study Focus on this review is on the face-to-face interviews, telephone interviews, focus groups with care leavers and foster carers	32 care leavers 31 foster carers

Included studies conducted with young people with learning disabilities or their parents or carers (N=9)

We identified 9 individual studies which focused on transition from children to adult services for young people with learning disabilities, from the perspectives of young people, their parents, or carers.

Table 17: Views studies - learning disabilities

Beresford (2013) UK	To investigate the role of multiagency transition services for young people with autistic spectrum conditions, to explore young people's and their parents' views of services, to explore costs and outcomes of the transition process, and to identify areas of good practice (what works, what does not work).	Mixed methods The study focused on five research sites with multi-agency transition systems. In four sites qualitative interviews were carried out with young people with autistic spectrum conditions and, separately, their parents. In each site, a survey of families was conducted.	Young people with high functioning autism or Asperger's syndrome aged 18-24 (N=20). Parents (N=36). Pre-transition parents = 12.8% (105/818), Pre-transition young people = 6.8% (56/818), Post-transition parents = 25.2% (28/111),
Bhaumik (2011) UK	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.	Mixed methods Combination of survey and in-depth interviews.	Young people with learning disabilities aged 16-19 years. Carers/parents. Survey (N=79) Interviews (N=24)
Broadhurst (2012) UK	To evaluate the 'My Way', approach to transition. My Way is personalised and community-based. Users of services seen as having skills, resources and the capacity to support each other.	Qualitative study Two year study Interviews with young disabled people, families, professionals and facilitators of MY Way.	Young people with long-term conditions, learning disabilities, or care leavers. (N=75)
Children's Workforce Development Council (2010) UK	To identify progress from the 'Aiming High for Disabled Children' initiative. This was a government guidance for disabled children's services in England. The study included transition experiences of young people and their carers.	This report describes the core competencies expected of professionals working with children and young people.	9 disabled young people Social care practitioners Carers/parents
Cowen (2010)	To describe	Local report	Young people

UK	Personalised Transition, which is a new way (at time of publication) of organising support for young disabled people and their families.	This report describes personalised Transition.	with complex needs Social care practitioners Health care practitioners Education professionals
Heslop (2007) UK	To explore the views of parents of young people with learning disabilities, regarding what factors contribute 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 background.	Qualitative study The study involved a mix of interviews with young people, parents and professionals in five local authority sites.	13 young people with learning disabilities. 27 Social care practitioners. 16 carers/parents
Kelly (2013) UK	To explore the transitional and early adult life experiences of young adults with learning disabilities. The study is based on a follow up study of ten young adults who were involved in research examining the family support needs of disabled children and their families ten years earlier.	Qualitative study Semi-structured interviews	10 Young people with learning disabilities aged 18-21 Key workers (all of whom were social workers) Transition co-ordinators, team leaders and senior managers Carers/parents
Milner (2008) UK	To investigate and collate experiences of transition from children's to adults' health services, for young people who have both learning difficulties and complex health needs.	Audit of the experiences of 21 young people in Northumberland.	21 young people with learning difficulties and complex needs in transition or after transition.
Newman (2009) UK	To explore the transition experiences of 49 young people with various support needs moving from secondary school to	Qualitative study A variety of media (including videos and photo diaries), as well as suitably adapted questions, was used	49 YP aged 14-25 with learning disabilities with multiple service needs.

	adult services.	to enable young people to take part.	
Pilnick (2011) UK	To examine how the process of transition from child to adult services is managed for young people with learning disabilities, when parents' or carers' views differ from young people's views.	Qualitative study Analysis of tape-recorded meetings (N=8)	28 young people with learning disabilities aged 18-19. Transition Co-ordinators. Carers/parents. Teachers. Connexions workers Personal Advisers.

Included studies conducted with young people with physical disabilities - within a social care and health care setting (N=1)

We found one study which had focused on the health and social care transitions of young men with Muscular Dystrophy.

Table 18 Views studies - physical disabilities

Author	Study aim	Methodology	Participants
Abbott (2009) UK	To investigate how the health and well-being of young men living with Duchenne Muscular Dystrophy, and that of their parents, can be maximised, particularly at the transition to adulthood. To consider the potential contribution of the National Service Framework for Long Term Neurological Conditions for this group of people (p.5)	A postal survey of parents with a son with DMD aged 15+ living in the South West, the West Midlands and the North East of England. Face to face interviews with 40 young men and their parents and siblings about growing older with DMD and the issues they faced at transition (p.5)	Young men with Duchenne Muscular Dystrophy Postal survey to 121 parents, 38 responses (32%). Face-to-face interviews with 40 families (95 individuals) Views and Experiences - Professionals

Narrative summary of the evidence

Findings generally support anecdotal evidence and what we already know from practice reports and policy concerns. An overwhelming message is that

information needs are pressing across all sectors, alongside guidance and support. Role confusion in terms of understanding who is responsible for orchestrating transition was also alluded to frequently. It is striking how similar young people's concerns are, across settings and across conditions. Overarching themes are: better involvement of parents, gradual move towards independence, active involvement in own care, personalised approach to transition and good quality information throughout.

Considering the large number of studies included for these questions, and the narrative nature of them, we have organised them according to the young people's main basis for needing a service, and also by the setting in which the study was conducted.

Transition for young people in health care settings

A number of studies considered the experiences of young people in healthcare settings, across a whole range of conditions. Initially, before selecting UK studies only, there were around 200 studies in this category. Although some were duplicates and many were conference abstracts only, it indicates a high level of interest in this area. It is worth noting that the forthcoming Cochrane review on transitions in healthcare settings will also synthesise studies on young people's experiences and views. Presented first are two reviews (Betz et al 2013 ++/+, Fegran et al 2014 ++/++) followed by six studies published after the search of the most recent review (Price et al 2011 +, Allen et al 2011 +, Lewis and Noyes 2013 +, Kirk et al 2013 ++, Beresford et al 2014 +, Tierney et al 2013 ++). These six individual studies are organised by condition: diabetes, epilepsy, life-limiting conditions and cystic fibrosis. Finally, three studies are presented that looked at the experiences of young people transitioning from CAMHS to AMHS (Day et al 2007 +, Singh et al 2010 ++, Swift et al 2013 ++).

- Betz et al (2013) Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. Nursing Outlook 61: 311-336 (Internal validity ++, external validity +)
- Fegran et al (2014) Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis.

International Journal of Nursing Studies 51: 123-135 (Internal validity ++, external validity ++)

The review by Betz et al (2013 ++/+) was conducted in the USA. Their objective was to (from abstract) “evaluate the research on health care transition for AEA-SHCNs [adolescents and emerging adults with special health care needs] from their perspectives”. They identified 34 studies from across a whole range of countries: Europe, USA, Canada, Australia and Hong Kong. The overall message from these studies was that young people want to be included in the process of transition planning, that they value good quality relationships with health providers, and that they would like the process to be personalised to suit their needs. Overwhelmingly, young people said that they had not received information about the transfer and therefore did not know what to expect after the transfer.

The review by Fegran et al (2014 ++/++) was conducted in Scandinavia (Norway and Denmark). Their objective was to (from abstract) “synthesize qualitative studies of how adolescents and young adults with chronic diseases experience the transition from paediatric to adult hospital care”. They identified 18 studies from Europe, USA, Canada and Australia. This review organised findings into four emerging themes: relationships, culture, transfer process and independence. The ‘relationships’ theme reflected the importance of relationships between health providers, young people and their families, and how these changed during transition. ‘Culture’ refers to the change in culture in the adult settings and how young people were unprepared for this. ‘Transfer process’ refers to the transition process, that this must include proper preparation and the transfer itself should be timed to when people are ready rather than being age-bound. ‘Independence’ related to the increased responsibility young people were given during the transition process, the changing role of parents and the fact that many young people were happy to transition out of paediatrics and felt that the paediatric clinic was increasingly becoming an inappropriate setting for them.

- Price et al (2011) Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with

diabetes. Child: care, health & development 37(6): 852-860 (Internal validity +)

- Allen et al (2011) Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service. Diabetic Medicine 28: 994-1000 (Internal validity +, Relevance to this guideline: Highly relevant)

Price et al (2011) conducted interviews with 11 young people in the context of a 'transition pathway', which is a transition model aimed at diabetes patients. Some of the young people were interviewed before the transition clinic was implemented and some were transitioned using the specialist clinic.

Young people in the interviews commented particularly on healthcare consultation and how this was conducted. Some young people seemed to feel like they were being lectured about their lifestyles and condition. This made them want to disengage with services. Others felt like their relationships with professionals post transition had improved. Young people liked to developed collaborative relations and valued quality and consistency in their interactions with staff.

The two themes that the authors felt were 'super-ordinate' in their findings were appropriate adolescent care and recognising the individuality of healthcare. The first of these themes was developed around the view that young people do not want to be treated like children, the interviewees said that they wanted be partners in their own care. Young people wanted control about how their appointments were conducted and be able to build relationships with professionals. Interviewees commented that services should be flexible about transition age. Young people commented that they felt that they should be allowed to choose when transition felt appropriate for them. Some said that they felt ready when they were 16 and under and others still did not feel ready at 18.

Allen et al (2011) interviewed 39 parents as well as young people. The study found that despite young people sometimes taking the lead in their care following transition, parents often still remained involved and supported decision making and condition management. Some clinics encouraged young

people to attend appointments alone and many young people chose this option over joint consultations, but when parents had the choice they preferred to attend appointments. The parents interviewed said that they would like to remain informed about their children's conditions because they were still involved in their care at home. Some clinics offered support to parents for their own needs via a specialist nurse who worked across paediatric and adult care.

- Lewis and Noyes (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. BMC Pediatrics 13: 169 (Internal validity +, Relevance to this guideline: Highly relevant)

This was a qualitative case study about the care of young people with epilepsy, interviewing 30 young people and 28 parents.

A key finding from the study was that young people wanted clear information about their conditions, without medical jargon. Young people wanted to transition to adult services and gain more control but also to have things explained adequately. There was a group of interviewees who had believed that they would grow out of their epilepsy and had not been prepared for the news that they would not. Other professed to limited knowledge of their condition. Some young people said that throughout transition they met with a variety of professionals and were given conflicting information about their conditions which was confusing. Some found that as they learned more about their epilepsy the more they were able to self-manage, adapting their lifestyles and gaining independence.

Young people said that they lacked the confidence to ask the right questions about their conditions, especially if their parents were not there, and some still allowed their parents to ask the questions. Some young people felt abandoned by adult services due to the differences in cultures between adult and children's services. Good relationships with clinicians was felt to aid

transition because they could foster confidence in the young people if they liked and respected their clinician.

Strongly linked to relationships with clinicians was the theme of engagement with services. Some of the young people interviewed had become disengaged with services, often due to poor first impressions of adult services and clinical staff. Some of the young people who were no longer attending services had had good relationships with staff in children's services and so felt disillusioned with how clinics were run in adult services. Those who had ongoing engagement with adult services said they had a good relationships with their clinician. These positive relationships helped young people to self-manage and deal with the social stigma attached to epilepsy.

As with other studies, parental involvement in transition was a key issue for the young people interviewed. Some young people were happy to take on full responsibility for their condition and others wanted to keep their parents involved throughout and after transition, for support and to help them get the right information.

- Kirk and Fraser (2013) Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study. Palliative Medicine 28(4): 342-352 (Internal validity ++, Relevance to this guideline: Highly relevant)
- Beresford et al (2014) Supporting health transitions for young people with life-limiting conditions: researching positive practice (The STEPP project). York: Social Policy Support Unit (Internal validity +, Relevance to this guideline: Highly relevant)

These studies both conducted qualitative interviews with young people and their parents. In both studies parents and young people both describe a sense of frustration about a lack of adult services and a lack of information about what support will be available following transition.

Kirk and Fraser (2013) found that young people and parents had received little information about what transition to adult's services would involve. Young people and parents said they felt abandoned as no one took control of their

transitions process. Interviewees reported having little or no information about the nature of adult's services for their children. Some parents felt that because of the life limiting nature of their child's conditions there was a lack of will from adult services to invest much time.

Parents reported that in some cases the services they had been using did not carry on into adult care, their child was discharged from several clinics and there was no clear support package in place. Parents reported a lack of support for them and no knowledge about whether services for their families like sibling services, respite and family breaks would still be available following transition.

Many of the comments are positive and young people appreciated having more autonomy over their cases without their parents present. Young people also commented that they received some emotional support related to their conditions as they entered adult care, which helped them come to terms with their conditions. Some parents were happy to allow their children to take over their own engagement with services (the adult hospice was a parent free zone) but some parents expressed anxiety about what would happen with end of life care following transition and whether they would be involved.

Similarly, Beresford et al (2014) found that young people and parents were frustrated about a lack of specialised services and professionals in adult services. Parents felt excluded by adult services despite being experts in their children's care. Adult services were seen as different in culture and practice and young people and their families did not feel prepared for the changes post transition. This study found the following to be helpful during transition: Preparation in paediatrics, including active involvement in consultations and teenage transition clinics, visits to the adult service, opportunities to meet adult services staff, information, especially in regards to differences in practice and procedures, young people having a choice about parental involvement, and all staff being made aware of young people's transition status.

- Tierney et al (2013) Liminality and transfer to adult services: A qualitative investigation involving young people with cystic fibrosis. International

Journal of Nursing Studies 50: 738-747 (Internal validity ++, Relevance to this guideline: Highly relevant)

This study spoke to young people who had undergone transition into an adult clinic not co-located with the children's service and which did not have an adolescent clinic.

Young people said that their staff in children's services had started to prepare them for transition. Some criticised how their emotional needs were not addressed, and they had found leaving children's service to be traumatic. Others felt the process was too gradual and they were left on hold waiting to enter the adult's clinic. Some young people commented that at transition age they began to take their CF more seriously and prepared to take responsibility.

Young people appreciated meeting staff from the adult's service and seeing pictures of the adult facility. As with many of the studies in this category, young people differed on the level of parental involvement they wished to maintain. Some were happy to speak to the doctor themselves, others found their new responsibility overwhelming and wanted to have parents present. Some parents came along to ask questions during the transition phase, which some young people found helpful.

Most of the young people said that once they had got used to the adults service they were OK with it. Many had their first experiences as an inpatient on the adult ward and most commented that they felt that it was the correct setting for them.

- 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)

This was an investigation into transition arrangements for young people with acute mental health problems, from children's to adults' services, including the views of young people and their families. The focus here is on their findings in regards to young people, which were elicited in focus groups with 13 young

people. The findings of the study were not presented in a great deal of detail, but some broad themes were identified.

There was a diversity of views in terms of the timing of the transfer, and whether adult services were appropriate for young people at that point in time. Some young people felt that they were ready to move into adult services because they felt patronised by children's services and wanted to be spoken to as adults and feel more independent: "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). Others were apprehensive about their transition and felt intimated by adult services: "I just feel slightly intimidated because I don't really understand it and also because there's some really unwell people in the CMHT service day service and I feel a bit frightened" (p149). There was consensus that transition timing need to be tailored to the needs of the young people and be "planned, gradual and flexible" (p151) because young people will feel ready to transition at different ages.

Some young people felt that adult services were more efficient in solving problems. GPs were seen as a potential resource during transition, in an advocacy role: "It was my GP who actually got it for us because my GPs 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).

The issue of parental support also emerged. Young people commented that parents could be kept informed through separate meeting or progress reports.

- Singh S, Paul M, Islam Z, Weaver T. (2010) Transition from CAMHS to Adult Mental Health Services (TRACK): A Study of Service Organisation, Policies, Process and User and Carer Perspectives. (Internal Validity ++ Relevance to this guideline - Highly relevant)

The aim of this study was to identify levers and barriers to transition from CAMHS to AMHS. It was a mixed methods study which included qualitative interviews with young people and carers. The overall findings from this study

will be revisited for question 3 on factors that help or hinder purposeful and planned transitions.

The view of young people and their families are striking in that they display the diversity of transition experiences and that different young people value different things from CAHMS or AMHS services.

The study identified several ‘optimal transition cases’, cases which were thought to be good examples of transition. These cases included; one transition planning meeting, a period of parallel care, good information transfer and engagement or discharge 3 months after transition. These cases were identified using a case note audit. Young people who experienced a smooth transition, well-orchestrated by professionals, met their new AMHS workers ahead of the move and received good information from their CAMHS workers. These young people still expressed anxiety about the move, but seem to have been prepared: “‘I was told about the transfer and I would be meeting the new care co-ordinator and the transfer would happen slowly…they explained how different it would be...” (p138). It is important to note that accounts by young people and their families did indicate that even these good examples of transition were not clear cut. Processes were complicated by relationships with key workers, parental involvement, personal issues such as pregnancy and housing problems and inconsistencies in service.

Some of the interviewees were transferred soon after entering CAMHS services, for these young people transition was a more rushed process: “… I hadn’t been seeing her for that long…she couldn’t really do much with me because I’m going to be seventeen soon” (p139). However, two these interviewees did report that they met their AHMS worker once before the move.

The most negative experiences were for those who were told at their last CAMHS meeting, or following this meeting about the move to AMHS. This was felt to be a sudden transition which lacked adequate preparation or information: “‘was just all of a sudden…I didn’t really like it” (p139).

A central theme in this study was the role of parents. Levels of parental involvement varied among interviewees. Most parents were less involved following transition or not involved at all. Some young people appreciated this and others felt unsupported. Some parents had good relationships with staff and others would have liked a point of contact to stay informed. Generally, those who did not engage with AHMS following transition had less parental involvement.

Social support was another theme. Two people felt that there was too much emphasis on medication in AMHS services and not enough psychological support and several young people who had gone through transition had stopped taking their medication. The interviewees tended to have a positive relationship with their key workers or felt neutral towards them. The young people whose worker had been changed did sometimes not know who their key worker was.

- Swift, K. Hall, C. Marimuttu, V. Redstone, L. Sayal, K. Hollis, C. (2013) Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): a qualitative analysis of their experiences (Internal validity ++ Relevance to this guideline: Highly relevant)

This study explored the transition experiences of young people with ADHD. The study isolated four themes from semi structured interviews carried out with 10 young people and their parents: Clinician qualities and relationship, responsibility for care, the nature and severity of conditions and expectations of adult care.

Clinician relationships appears to be a key theme throughout the literature on transitions. Young people and parents in this study said that their relationships with clinicians were key to the success of their transition experience, how they engaged with services following transition and their views more generally about their experiences. Young people appreciated clinicians who were supportive and informative, non-judgemental and listened. The interviewees criticised changes to their clinical team and a lack of support when they

entered AHMS. Both young people and parents liked workers who seemed invested in their cases and were prepared to “go the extra mile” (p5) for them.

The role of parents is another recurring theme in the transition literature, and this study found that young people were often not responsible for their own care, even after transition. Parents commented that they still had to support their children in daily activities. Parents were frustrated by adult services, since they tended not to see that this situation was appropriate for the child, given their needs. Some young people felt dumped into adult services and had experienced several changes to their key clinician. Parents said the transition process would be improved if they a) met the new clinician in advance, b) were given a written overview of the transition process, and c) saw the same clinician consistently after transfer.

Many of the young people and parents felt that adult services were not suitable for them due to the nature of the ADHD condition. Some felt that their ADHD was too severe for them to be appropriately moved to adult services. Others worried that they would lose eligibility for services in a AHMS because their ADHD was not severe enough.

Young people and families wanted to know what to expect from adult services. They wanted to be reassured that services would be consistent. Some people felt that they had unrealistic expectations of adult services ahead of transition and would have benefitted from more information about the change of culture and the nature of services. Some families wanted to know if they would still be eligible for services in AMHS and what would happen if services were going to stop.

Transition for care leavers

The four studies included on the views of young people leaving care, and their families, included one good quality and recent systematic review (Hiles et al 2014, +/++). One study evaluated the ‘Staying Put’ transition programme which gave young people the opportunity to stay on in their placements beyond their 18th birthday (Munro et al 2012, ++). Another study compared minority ethnic young people’s experiences with that of their white peers (Barn

et al 2006, ++). The fourth study reported on a focus group with young people about their leaving care experiences (Hiles et al 2014, ++). The four studies are summarised below, in regards to their findings on young people and families' experiences and views on what works well.

- Hiles et al (2013) Young people's experience of social support during the process of leaving care: a review of the literature. Children and Youth Services Review. 35(12): 2059-2071. (Internal validity +, External validity ++)

The aim of this review was to collate and synthesise research relating to young people's experiences of social support during their transition from care. The included studies highlighted the vital role of social support for young people during their transition from care. This included an earlier phase of the 'Staying Put' evaluation, which means this was represented both in this review, and in our own sample (Munro et al 2011 and 2012).

Overall, this review found that young people were wary of building new relationships and this affected their transition. Conversely, those who had a history of stable placement(s) whilst in care, as well as a later and more gradual transition to leaving, often managed transition well. Some care leavers said they had nobody to talk to at all, or had to deal with many professionals and were therefore not clear about different roles. Mentoring relationship were also valued by care leavers, especially because of the emotional and appraisal function. 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. Whilst many found that changed circumstances over the years led to improved relationships upon leaving care, others found the opposite.

There was an overwhelming need for practical support (such as getting furniture, and sorting out bills), together with emotional support, and finding accommodation. Those who might be considered amongst the most vulnerable (for example with mental health, emotional or behavioural difficulties) were more likely to experience both homelessness and multiple

moves before, during and after transition out of care. As far as support to access education and employment, in the UK context, some described receiving considerable help from professionals within the leaving care service, others did not. Many care leavers said money was the most significant day-to-day issue and budgeting skills were lacking. In the UK context, care leavers mentioned large regional differences in the levels of financial support given to them by the local authority.

In the UK context many young people thought they were not being listened to in the planning meetings and thought that the 'Pathway Plan' was completely ignored. Young people want more control over the timing of leaving care, and that this should happen gradually. Care leavers often spoke of the burden of having to adjust to an overwhelming amount of responsibility, without some sort of safety net that allowed them room to learn from mistakes. While allowing 16–18 year olds to leave and return (Munro et al., 2011), was perceived as positive, in reality the scarcity of foster placements meant it was unlikely for someone to return to the same placement. Furthermore, a number of people who wanted to return after the age of 18 were prevented from doing so, thus indicating that care leavers would value the scheme being extended to the age of 21.

- Hiles Dominic, et al (2014) "So what am I?": multiple perspectives on young people's experience of leaving care. Children and Youth Services Review. 41: 1-15. (Internal validity ++, Relevance to guideline: highly relevant)

This was a study which, among other things, drew on a focus groups with young people who had left care.

Young people said they were sometimes confused, 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. 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.

Young people spoke of great efforts in getting the support they needed both from professionals and people of their social network. This was contrasted with support where they had been offered the wrong type of support 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.

- Munro, et. al. (2012), Evaluation of the Staying Put: 18 + Family Placement Programme: final report (Internal validity ++, Relevance to guideline: Highly relevant)

This was a mixed method study or evaluation of the staying put pilot that spanned 2 years, reported here are findings from semi-structured interviews with 21 young people who stayed put and 11 who did not, and semi-structured interviews with 31 foster carers

The majority of foster carers were willing to offer staying put placements, primarily because they viewed young people as ‘part of the family’. The majority of young people (83%) judged to have a strong and secure base within their current foster placement, chose to stay put, and most who stayed put (84%) were close to their foster carers and would seek advice and support from them. 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.

Young people said that staying put gave them more control over the timing of their transition from care to independence, giving young people the chance to stay in a nurturing family situation, gain confidence and prepare for independence, and receive ongoing support. They also felt that staying put gave them continuity and stability to increase chances to engage with Employment, Education and Training (EET).

Most young people were positive about their leaving care personal advisers and the support they received (84%) with more confidence expressed by those who stayed put (90%) than those who did not (73%). Over half of young people said that their support networks were weakened after their transition to independent living.

- Barn et al (2006) Review of Life after Care: The Experiences of Young People from Different Ethnic Groups (Internal validity ++, Relevance to guideline: Highly relevant)

This study focused on 261 care leavers in Leaving Care Teams from across 6 local authority social services departments in England. Managers and professionals based in the Leaving Care Teams were also interviewed.

Most young minority ethnic 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, and many did indeed report having a good relationship with their social worker. 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.

Divergence of views did exist between some 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. For most young people, this sort of support and preparation for leaving care either started too close to transition age, resulting in some individuals having to learn to adapt quickly and 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 for independent livings, such as domestic tasks, self-discipline and being organised.

Transition for young people with learning disabilities

We identified ten studies which had gathered the views of young people with disabilities, primarily learning disabilities, and their families. One of these studies has not been reviewed here due to time constraints, but since this study was included to question 4.5.7 (multiple services) at last Guideline Committee (Beresford et al 2013, +) we will include it in our summary and evidence statements. The nine other studies are listed below with a brief summary of their key findings.

- Bhaumik S, Watson J, Barrett M, Raju B, Burton T, Forte J. (2011) Transition for Teenagers With Intellectual Disability: Carers' Perspectives (Internal validity +, External validity ++)

This high quality mixed methods study gathered carers' views on transition procedures for young people with learning difficulties. The study conducted a postal questionnaire followed by in-depth interviews with the carers of young people with learning difficulties. The study achieved a final sample of 79 carers for the questionnaire and 24 in-depth interviews. The findings show concern among carers about the transition process. Only 26% of carers were satisfied or very satisfied with the quality of the transition process. The study found a link between satisfaction levels and the use of a transition plan, but only 31% of carers knew of a transition plan and even less had a copy of it. Carers also reported problems following transition; nearly 50% of respondents reported problems with accessing adult disability services.

The use of multiple services meant that during transition there was a need for different handovers between services, difficulties in meeting eligibility criteria for various services and a need to navigate disparity in handover ages. The main concerns for carers around transition related to 1) difficulties in accessing services, 2) concerns around the mechanisms of the transition process, and 3) unmet needs. Carers wanted more information on the transition process in general and had problems finding the help they needed to access services. Issues with accessing services was coupled with a lack of specialist services and recreational activities for young people with learning difficulties. Concerns relating directly to transitions included a lack of clarity

about the responsibilities of professionals and their role in the transition process. Carers commented on a lack of commitment from staff in attending key meetings and a lack of support for themselves. There was also a perception that transition planning had started too late.

The study suggested that the transition process should be more proactive from services and starting earlier, be more continuous and of longer duration. People wanted the transition planning to be co-ordinated with annual reviews, and clearer, earlier, and more comprehensive information provision about the transition process and teenagers' options. People also wanted greater involvement of professionals in the process, clearly defined responsibilities for each professional, and a key worker who knows the teenager well and supports the parents through transition.

- Broadhurst et al. (2012) An evaluation of the My Way transition programme (Internal validity +, Relevance to guideline: Highly relevant).

This is an evaluation which included qualitative interviews with 75 disabled young people, of whom 59 had a learning disability. The interviews conducted prior to the start of My Way highlighted the negative experiences of a considerable number of families, with poorly planned and chaotic transitions and poor outcomes for young people. Young people were not always properly supported to explore suitable options. Most young people, their families and professionals said at the end of the project that My Way transitions had been successful; and had consolidated relationships between these key players.

- 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? Children's Workforce Development Council. http://dera.ioe.ac.uk/2760/1/Microsoft_Word_-_PLR0910056Harrison.pdf (Internal Validity – , Relevance to this guideline: Highly relevant)

This study explored 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. Nine young people were interviewed about their experiences.

Less than half the group knew what ‘transitions’ meant, let alone a ‘transition plan’ and only 3 people got involved in devising this. There was a lot of disillusion with the transitions service especially from parents. As far as future options, information often went directly to parents, totally bypassing young people, pointed out by a parent as not being 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.

- Cowen (2010) Personalised transition: innovations in health, education and support. http://scottishtransitions.org.uk/wp-content/uploads/personalisedtransitionpdf.pdf (Internal validity -, Relevance to this guideline: Highly relevant)

This report was based on interviews with parents and professionals, and from workshops with young people. It does not include a methods section and so it is not clear how the views were collected, or how many people informed them.

This report emphasise the importance of individual budgets and person-centred planning. Having a key worker or transition co-ordinator was seen as essential. For example, one case study of a parent (p.20) found that individual budgets had been a life changing experience for the young person, since these had given him the opportunity to do activities of his choice, supported by a personal assistant who also organised all the admin work. In another case, one young person had used his individual budget to build up a team of personal assistants to support him throughout the week.

- Heslop & Abbott (2007) School's Out: Pathways for young people with intellectual disabilities from out-of-area residential schools or colleges. Journal of Intellectual Disability Research. 51: 489-496. (Internal validity: ++, Relevance to this guideline: Highly relevant)

During the process of transition it was important to parents that they were well-connected with other parents or with key professionals. These other

people were usually their main source of information, they would provide suggestions for what might be done or they would signpost parents to support agencies. Parents said appropriate information to help young people and their families to make informed choices is essential for a good transition process. The need for a key worker or a named transition lead was raised by parents in this study.

Parents said it was also important to take an active part in negotiating with professionals and advocating on their child's behalf to get the best possible outcome. Good forward planning between all the parties involved (parents, the current and future residential school/college; and the transition lead) was really important including allowing adequate time to prepare. This could include things like ensuring appropriate aids or equipment are in place and staff know how to operate them; and planning ahead to provide for the social, leisure and communication needs of YP. 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.

- Kelly (2013), Don't box me in: disability and transitions to young adult life (Internal validity++, Relevance to guideline: Highly relevant)

This study aimed to explore the transitional and early adult life experiences of young adults with learning disabilities through qualitative methods: semi-structured interviews with young people, families and carers and professionals; case file reading; and biographical narrative techniques with ten young adults.

Some areas had designated transition coordinators and others had embedded the transition support function within the remit of the key worker role, which led to some confusion about roles. Young adults and their families reported varied experiences of key worker support during their transitional years. Good

practice of key workers included building trusting relationships, regular contacts, prioritising of young people's and parents' views, signposting to other sources of support and advocacy. Poor practice was inconsistent contact, lack of follow up after a crisis in the family, and breaks in access workers at key transitional times.

Young adults were often given with limited choices or only involved when decisions were already made by parents or professionals acting on behalf of them, despite overall consensus that disabled young people should participate in decisions affecting them. A gap in day opportunities for young people who have personal, health or mobility related care needs was identified and concerns raised that these young people are being inappropriately placed in settings for those with more complex needs.

Loss of social networks as service settings change and parental fear about risks can be an issue for some disabled people. Most young adults looked forward to engaging in personal relationships but 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.

Young adults and parents lacked knowledge of supported living options for young people with learning disabilities, not helped by shortages in supply of accommodation so that young people with learning disabilities are able to enjoy living independently or with support in the community. Some parents had no knowledge of, or could not cope with the demands of, direct payments and could not identify a service provider or cope with managing these.

- Milner, C. Experiences of health transition for young people with learning difficulties and complex health needs in Northumberland (Internal validity +, Relevance to this guideline: Highly relevant)

Milner 2008 is a well conducted study with a high level of relevance to this guideline. The study used qualitative methods to elicit views from young people and their families with complex needs. The majority of the views come from parents or carers.

The key findings from the study were: There was positive feedback about health services, personal relationships between professionals and patients were very important. The study found that keeping services turning over and keeping things moving was valued, and that families that moved experienced complications and gaps in service provision.

Views and experiences of transition processes specifically revealed the following key themes: A lack of information about transition, transition can be abrupt, rather than a gradual process. There is a lack of handover between professionals across the transition process and that finally transition as residential colleges and schools was well carried out and integrated into planning.

“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” (p.51)

“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” (p.52)

“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” (p.52)

“I'm surprised that there was apparently no contact between the physiotherapy services before and after she left school” (p.52)

The study collected views on how transition processes might be improved, the findings were organised into the following seven recommendations, accompanied by testimony from parents: A period of overlapping services can help prepare for transition; Specialised workers to support people with learning difficulties may be established; A regular health check, especially for patients with long term conditions, to monitor long term conditions and emerging issues; Improved information around transitions; Flexibility about

when the transition takes place; A planning meeting to introduce the transition plan and bring together key individuals.

- Newman G, Collyer S, Foulis M, Webster S (2009) A multi-agency consultation project with young people with support needs at the transition between children's and adult's services. International Journal of Transitions in Childhood, 3:45-55. (Internal validity: ++, Relevance to this guideline: Highly relevant)

This study found that some young people were more able to articulate their needs than others, and that this appeared to influence the outcome of their transitions. Young people who left school without a plan in place were housebound for a period, despite being well known to services. Some young people felt they had no control over decisions about their future. For those with more profound disability choices were lacking. 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 they leave children's services, especially for those with more complex needs, exacerbated by lack of transport and access to funding. Some YP 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 care was also lacking for some young people and their families.

Again, this study found that information was lacking for some young people, including information about what would be available in higher and further education. Some young people felt they would benefit from guidance to navigate whatever information was available. 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.

High levels of anxiety was experienced for young people and their families in relation to medical equipment (e.g. made to measure gait trainer, ear thermometer) which had to be returned to children's services after a transition

and reapplied for after transfer to adults' services. Similar anxiety was caused for one young person with a physical disability whose regular physiotherapy, equipment and support were discontinued as he was transferred into Adults' services.

For some young people, especially those who had been or were not in education employment or training after leaving school, having one consistent support worker throughout was valuable. The key worker from the careers service provided support for planning, in organising and completing applications, and even in some cases transport to training. One young person on a Direct Payments and Independent Living Fund reported having a good package of support, but only with intensive support from his parents.

Young people had experienced 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 experience of these. Young people wanted to be able to invite other people to the meetings and to be better prepared for meetings in advance.

- Pilnick 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 guideline: a bit relevant)

This study examined how the process of transition of young people with learning disabilities was 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 was used to examine how professionals manage and negotiate this conflict and how some points of view or courses of action ultimately prevail over others.

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. But, strategy documents including Valuing People (2001) and the updated Valuing People Now (2009) still have not recognised the fact that impaired capacity should affect this right. On a

practical basis, parents/carers are central in terms of providing support and helping the young person to explore options, 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 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.

Transition for young people with physical disabilities, across health and social care settings

We identified one study which had considered transition for young men with Duchenne muscular dystrophy. Because this was the only study with a social services focus for young people with physical disabilities (not learning disabilities), we have not drawn out specific evidence statements from this. However, we note that this study reflected findings from most other studies in terms of: lack of support and transition planning, lack of post-transfer support in adult services and flexibility and information seen as essential to a good transition experience.

- 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 ++, External validity ++)

This study explores the views and experiences of young men with Duchenne muscular dystrophy in three regions in the UK. The study used a postal questionnaire and qualitative interviews with young people, parents and carers. The questionnaire found that families had been in contact with a range of services and different types of clinics ahead of transfer but few had a key worker, care coordinator or social worker. Over half of respondents said that they had had no transition planning.

In relation to health and social care the general feeling among patients and families taken from in-depth interviews, was of uncertainty about the transition process and trepidation about what services would be available for them in adult services. Families found that they lost services like physiotherapy,

received variable support from occupational therapy for adaptions and that hospice care was no longer available following transition and no alternative was provided.

Parents said that they struggled to get their children's needs met and achieve a coordinated approach from services. Transition was difficult because there was uncertainty about which adult professional they would be meeting with, if a service existed at all. In one area there was no adult services neuromuscular consultants working in the area, this situation left families concerned about services for their children following transition.

"I would just like more information on transition and exactly … how it goes. I mean is it [adult 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?" (p.105)

"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" (p.105)

The views were not all negative, some parents reported that they were told about transition ahead of time and that there was some flexibility in the process. Some families had good relationships with their GP's and planned services through them. Many interviewees used the muscle centre in the area, this service was available to all ages, required no transition, and was a greatly valued service.

The interviews showed that few families were prepared for transition. Young people and Families found that there was no accepted transition process within social care. What support they did receive was described as 'handover' and following transition they no longer received support from a single named worker, instead families said that they were allocated to the duty social worker. The families that did receive the services of a social worker, found that they lost this support following transition, or that contact with social care staff was sporadic.

Families perceived that services did not know how to treat their children because of the life limiting nature of the condition, parents felt that there were few services for their children or themselves, families felt unsupported and had a perception that services did not care what happened to them following transition. Parents and young people both expressed reservation with the quality of care in adult services. Parents felt that they did not know what the culture would be like in adult 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 …" (p.107)

Young people did not appreciate the focus, in appointments around transition age, on their deteriorating health, they felt it was demotivating, given that many of them had hopes for the future for the future aside from their condition.

Gaps in the evidence

There was an overwhelming amount of evidence to address the questions on service users and carers' experiences. The evidence covers a range of groups, and it is striking how similar their concerns are, which indicate saturation in the research and findings.

Evidence statements

ES16	Views of care leavers supported by social care services: consistency of support There is evidence from one moderate quality and three good quality studies (Hiles et al, 2013, +/++, Hiles et al, 2014, ++, Munro et al, 2012, ++, Barn et al, 2006, ++), one of which is a systematic review (Hiles et al, 2014, +/++), that young people leaving care appreciate consistent and ongoing support during transition. This is particularly true for those who have experienced multiple placements or have mental health needs.
ES17	Views of care leavers supported by social care services: support to make contact with birth families There is evidence from one moderate quality systematic review (Hiles et al, 2014, +/++) that leaving care is a period when many care leavers want to regain contact with their birth families, and some will need emotional support with this.
ES18	Views of care leavers supported by social care services: practical support to become independent There is good quality evidence from one moderate quality and three

	good quality studies (Hiles et al, 2013, +/++, Hiles et al, 2014, ++, Munro et al, 2012, ++, Barn et al, 2006, ++), one of which is a systematic review (Hiles et al, 2014, +/++), that young people leaving care would like high levels of practical support in relation to their accommodation, education, employment and general practical issues which arises when moving to independence.
ES19	Views of young people with learning disabilities and their parents / carers, supported by social care services Across seven mixed quality studies (Broadhurst et al, 2012, +, Children's Workforce Development Council, 2010, -, Cowen, 2010, -, Kelly, 2013, ++, Newman et al, 2009, ++, Pilnick et al, 2011, +) and supported by the good quality study by Beresford et al (2012, +) reviewed for the question on multiple services, there is evidence that transition planning should be personalised and involving young people in the planning. Young people's participation is challenged when they have learning disabilities, in that services sometimes continue to talk to their parents only.
ES20	Views on parent or carer involvement in transition planning There is strong evidence from six studies - four of which are moderate quality, two of which are good quality (Bhaumik et al 2011+/++, Broadhurst et al, 2012, +, Kelly, 2013, ++, Milner 2008, +, Newman et al, 2009, ++, Pilnick et al, 2011, +) - and one low quality study (Cowen, 2010, -), that it is essential that parents (or someone else with primary caring responsibility or in a primary relationship role) are involved in young people's transition planning. This was also supported by Beresford et al (2012, +), reviewed for the question on multiple services. While the role of parents might change during this period, depending on the young person's capacities, most young people will continue to have a close relationship to their parents as they grow into adulthood. Balancing young people's need for increased independence with parents' role can be difficult, but is nevertheless something which needs to be considered when planning the transition out of children's services.
ES21	Views on the information and information support need for young people with learning disabilities before and during transition There is strong evidence from three moderate quality and two good quality studies (Bhaumik et al 2011+/++, Broadhurst et al, 2012, +, Kelly, 2013, ++, Milner 2008, +, Newman et al, 2009, ++) and two of low quality (Children's Workforce Development Council, 2010, -, Cowen, 2010, -), that young people with learning difficulties and their families need substantial information in advance of and during transition, and help with interpreting the information. This was also found when reviewing for question 4.5.7 (multiple services). For example, while independent budgets has been found to be helpful by two mixed quality studies (Newman et al 2009 ++, Cowen 2010 -) there is evidence from one good quality study here (Kelly, 2013, ++) that some parents did not know how to manage budgets or how to self-commission 'services' using these. Information is needed on the transition process, what to expect after transfer, and what happens after equipment is returned to children's services.
ES22	Views on the role of a key worker during transition There is strong evidence from three moderate and two good quality studies (Bhaumik et al 2011+/++, Broadhurst et al, 2012, +, Kelly, 2013, ++, Newman et al, 2009, ++, Pilnick et al, 2011, +) and one low quality

	study (Cowen, 2010, -) that young people and their parents value the support of a key worker, as long as this is consistently provided.
ES23	Views on the support needs of young people with learning difficulties making transition There is evidence from one good quality study (Newman et al, 2009, ++) that transition planning for young people with learning disabilities should include concerns about their work or education opportunities, social needs and housing. This was also supported by evidence from a moderate quality study by Beresford et al (2012, +), reviewed for the question on multiple services.
ES24	Young people's and family/carers' views about the critical factors affecting their transition experience in health care, including mental health: There is overwhelming evidence from two good quality systematic reviews (Betz et al, 2013, ++/+, Fegran et al, 2014, ++/++) as well as five moderate quality and four good quality studies (Price et al, 2011, +, Allen et al, 2011, +, Lewis and Noyes, 2013, +, Kirk and Fraser, 2013, ++, Beresford et al, 2014, +, Tierney et al, 2013, ++, Day et al, 2007, +, Singh et al, 2010, ++, Swift et al, 2013, ++/-) that: - Relationships to care providers are very important to young people and their parents, and these needs to be maintained during transition. - Young people and their parents want good quality information about the transition process, including information about the change in culture from paediatrics to adult settings. - The transfer process should be timed according to young people's capacities and needs, not fixed to a particular age. - While acknowledging the changing role of parents, these studies all suggest that there is not one model for how to involve parents during transition and after, and that some young people want continued involvement while others do not. The transition planning needs to factor this in, so that young people who want their parents at appointments can make this choice. - Young people value the increasing independence that might go alongside transition into adult services. They want to be increasingly involved in their care to facilitate this. Again, however, it is important to note the individual differences and that parents of some young people will continue to be heavily involved in their care throughout their lifecourse.

3.6 Factors that help or hinder purposeful and planned transitions from children's to adults' services

Review question

One question was about barriers and facilitators to transition from children's to adults' services. The objective for this question was to assess which factors

impact on young people's transitions so that they are deemed 'successful' or 'unsuccessful' beyond the planning of the transfer.

The review question was:

- What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research?

Searching for studies

Electronic databases in the research fields of health, social care, and social science were searched using a range of controlled indexing and free-text search terms based on the population 'young people' and process 'transition'. No filter was used for study design, and one overall search was conducted to address all review questions. In addition, a range of websites of relevant organisations were searched too, for grey literature. The search captured both journal articles and other publications of empirical research. The search was restricted to studies published from 1995 onwards. A detailed description of the full search, including all search terms and sources, is provided in Appendix A.

Study inclusion criteria and selection

A large number of studies were coded to this question after the second round of screening (N=417). These were re-screened on titles and abstracts to ascertain their relevance and further studies were excluded due to either being miscoded or duplicates. With a remaining 302 studies we still needed to reduce the numbers and therefore re-screened all these first by dividing them into three categories: research, young people and families/carers' and professionals' perspectives. Each of these categories where then re-screened to include only studies that had asked the same question as us. Due to continuous high number of studies we decided to retain our previous inclusion criteria for views studies of young people and their families/carers, that these should be conducted in the UK only, and we only included systematic reviews published in 2006 or later. In the research category we also focused primarily on studies which had considered service factors related to transition, or a

combination of individual and service factors. This meant that some US-based studies focusing on individual factors only, were excluded. All of these excluded studies looked at patients' characteristics (in particular age, race and insurance status) and whether they started using adult services. There was quite a wide range of interpretation in terms of what constitutes a successful transition and again, we focused on including studies whose definition resembled ours (purposeful and planned).

During this process, further studies were excluded due to the full-text showing that the study was not actually about service transition after all, or that it focused exclusively on educational transitions without consideration of health and social services' role in this.

We also went through the findings of all reviews and individual studies included for the effectiveness questions, and extracted any findings related to this question, as stipulated in the protocol.

Our final number of included studies for this question was 38, spanning a whole range of study designs due to the multi-layered nature of the question.

We included 11 systematic reviews for this question, including reviews which were used to address previous questions presented at the Guideline Committee. Due to the very large number of studies, we have not summarised each study here, but we have focused on the systematic reviews and how they are supported or challenged by individual studies. We have organised the studies within four categories: physical health care, mental health, criminal justice and social care.

Included studies

Due to the large number of studies we have presented them as reference lists, organised according to setting. See Appendix A for more detailed information about inclusion criteria.

Physical health care settings

- Systematic reviews (N=7)

Binks JA et al (2007) What Do We Really Know About the Transition to Adult-Centered Health Care? A Focus on Cerebral Palsy and Spina Bifida. Archives of Physical Medicine and Rehabilitation. 88(8): 1064-1073. (+/+)

Bloom R et al (2012) Health Care Transition for Youth With Special Health Care Needs. Journal of Adolescent Health. 51: 213-220. (++/++)

Crowley R et al (2011) Improving the transition between paediatric and adult healthcare: a systematic review. Archives of Disease in Childhood. 96: 548-554. (-/++)

Jordan L et al (2013) Systematic review of transition from adolescent to adult care in patients with sickle cell disease. Journal of Pediatric Hematology/Oncology. 35(3): 165-169. (+/+)

Kime N et al (2013) Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes. UK: NHS Diabetes. (+/++)

Doug M (2011) Transition to adult services for children and young people with palliative care needs: a systematic review. Archives of Diseases in Childhood. 96(1): 78-84IS. (+/++)

Watson R et al (2011) Models of transitional care for young people with complex health needs: a scoping review. Child: care, health and development. 37: 780-791. (-/++)

- Individual studies

Allen D et al (2012) Continuity of care in the transition from child to adult diabetes services: A realistic evaluation study. Journal of Health Services Research and Policy. 17: 140-148. (+/++)

Andemariam et al (2014) Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care. Pediatric Blood and Cancer. 61(4): 697-701. (-/+)

Beresford B et al (2014) Supporting health transitions for young people with life-limiting conditions: researching positive practice (The STEPP project). : . http://php.york.ac.uk/inst/spru/research/summs/stepp.php (+)

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

Cheak-Zamora C et al (2013) Disparities in Transition Planning for Youth With Autism Spectrum Disorder. Pediatrics. 131: 447-455. (+/+)

Downing J et al (2013) Transition in endocrinology: The challenge of maintaining continuity. Clinical Endocrinology. 78: 29-35. (+/-)

Garvey KC et al (2013) Health care transition in young adults with type 1 diabetes: barriers to timely establishment of adult diabetes care. Endocrine Practice: Official Journal Of The American College Of Endocrinology And The American Association Of Clinical Endocrinologists. 19(6): 946-952. (++/+)

Kipps S et al (2002) Current methods of transfer of young people with Type 1 diabetes to adult services. Diabetic Medicine. 19(8): 649-654. (-/++)

Mills J et al (2013) Ensuring the successful transition of adolescents to adult services. Learning Disability Practice. 16(6): 26-28. (+)

Por J et al (2004) Transition of care: health care professionals' view. Journal of Nursing Management. 12(5): 354-361. (+/++)

Sebastian 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. Journal of Crohn's and Colitis. 6(8): 830-844. (+/++)

Shaw KL et al (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: Results of a postal survey. Rheumatology. 43: 211-219. (+/++)

Reid GJ et al (2004) Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. Pediatrics. 113: e197-e205. (+/++)

Mental health care settings

- Systematic reviews

Montano CB, Young J (2012) Discontinuity in the transition from pediatric to adult health care for patients with attention-deficit/hyperactivity disorder. Postgraduate medicine. 124(5): 23-32. (-/-)

Paul M et al (2014) Transition to adult services for young people with mental health needs: A systematic review. Clinical Child Psychology And Psychiatry. (++/++)

Swift KD et al (2013) ADHD and transitions to adult mental health services: a scoping review. Child: Care, Health And Development. (++/+)

- Individual studies

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.. Advances in Mental Health and Intellectual Disabilities. 5: 9-16. (++)

Singh SP et al (2010) Transition from CAMHS to adult mental health services (TRACK): a study of service organisation, policies, process and user and carer perspectives. : National Institute for Health Research. Service Delivery and Organisation Programme. (++)

Richards M, Vostanis P (2004) Interprofessional perspectives on transitional mental health services for young people aged 16-19 years. Journal of Interprofessional Care. 18: 115-129. (++)

Social care settings

- Systematic reviews

Morris M, Stein M (2009) Increasing the number of care leavers in 'settled, safe accommodation': research review 3. . : . (Rated '+' on internal and '+' on external validity)

- Individual studies

Barn R et al (2006) Life after care: The experiences of young people from different ethnic groups. York: Joseph Rowntree Foundation (++/++)

Broadhurst S et al (2012) An evaluation of the My Way transition programme. Tizard Learning Disability Review. 17(3): 124-134. (+)

Beresford B, Cavet J (2009) Transitions to adult services by disabled young people leaving out of authority residential schools. York: University of York: Social Policy Research Unit. (++)

Craston M et al (2013) Impact Evaluation of the SEND Pathfinder Programme Research report. : Department for Education. http://www.opm.co.uk/wp-content/uploads/2014/02/DFE-RR281.pdf (++/+)

Heslop P, Abbott D (2007) School's Out: Pathways for young people with intellectual disabilities from out-of-area residential schools or colleges. Journal of Intellectual Disability Research. 51: 489-496. (++)

Hiles D et al (2014) "So what am I?": multiple perspectives on young people's experience of leaving care. Children and Youth Services Review. 41: 1-15. (++)

Kelly B (2013) Don't box me in: disability and transitions to young adult life. http://www.barnardos.org.uk/don_t_box_me_in_-_final_report.pdf (++)

Fraser M (2012) Self-directed support and disabled young people in transition (part 2). Journal of Integrated Care. 20(4): 223-230. (+)

Munro ER et al (2011) Evaluation of the Right2BCared4 pilots: final report. Loughborough: Loughborough University. (-/+)

Munro ER et al (2012) Evaluation of the Staying Put: 18 + Family Placement Programme: final report. : Great Britain. Department for Education. (++/++)

HM Probation (2012) Transitions: an inspection of the transition arrangements from youth to adult services in the criminal justice system. (++)

Narrative summary of the evidence

For this synthesis we went through the findings of each review and each individual study, and considered the amount of evidence to underpin each identified 'factor'. We have emphasised findings which are underpinned by one or more systematic reviews over findings underpinned by individual studies only. However, there are overwhelmingly similar themes emerging from all these studies, and these reflect themes which have come up in previous narrative summaries as well as Guideline Committee discussions.

While the question we are addressing asks about factors identified by research, young people, carers and professionals, we have not had the time to single out factors identified by these different sources. This is due to the time constraints in the face of so many included studies as well as the fact that many studies draw on a range of informants and so 'research' is not easily distinguished from professionals' or service users' views.

While the findings presented here are supported by a wide range of studies, it is important to note that the quality of the evidence varies, and while there are clear messages coming out from the literature in terms of service users' and professionals' views, there is less evidence (as found when addressing the questions about effectiveness) on how factors that hinder transitions can be best overcome. All the systematic reviews also stated that while there is a large amount of studies on transition, there is a lack of studies which evaluate the impact of transition models or programmes.

Transitions in health care settings

We identified 20 studies which had investigated factors that help or hinder purposeful and planned transition in health care settings (paediatric to adult health care services) either generally for all young people with a long-term

condition or for particular conditions. Due to the high number of studies we have not presented a summary of each of the 19 studies since their characteristics and key findings are presented in the tables. We have summarised findings in this section, first presenting service factors which hinder or help transitions, then personal factors which hinder or help transitions and finally evidence of particular transition concerns for certain conditions.

- Service factors which help or hinder purposeful and planned transitions

The most frequently cited factor which impedes on a successful transition is the absence of a structured transition programme which can result in a sudden transfer to adult services with little or no preparation. This factor was identified by 4 systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al (2013, + internal and + external validity, Watson R et al 2011,– internal validity and ++ external validity, Binks JA et al 2007 + internal validity and + external validity) as well as by four individual studies (Care Quality Commission (2014, overall assessment ++, Por J et al 2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity, Mills et al 2013, overall assessment +).

In this context, a structured transition programme means a pathway for transition where young people and their parents/carers know who their contacts are during the process, what will happen, and where they are going after they leave paediatric services. Commitment to this programme must come from all adult and children's services which either will be or are providing care to the young person.

Two studies (one systematic review and one single study) emphasised the importance of this transition plan starting "years before child is ready so that when it happens it is not such a shock and everyone is prepared" (Adult nurse cited in Por J et al 2004, rated '+' on internal and '++' on external validity). The systematic review supporting this was by Binks JA et al (2007 rated + on internal validity and + on external validity), and they emphasised that the

transition plan should also focus on young people as 'competent' rather than 'disabled'.

The transition plan and care delivery during the transition period should addresses life-style changes for young people, especially information about sexual health and drugs and be personally designed to meet the young person’s needs (systematic review by Kime et al 2013, + internal and ++ external validity).

The report by the Care Quality Commission (2014, overall assessment ++) concluded that there are serious barriers in the current health care system for all young people transitioning from children's to adults' services. One specific recommendation from this report was that General Practitioners should always be involved in the transition planning for young people with complex health care needs.

A related factor which impedes transition is poor inter- and intra-agency coordination, gaps in levels of integration between sectors, lack of communication between paediatric and adult physicians and other adult care services in the community. This was found by three systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al 2013, + internal and + external validity, Binks JA et al 2007, + internal and + external validity), and 5 individual studies (Allen et al 2012, + internal and ++ external validity, Care Quality Commission 2014, overall assessment ++, Por J et al 2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity, Mills et al 2013, overall assessment +).

Insufficient information was identified as an important factor which hinders successful transition, identified by two systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al 2013, + internal and + external validity), and 5 individual studies (Beresford B et al 2014, overall assessment +, Care Quality Commission 2014, overall assessment ++, Por J et al 2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity, Mills et al 2013, overall assessment +).

Factors within adult services identified as hindering purposeful and planned transition were:

- Adult services not being involved in the transition planning and therefore not being prepared for young people transitioning in from paediatrics.
- Adult services not knowing how to provide services and treat young adults.
- Delays in adult appointments after discharge from paediatric services.

These three factors were identified by three systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al 2013, + internal and + external validity, Binks JA et al 2007, + internal and + external validity), and two individual studies (Garvey KC et al 2013, ++ internal and + external validity, Beresford B et al 2014, overall assessment +).

In addition, lack of access to specialist and allied health professionals due to age limit, or higher eligibility criteria in adult services was identified as a factor which hinders transition by one systematic review (Kime et al 2013, + internal and ++ external validity).

In a survey of gastroenterologists, those in paediatric services rated 'transition' as a more important issue than did their adult peers, confirming the suggestion that one factor that hinders successful transitions into adult services are priorities within adult services themselves: "with 47% (162/358) of the adult gastroenterologists and 79% of the paediatric gastroenterologists describing the value of a structured and individualised transition as very important (p=0.001)" (p832 in Sebastian S et al 2012, + internal and ++ external validity).

Related to this, two systematic reviews reported that differences in care between paediatric services and adult-oriented services can hinder purposeful and planned transitions (Kime et al 2013, + internal and ++ external validity, Jordan L et al 2013, + internal and + external validity).

Rigid policies and protocols can create inconsistencies in care, as identified by one systematic review (Kime et al 2013, + internal and ++ external validity), and equally the importance of flexibility in transition was identified by two other

systematic reviews (Watson R et al 2011, – internal and ++ external validity, Binks JA et al 2007, + internal and + external validity). In a relatively recent survey of UK gastroenterologists, the majority of all 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 also stated that the state of remission of disease influenced the timing of transition planning and transfer (Sebastian S et al 2012, + internal and ++ external validity).

Lack of adequate resources and time was identified as barriers to provision of care during the transition period by one systematic review (Kime et al 2013, + internal and ++ external validity) and two individual studies (Shaw KL et al 2004, + internal and ++ external validity, Care Quality Commission 2014, overall assessment ++). This was also found by the individual study by Sebastian S et al (2012, + internal and ++ external validity), and this study connected ‘inadequate resources’ to lack of training.

Meeting adult providers and visiting adult facilities in advance of transitioning was found to be a factor which help transition, and supported by four systematic reviews (Jordan L et al 2013, + internal and + external validity, Bloom R et al 2012, ++ internal and + external validity, Crowley R et al 2011,– internal and ++ external validity, Binks JA et al 2007, + internal and + external validity), as well as three individual studies (Beresford B et al 2014, overall assessment +, Kipps S et al 2002, - internal and ++ external validity, Por J et al 2004, + internal and ++ external validity). In one study there appeared to be a higher satisfaction amongst patients who received care in the two districts where they provided an adolescent clinic or a young adult clinic before transfer to adult services, and where young people were also introduced to the adult provider prior to transfer into adult services (Kipps S et al 2002, - internal and ++ external validity).

Resistance from paediatric care providers to “let go” of their long-standing relationships with young patients and distrust of adult-centred health services,

and equally that young people and their parents do not want to leave paediatric services were identified by two systematic reviews as a barrier to transition, especially when young people have a history of disrupted care and therefore find it challenging to trust new providers (Kime et al 2013, + internal and ++ external validity, Binks JA et al 2007 + internal and + external validity). Delayed referrals was also identified as a barrier by one individual study (Mills et al 2013, overall assessment +).

Finally, the parents' involvement in their children's care was seen by professionals as a factor that hinders transition planning, while as we also saw for the question on young people's views at Guideline Committee 7, young people themselves want to be in charge of the extent to which parents continue their involvement or not and parents being excluded from clinics can be a factor that hinders their transition into adult services. This was found by one systematic review (Kime et al 2013, + internal and ++ external validity, and three individual studies (Beresford B et al 2014, overall assessment +, Por J et al (2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity).

- Personal factors which help or hinder purposeful and planned transition

Transition is dependent on the extent to which a young person has good knowledge of their own condition, is involved in their own care, feels able to take on more responsibility in regards to attending clinics and is proactive in terms of their provision, as well as own use of services (Kime et al 2013, + internal and ++ external validity). In response to this one systematic review (Crowley R et al 2011,– internal and ++ external validity) found that educational programmes can help transition, but it is important to note that one study (Allen et al 2012, + internal and ++ external validity) found that young people were not interested in attending peer support groups or additional education sessions. This will of course vary, but the impact of training is also questioned by one trial included for the effectiveness question (Betz et al 2010, + internal and + external validity).

Importantly, the systematic review by Kime et al (2013, + internal and ++ external validity) found evidence that young people do not always adhere to their transition plan, which emphasises the importance of researching the effectiveness and acceptability of different types of models. The individual study by Garvey et al 2013 (++ internal and + external validity), found that competing life priorities did hinder transition for some young people. The review by Jordan L et al (2013, + internal and + external validity) concluded that there is evidence to show that 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, which is somewhat counter-intuitive and therefore worth noticing.

We included some individual studies which had considered the correlation between successful transition and individual factors such as condition and diagnosis, age and ethnicity. No clear picture emerged from these studies, and it is also important to note that some of them were US-based studies with limited relevance to our UK context. However, it is interesting that two studies both found that a gap of care over 6 months between transfer from paediatrics to adult services was indicative of nonattendance at adult services (Downing J et al 2013, + internal and - external validity, Garvey KC et al 2013, ++ internal and + external validity).

Two individual studies also found that the longer the distance from a young person's home to the adult clinic the less likely that the young person would transition successfully (Reid GJ et al 2004, + internal and ++ external validity, Andemariam et al 2014, - internal and + external validity).

- Evidence of transition concerns for particular long-term conditions

The systematic review by Binks et al (2007, + internal and + external validity) concluded that the barriers to transition experienced by young people with spina bifida and cerebral palsy were similar to those experienced by young people with other complex health conditions.

For young people with HIV, there is a perceived increase in stigma on transitioning to adult care, difficulty with adherence to medication regimen,

difficulty with adolescent sexuality, and the young people often coming from disorganised social environments (Kime et al 2013, + internal and ++ external validity).

In relation to young people with sickle cell disease, the systematic review by Jordan L et al (2013, + internal and + external validity) made two recommendations ("on the basis of inconsistent or limited-quality patient-oriented evidence" p167): First, that 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. Second, that health care providers should be educated about transition.

We found one study which focused on health care transitions for young people with learning disabilities (Mills et al 2013, overall assessment +). This study also identified similar factors that help or hinder their transition, but that in addition, when young people were referred to adult learning disability services, it was unclear which health professional was the lead person for their care.

The recent report by the Care Quality Commission in the UK (2014, overall assessment ++) found that no clear procedures exist to record assessments of family members regarding their ability to manage the care of young people with complex needs. There seemed to be 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, while other parents felt abandoned by health and social care staff. Furthermore, commissioning staff pointed out that there were gaps in the processes with guidance and protocols for transition not being adhered to. For instance, attendance by health professionals at transition planning meetings was sporadic. Where young people mainly had a single health condition, what worked well was: a) having staff who were knowledgeable about the health condition of the young person because of their long-term involvement with them, b) provision of adolescent clinics, c) good communication with young people, their parents and each

other, d) appropriately tailored information (pp8-19). All of these factors mirror what was found by aforementioned systematic reviews and across conditions.

As identified in previous research reviewed for other questions, young people with autism appears to be at risk of a poorer transition than those with more or with less complex needs (Cheak-Zamora C et al 2013, + internal and + external validity). And one individual study found that young people with multiple conditions (comorbid medial conditions) were more likely to transfer successfully (Reid GJ et al 2004, + on internal and ++ external validity). The same study found that young people with substance misuse problems were more likely to not transfer successfully to adult care.

Transitions in mental health care settings

We identified 6 studies which were concerned about transition from CAMHS to AMHS. Three of these were systematic reviews, but one review was of such poor quality that it is only partially referred to here when its findings mirror those of other studies (Montano, Young 2012, rated – on internal and - on external validity).

- Gaps in transitional care

The systematic review by Paul et al (2014, rated ++ on internal and ++ on external validity) was also used for our effectiveness questions. In terms of factors that help or hinder purposeful and planned transitions from CAMHS to AMHS, this review found that there are significant gaps in mental health transitional care. These include a general lack of services, especially suitable, responsive services that are young adult-friendly, which in turn limits the uptake of AMHS services by young people and a higher thresholds for eligibility in adult services. Parents were concerned about the effects of stigma, which deterred many young people from using services.

- The impact of specific conditions

Paul et al (2014) also found that adult services often cannot able to accommodate young people with particular disorders such as ADHD and emotional/neurotic disorders although, more broadly, a pre-existing severe

mental illness or admission to a mental health hospital, or being on medication, increased the chances of making a transfer to AMHS. A second systematic review by Swift et al (2013, rated ++ on internal and + on external validity) focused on evidence in regards to transitioning into adult services for young people with ADHD. This is one of the conditions, also identified by Paul et al 2014), for whom there is a lack of adult services, with many professionals being doubtful about the existence of ADHD in adulthood. This was also a finding in the systematic review by Montano and Young (2012, rated – on internal, and – on external validity). The authors found evidence of inconsistent service thresholds for adult services, as well as unmet service user needs.

In addition to these two reviews we identified three individual studies which investigated the transition between CAMHS and AMHS. The comprehensive study by Singh et al (2010, overall assessment ++) concur with the two systematic reviews above in several ways: young people not meeting eligibility criteria for AMHS, or lack of appropriate adult specialists, the need to align referral thresholds. Specific to this study is the finding that looked after children and young people from some minorities have specific health issues or problems accessing support.

The TRACK study highlights four factors which comprise an optimal transition: continuity of care, a period of parallel care with the involvement of both CAMHS and AMHS, at least one transition planning meeting, and information about the transfer from CAMHS to AMHS.

- The benefit of collaborative working between health and social care

The second individual study included was by Kaehne (2011, overall assessment ++) which examined the perspectives of mental health professionals about partnership work and service gaps in transition for young people with intellectual disabilities.

As well as different eligibility criteria between CAMHS and AMHS, related to the age of young people, and the ‘acute disorders’ focus of the AMHS service model, both issues which are referred to in the reviews by Paul et al. (2014)

and Swift et al. (2013), mental health professionals in this study emphasised the need for close cooperation with social services. Interviewees pointed out that 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 learning disabilities and those with high-functioning autism or Asperger syndrome). This has previously been emphasised by a study included for the question on young people receiving multiple services (Beresford et al 2012). CAMHS staff were unaware about the services offered by adult social care and felt marginalised from them and the wider health care sector with regard to transition. CAMHS staff lacked knowledge about the role of the transition planning groups (led by social care and education) and their protocols.

More broadly, the review by Paul et al (2014) noted that where the agencies involved in transitions (CAMHS, social care, the voluntary sector agencies) showed evidence of working collaboratively, this helped transitions. In terms of collaboration between children's and adult services, lack of joint working (Paul et al.2014; Swift et al. 2013) was acknowledged as an issue that needs addressing - one suggestion was for a transitional worker or team to act as a bridge between children's and adult mental health services.

- The need for age-appropriate or adapted settings and co-ordinated handover

The third individual study included here was by (Richards and Vostanis 2004, overall assessment ++), which also interviewed professionals about their views on the transitional mental health services for young people aged 16-19 years. Many interviewees felt that adult services were not age-appropriate or adapted to young people's needs, as echoed by Paul et al. (2014). Transitions were seen as a straightforward process, for those with severe mental illness (Paul et al. 2014; Swift et al. 2013), but specific groups fell between services, such as young people with behavioural or relationships difficulties who were deemed unsuitable and too challenging for admission to an inpatient adolescent unit. A lack of formal structures governing the handover procedure

was mentioned both in this study and Paul et al. (2014), but care planning was particularly inadequate for those young people who did not engage at all.

- Stigma and confidentiality

As with Paul et al. (2014), stigma about the mental health label was mentioned, but this study claimed that non-statutory services were perceived as less stigmatising and potentially more engaging for young people. In fact, non-statutory services were thought on the whole to be more flexible, and made efforts to engage with non-attendees, as well as actively support young people in engaging with other services. This study also pointed to the issue of confidentiality being a key worry for young people, who may not disclose that they have a mental health problem because of worry that family members might find out.

- Access to, and communication between, services

Practical and social problems such as access to housing for older adolescents was referred to in regard to care leavers and young offenders, whilst Swift et al. (2013) mentioned this in the context of young people with ADHD. Communication was seen as variable and mentioned by both Paul et al. (2014) and Swift et al. (2013), with reasons suggested being services operating under different management structures, with separate planning and development processes and limited joint discussion.

Transitions in social care

We identified 12 studies which were situated within social care, or concerned with transition for disabled young people in which health and social care were considered as central agencies in their transition led by education. Due to the high number of studies we have not presented a summary of each of the 12 studies since their characteristics and key findings are presented in the tables. Our narrative summary is organised according to service user group.

- Factors that help or hinder care leavers' transition

First, a gradual transition process that facilitates independent living was found to help transition for care leavers. We found one systematic review (Morris & Stein 2009, + internal and + external validity) which focused on how to increase the number of care leavers in ‘settled, safe accommodation’. This good quality review concluded that a gradual transition process from being in care to living independently is likely to contribute to young people's well-being, employment, education and accommodation status after transfer out of care. Being in safe and stable accommodation, often achieved by leaving care at a later age, was found to increase engagement in employment or training, and to increase well-being. An integrated approach with children’s services, housing services and adult services is essential in preparing young people for adulthood. Amongst other factors that help purposeful and planned transitions, young people value flexible services which focus on individual needs, and span practical and social needs. Sometimes individuals wish to establish contact with birth families, so this should be facilitated where possible.

Related to the importance of addressing practical needs, a study by Barn et al (2006, ++ internal and ++ external validity) spoke to young people and professionals about leaving care. Young people in this study were concerned about debt and fear of losing their tenancies because of their lack of budgeting skills, and similarly in another study professionals felt that their lack of budgeting power hindered transition in that they had to “beg” for money on behalf of their young people (Hiles et al 2014, overall assessment ++).

Second, training of, and relationship with foster carers was also found to be helping care leavers during transition. It is also important to identify 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, including young offenders (Morris M & Stein M 2009, + internal and + external validity).

Two pilot evaluations (Right2BCared4 and Staying Put) included for the views questions were also coded to this question on factors that help or hinder purposeful and planned transitions (Munro et al 2011, - internal and + external

validity and Munro et al 2012, ++ internal and ++ external validity). Both these studies found that flexibility in terms of moving into independence facilitated the transition, especially with the option for young people to move back into foster care if they changed their minds. However, the studies also found that the importance of foster care depended on the relationship young people had with their foster carers, and so this was not an realistic option for many young people.

Third, the assessment of transition needs should include cultural needs. One of the studies found that pathway plans could hinder transition when they did not include a comprehensive assessment of all transition needs, and when they were not updated due to changed circumstances (Munro ER et al 2011, - internal and + external validity). Clarity in terms of transition planning was also identified by Hiles D et al (2014, overall assessment ++) and the uncertainly many young people face as they turn 18 and still do not know whether they can stay in their placement or whether they have to move on. Considering that young people in care are often there due to earlier traumatic experiences, the study comment on the paradox that they are not supported appropriately during this difficult period in their lives.

Two individual studies (Hiles et al 2014, overall assessment ++, Barn et al (2006, ++ internal and ++ external validity) reported professionals' concerns about lack of time and resources to provide sufficient transition support for care leavers, lack of training and a complicated system which meant that they often responded to crisis situations instead of investing in long-term quality relationships and working. Hiles et al 2014 also spoke about the lack of integration between services, especially CAMHS.

Barn et al (2006, ++ internal and ++ external validity) found that, despite the lack of a policy framework within services for meeting the needs of minority ethnic care leavers, there was evidence of culturally sensitive practice and awareness of the issues of diverse ethnic groups. Leaving care at an early age was identified as a key factor resulting in transition difficulties. Professionals expressed the need for suitable and proper training to ensure that staff were prepared to deal with young people from diverse backgrounds.

The involvement of care leavers was considered to be vital in shaping services.

- Transition for young people with learning disabilities or learning difficulties

Four studies looked at factors that help or hinder transition into adult services for young people with learning disabilities. These studies were quite different in their focus. One study by Kelly (2013, overall assessment ++) focused on general concerns during this period, as expressed by young people's key workers. Craston M et al (2013, ++ internal and + external validity) is the evaluation of the SEND pathfinder pilots, and this has only some relevance to our question as they did not focus specifically on the transition from children's to adults' service, but we did include it here since there were some pointers of relevance. Broadhurst et al (2012, overall assessment +) was an evaluation of the My Way transition programme and also included for our views questions. Finally, the study by Fraser (2012, overall assessment +) focused on barriers and facilitators in relation to self-directed support for young people, including during transition. Again, this study has part relevance for our scope and question, hence it is included here.

The study by Kelly (2013, overall assessment ++) found the following factors which can hinder purposeful and planned transition into adult services, as identified by the key workers of young people with learning disabilities:

Demands on the key worker role in terms of administrative tasks and increasing caseloads, resulting in not enough time with families and young people. Pressures on staff within the care sector was also found to be a factor that hinder transition in Broadhurst et al (2012, overall assessment +).

Contradictions between the goal of person-centred planning and available time and resources

Different cultures in children's and adult services: Person-centred planning was more regularly used in children's services in spite of a general opinion that person-centeredness should be the guiding philosophy of adult learning disability services too

Young people having little knowledge of disability rights or understanding of the social model of disability

Anxious parents wanting control over young people's personal relationships for fear of exploitation. This concern was also expressed in the narrative summary of 'views' studies.

This study found that key workers saw the carer assessment process as an opportunity to improve working relationships with families and develop an appreciation of the experiences and needs of carers (Kelly 2013, overall assessment ++).

The study by Fraser (2012, overall assessment +) focused on facilitators and barriers to informed choice in self-directed support for young people with disability in transition. Young people themselves felt that self-directed support had the potential to increase outcomes, choice and control for children with disabilities, but adults and practitioners were concerned about young people's capacity to choose their own care and that they might misuse funds. Another concern was that parents would have to bear the burden of managing the personalised budget and being the manager of the care package. Managers also suggested that conflicts could develop between the young person receiving services and their parents.

The study by Broadhurst et al (2012, overall assessment +) found that when the person-centred plan was implemented, this was a factor that helped with the transition.

- Transition for young people with learning disabilities placed in residential schools

Two good quality studies were found that focused specifically on transition for young people in residential schools. Beresford and Cavet (2009, overall assessment ++) was a comprehensive case study drawing on interviews with health and social care professionals, and Connexions staff, as well as young people themselves. In terms of barriers to transition, specific to this group, the study found:

- The ‘independent’ nature of the schools, which meant that they did not need to adopt government practice or procedures. Practitioners had no control or influence in this process or in how schools worked with the young person. In addition some schools had related adult residential provision which constituted a conflict of interests between the school and what local authority staff viewed as the best interests of the young person (transitioning the young person back into the home authority)
- The geographical distance between the home authority and the school resulting in logistical challenges in terms of visits by home authority staff. Also, the reason for the placement may still be present at transition: “Most of them 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) This was true also in terms of health care needs.
- Passing information between schools and other agencies (health and social care) could be problematic.
- There was a lack of established transition procedures.
- For some young people with communication challenges, there were difficulties accessing the young person’s views
- The placement in a residential school may have led to institutionalisation which for transition might result in difficulties in terms of transferring independence skills
- 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. Added to this is the loss of social networks.

This study also identified particular barriers related to health care transition, which is dual for these young people in that it is both a transition from children's to adults' services, and a transition between authorities. Particular problems were:

Delayed transfer of the young person’s GP from the host authority back to the home authority, clarifying responsibilities between home and host authorities with regard to funding and carrying out health assessments, health

professionals often not allowed by their job contracts to work outside of their authority – all these factors resulting in a period without health care (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.

Funding issues related to a young person's complexity of need: 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.

Heslop and Abbott (2007, overall assessment ++) was also an in-depth qualitative study, drawing on interviews with parents and young people, and social care practitioners. They found that the relationship between parents and professionals was an essential factor in enabling transition out of residential schools, and that this was enhanced when parents took an active part in negotiating with professionals and advocating on their child's behalf to get the best possible outcome. It is worth noting that this was resented by some respondents. Another factor that help transition is appropriate information to help young people and families make informed choices. Echoing a finding by Beresford and Cavet (2009, overall assessment ++), this study too found that 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 is essential to a successful transition.

Transitions for young people in criminal justice settings

We identified an inspection of transition arrangements in the criminal justice system, by the HM Probation Service. This is the first source of information we have found, to include for any of our questions, in regards to this population. However, this report talks about the transition arrangements within the criminal justice system, with limited reference to the role of social workers or health care teams (HM Probation (2012) Transitions: an inspection of the

transition arrangements from youth to adult services in the criminal justice system, Overall assessment ++).

Young people and young adults subject to community and custodial sentences were interviewed about their transition experiences. Practitioners and managers from criminal justice agencies, and partner agencies such as health, social care and education were also asked for their views.

There were examples of good practice, e.g. in the absence of appropriate adult health services, young people's health services sometimes stepped in. Many staff in both young people's and adult health services felt that they received appropriate information from each other during transfer and that decisions were usually based on where the young person's needs could be best met. Health services staff knew of local probation-Youth Offending Team (YOT) case transfer protocols, but having said this, most had been marginally involved in transfers.

The factors that hindered effective transitions included case transfer meetings not happening regularly and parents/carers seldom being invited. After transfer from YOTs to supervision by the probation trust and other adult services, new intervention providers did not always try to establish if there had been a former provider. Probation staff reported that neither the work of YOTs nor child and adolescent development was given prominence in their in-service training. Overall, there was inadequate timely sharing of information between youth-based and adult-based services to enable sentence plans to be delivered without interruption. This was a similar situation for young people in custody. And furthermore, 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.

Gaps in the evidence

There is a large amount of evidence on what hinder purposeful and planned transition from children's to adults' services, and hardly any evidence to address the problems identified.

1 # Evidence statements

ES #	Evidence statement
ES24	Lack of structured transitions programmes as hindrance to transition There is moderate quality evidence from 4 systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al (2013, + internal and + external validity, Watson R et al 2011,– internal validity and ++ external validity, Binks JA et al 2007 + internal validity and + external validity) and three individual studies (Care Quality Commission (2014, overall assessment ++, Por J et al 2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity) that the absence of a structured transition programme can hinder effective transition
ES25	Poor inter- and intra-agency communication and coordination Poor inter- and intra-agency coordination, gaps in levels of integration between sectors, lack of communication between paediatric and adult physicians and other adult care services in the community can hinder transitions, according to moderate quality evidence from three systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al 2013, + internal and + external validity, Binks JA et al 2007, + internal and + external validity), and 4 individual studies (Allen et al 2012, + internal and ++ external validity, Care Quality Commission 2014, overall assessment ++, Por J et al 2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity).
ES26	Lack of information as hindrance to transition There is moderate quality evidence from two systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al 2013, + internal and + external validity) and 4 individual studies (Beresford B et al 2014, overall assessment +, Care Quality Commission 2014, overall assessment ++, Por J et al 2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity) that insufficient information to young people and their parents/carers about transition and what it will entail will hinder transitions
ES27	Factors related to adult service culture and involvement There is moderate quality evidence from three systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al 2013, + internal and + external validity, Binks JA et al 2007, + internal and + external validity), and two individual studies (Garvey KC et al 2013, ++ internal and + external validity, Beresford B et al 2014, overall assessment +) that illustrates factors related to adult services can hinder transition. Specifically, these include the culture, approach, differences in care provided, lack of involvement, lack of preparation, lack of training and resources in adult services.
ES28	Limited access to specialist support in adult health services Lack of access to specialist and allied health professionals due to age limit, or higher eligibility criteria in adult services was identified as a factor which hinders transition by one good quality systematic review (Kime et al 2013, + internal and ++ external validity).
ES29	Resource and time limitations Lack of adequate resources and time hinder transitions (moderate quality evidence from one systematic review (Kime et al 2013, + internal and ++ external validity) and three individual studies (Shaw KL et al

	2004, + internal and ++ external validity, Care Quality Commission 2014, overall assessment ++, Sebastian S et al 2012, + internal and ++ external validity.
ES30	Professionals' and young people's preference for staying in paediatrics Resistance from paediatric care providers to "letting go" of their long-standing relationships with young patients and distrust of adult-centred health services can hinder transitions, as can the preference of young people and their parents to remain in paediatric services. This comes from moderate quality evidence from two systematic reviews by Kime et al 2013, + internal and ++ external validity, and Binks JA et al 2007 + internal and + external validity).
ES31	Limiting policies and protocols Rigid policies and protocols can hinder transitions, according to moderate evidence by three systematic reviews (Kime et al 2013, + internal and ++ external validity, Watson R et al 2011, – internal and ++ external validity, Binks JA et al 2007, + internal and + external validity).
ES32	Parental involvement as a barrier to transition Parental involvement has been identified by professionals as a barrier to transition. Conversely, lack of parental involvement has been identified by young people as a barrier to transition. This is based on good quality evidence in one systematic review (Kime et al 2013, + internal and ++ external validity, and three individual studies (Beresford B et al 2014, overall assessment +, Por J et al (2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity).
ES33	Opportunity to experience adult services pre-transition Meeting adult providers and visiting adult facilities in advance of transitioning can help transition. This is based on moderate quality evidence supported by four systematic reviews (Jordan L et al 2013, + internal and + external validity, Bloom R et al 2012, ++ internal and + external validity, Crowley R et al 2011,– internal and ++ external validity, Binks JA et al 2007, + internal and + external validity), and three individual studies (Beresford B et al 2014, overall assessment +, Kipps S et al 2002, - internal and ++ external validity, Por J et al 2004, + internal and ++ external validity). Related to this, there is low quality evidence from one systematic review (Binks JA et al 2007, + internal and + external validity), and one single study (Por J et al 2004, + internal and ++ external validity) that indicates early transition planning can help transition.
ES34	Transition plans that address health & lifestyle factors broadly, and involvement of GPs Transition plans that address lifestyle changes such as sexual health and drugs and which can be personalised to the young person's needs can help transition; (low quality evidence from one systematic review (Kime et al 2013, + internal and ++ external validity). as can involvement of General Practitioners in the transition (according to low quality evidence from one good quality report by the Care Quality Commission, 2014, overall assessment ++)
ES35	Importance of consistent provision There is moderate quality evidence from two good quality individual studies that a gap over 6 months from the transfer from paediatrics to the first adult clinic appointment is a barrier to successful transition (Downing J et al 2013, + internal and + external validity, Garvey KC et al

	2013, ++ internal and + external validity).
ES36	Factors that help and hinder transitions for specific conditions There is moderate quality evidence from a good quality systematic review by Binks et al (2007, + internal and + external validity) that the barriers to transition experienced by young people with spina bifida and cerebral palsy are similar to those experienced by young people with other complex health conditions. Similarly, the recommendations for young people with sickle cell disease, made by a systematic review of good quality (Jordan et al 2013, + internal and + external validity) are the same as those found in other reviews for all young people with long-term conditions and transition in healthcare settings. However, as identified in previous research reviewed for other questions, young people with autism appears to be at risk of a poorer transition than those with more or with less complex needs (Cheak-Zamora C et al 2013, + internal and + external validity). And one individual study found that young people with multiple conditions (comorbid medial conditions) were more likely to transfer successfully (Reid GJ et al 2004, + on internal and ++ external validity). The same study found that young people with substance misuse problems were more likely to not transfer successfully to adult care. There is moderate quality evidence from one good quality systematic review that there are particular barriers for young people with HIV when transitioning to adult care, related to increased stigma, difficulty with adherence to medication regimen, difficulty with adolescent sexuality, and the young people often coming from disorganised social environments (Kime et al 2013, + internal and ++ external validity).
ES37	Distance between clinic and home as a barrier to transition There is low quality evidence from two individual studies that the longer the distance from a young person's home to the adult clinic the less likely that the young person would transition successfully (Reid GJ et al 2004, + internal and ++ external validity, Andemariam et al 2014, - internal and + external validity).
ES38	Evidence on effective transition interventions/programmes One systematic review concluded that a lack of service evaluations and agreed process and outcome measures for transition hinder opportunities for comparing different service models and guide service development. This included a lack of formal evaluation of the experience of users against any outcome measures. Many of the reported service models highlight that young people have different individual experiences of transitional care and recognize the need for flexibility when supporting transfer of clinical care. It is important to be able to record these experiences in a systematic way (Watson R et al 2011,– on internal and ++ external validity).
ES39	Factors helping transition out of care There is evidence from one good quality systematic review and four good quality individual studies, that factors which help young people transition out of care relate to the process of independence being flexible, gradual and supported by professionals and carers. There is evidence from two good quality individual studies that the current system of care can hinder successful transitions, due to lack of resources and time for professionals to work with young people in-depth and long-term to address these factors.
ES40	Long-term planning of post-school support for young people in out-of-

	authority residential school placements An important factor that help transition for young people placed in out of authority residential schools is early long-term planning of what will happen after they leave this school. This is evidenced by findings from two high quality qualitative studies (Beresford and Cavet 2009, overall assessment ++, Heslop and Abbott 2007, overall assessment ++). It may be that the SEND pathfinder approach will improve this situation (Craston M et al 2013, ++ internal and + external validity).
ES41	Factors that hinder transition for young people in out-of-authority residential schools Factors that hinder transition for young people placed in out-of-authority residential schools are, evidenced by one high quality qualitative study (Beresford and Cavet 2009, overall assessment ++): Geographical distance between the school and home authority The independent nature of schools which means they do not need to collaborate on transition planning Competing business interest of some independent schools and adult placements for young people, against local authority guidelines which stipulate that one long-term goal is for the young people to return to their original home authority Complex health care needs which were present at the time of referral to the residential school are still there at the time of transition, and so the needs for moving out of authority are still in place. Institutionalisation of young people who have spent a long time in residential schools, leading to challenges in terms of preparation for independence. Moving from the residential school might result in loss of friendships and present challenges in terms of moving back to a family they no longer 'know'.
ES42	Factors that hinder health care transition for young people in out-of-authority residential schools Factors that hinder successful health care transitions for young people placed in out-of-authority residential schools, evidenced by one high quality qualitative study (Beresford and Cavet 2009, overall assessment ++): Structural arrangements which hinder health professionals in visiting young people out of authority, and which hinder transfer of young people from one authority to another (e.g. changing GPs). Funding discussions in terms of which sector/agency is in charge of which part of the overall care package. Factors which hinder transition for this group of young people, and which are similar for all young people with a disability and across health and social care: Lack of transition plan or model Lack of integrated information sharing between agencies and sectors Involving young people who have communication challenges in their transition planning These factors were identified by a range of studies reviewed for this question, and conducted in health care settings, and were also identified by one high quality study for this population (Beresford and Cavet 2009,

	overall assessment ++).
ES43	Transition protocol or plan Having a transition protocol or plan is a factor that help young people with learning disabilities transition into adult services, here evidenced by two good quality studies (Craston et al 2013, ++ internal and + external validity, Mills et al 2013, overall assessment +).
ES44	Self-directed support If good practice in transition is seen to include self-directed support to young people, there is evidence from one good quality qualitative study (Fraser 2012, overall assessment +) that young people like the idea, but that its implementation might be hindered by adults' concerns about young people's capacity.
ES45	Factors that hinder purposeful and planned transitions: Time and resources pressures was found to be another factor which hinders transitions for this group, also identified for other groups and in other settings, and here evidence by one high quality study from Northern Ireland (Kelly 2013, overall assessment ++). The same study (Kelly 2013, overall assessment ++) also mirrored the finding that different cultures in children's and adult services can be a factor that hinders purposeful and planned transitions. It is the experience of social care practitioners, evidenced here by one high quality study (Kelly 2013, overall assessment ++), that parents' concerns about young people's vulnerability is a factor that makes transition planning challenging.
ES46	Overall factors that impact on mental health transitions Overall, factors identified as hindering or helping the transition of young people from CAMHS to AMHS mirrored many of those identified for other settings: Lack of young adult friendly services was found by one high quality systematic review by Paul et al (2014, ++ on internal and ++ on external validity), and one high quality study by Richards and Vostanis (2004, overall assessment ++). Lack of integration with other services, and poor communication, both between other services and between children's and adult services, found by two systematic reviews (Paul et al 2014, ++ on internal and ++ on external validity, Swift et al 2013, ++ on internal and + on external validity) and one high quality qualitative study (Richards and Vostanis 2004, overall assessment ++) One high quality qualitative study found that CAMHS staff felt unclear about the social care transition and isolated from general health and social care transition processes (Kaehne 2011, overall assessment ++). As for some physical health conditions for which there is now increased survival into adulthood, there is also for some mental health conditions a lack of services due to the conditions being considered limited to childhood and adolescence. This was evidenced by three systematic reviews (Paul et al 2014, ++ internal and ++ on external validity, Swift et al 2013, ++ on internal and + on external validity, and Montano and Young 2012, - on internal and – on external validity), and one individual study (Singh et al 2010, overall assessment ++).
ES47	Eligibility thresholds Specific to some young people using CAMHS, a factor which hinders

	their transition into adult services is that they are not deemed eligible due to high service thresholds, this was identified by all included studies (two high quality and one low quality systematic review, and three high quality individual studies).
ES48	The impact of being on medication or hospitalised Specific to some young people using CAMHS, a factor which helps their transition into adult services is if they have a severe condition which has resulted in them being on medication or being hospitalised. This is supported by two high quality systematic reviews (Paul et al 2014, ++ on internal and ++ on external validity, Swift et al 2013, ++ on internal and + on external validity) and two high quality individual studies (Kaehne 2011, overall assessment ++, Richards and Vostanis 2004, overall assessment ++).

Economics

This is a summary of the results of the economic analysis and any modelling undertaken for this review question. For further details on economic modelling, please see Appendix C3.

An economic analysis was attempted on the “Staying Put 18+” program (Munro et al 2012) (in comparison to standard care leaving services). It was selected in agreement with the Guideline Committee after considering the lack of other available options (see rationale below). However, due to the limitations in study design the results could not be used reliably for an economic analysis. Therefore, there was no economic modelling based on this study.

No other economic models were attempted for a range of reasons:

1. The poor quality of the evidence with respect to internal validity.

Hagner (2012), Prestidge (2012), Pole (2013), Nakhla (2009); Cadario (2009); MacDonald (2009), Certo (2003)

2. Where one study (Huang, 2014, US study, ++/+) did find positive results, these were in intermediate outcomes. The specific intermediate outcomes that improved included “Disease management”, “Health-related self-efficacy”, and “Patient-initiated communication. Additional economic analysis would be useful where these could be linked to final health outcomes.

However, we anticipated it would be unlikely to find data to support such links to final health outcomes to support a cost-utility analysis.

3. In another instance, (Betz, 2010, US study, +/+) the quality of the evidence was good, but the intervention demonstrated no benefit. Therefore, no new information would be generated in conducting economic analysis.

4. In another study, (Bent, 2002, UK study, +/++) the quality of the evidence was good, the intervention demonstrated benefit, but the evidence on cost-effectiveness was available and there was no need for additional economic analysis. Furthermore, there was not a significant amount of uncertainty associated with results to warrant further economic analysis.

5. The Guideline Committee did not consider the specific intervention itself to be a priority for analysis (Lee, 2011, US study, +/+). Specifically, the Guideline Committee wanted to emphasise that the intervention needs to be delivered in a way that is understandable to the individual rather than to emphasise and recommend the intervention specifically.

3.7 Evidence to recommendations

This section of the guideline details the links between the guideline recommendations, the evidence reviews, expert witness testimony and the Guideline Committee discussions. The information is presented in a series of linking evidence to recommendations (LETR tables).

Linking Evidence to Recommendations (LETR) tables

Topic/section heading	Overarching principles
Recommendations	1.1.1 Involve young people and carers in all aspects of service design, delivery and evaluation related to transition by: • considering co-producing transition policies and strategies with them • asking them whether the services helped them achieve agreed outcomes • considering co-producing, planning and piloting materials and tools • feeding back to them about the effect their involvement has had.

	1.1.2 Use person-centred approaches to ensure that transition support: • takes full account of the young person's views and needs • is strengths-based and focuses on what is positive and possible for the young person rather than on a pre-determined set of transition options • identifies the support available to the young person, which includes but is not limited to their family or carers • is developmentally appropriate, taking into account their maturity, cognitive abilities, needs in respect of long-term conditions, social and personal circumstances and psychological status • treats the young person as an equal partner in the process • supports the young person to make decisions and builds their confidence to direct their own care and support over time • fully involves the young person in terms of the way it is planned, implemented and reviewed • addresses all relevant outcomes, including those related to employment, community inclusion, health and wellbeing including emotional health, and independent living • involves agreeing goals with the young person • includes review of the transition plan with the young person at least annually or more often if their needs change. 1.1.3 Health and social care service managers should work together in an integrated way, involving colleagues in education to ensure a smooth and gradual transition for young people moving from children's to adults' services[25]. This could involve, for example, developing: • a joint mission statement or vision for transition • jointly agreed and shared transition protocols, information-sharing protocols and approaches to practice. 1.1.4 Service managers in both adults and children's services, across health and social care, should proactively identify and plan for young people in their locality with transition support needs. 1.1.5 Every service involved in supporting a young person should take responsibility for sharing safeguarding information with other organisations.
Research recommendations	Transition support for young adults • What approaches to providing transition support for those who move from children's to adults' services are effective and/or cost-effective?
Review questions	What are young people's experiences of transitions? What works well?

[25] For young people with education health and care (EHC) plans (see the gov.uk guide), local authorities and health commissioners **must** work together in an integrated way, as set out in the Children and Families Act 2014.

	What are the experiences of families and carers and in respect of young people's transitions? What works well? What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research? What is the effectiveness of support models and frameworks to improve transition from children's to adults' services? These models include early transition planning, joint working or protocols between children's and adult services, and signposting young people to, or offering them support from, the voluntary and community sector. What is the effectiveness of interventions designed to improve transition from children's to adults' services? These interventions include any specific intervention which is there to support transition, for example keyworkers, transition clinics or information evenings, provided by any agency, statutory or voluntary.
Quality of evidence	There is a large research literature on the transition from children's to adults' services. Much of this literature are opinion pieces and expert reviews, primarily stating the problems encountered by service users, carers and clinicians in advance of, during and after transfer. We did not find good quality evidence on effective approaches to deliver transitional care but we found good quality evidence on people's views and experiences. Several evidence statements were backed up by systematic reviews, but this can be misleading because the reviews all noted the lack of good quality evidence on effective approaches and their conclusions were, like ours, based on a combination of low-quality effectiveness evidence and good quality views evidence. The principles of good transitional care practices outlined in these recommendations are based on a combination of research and expert opinion. They reflect findings from a raft of studies, of varying quality and design.
Relative value of different outcomes	These recommendations are not based on studies measuring outcomes. The qualitative research literature based on stakeholders' views indicate some principles for good transitional care, which are reflected in these recommendations.
Trade-off between benefits and harms	These recommendations were informed predominantly by data on views and the Guideline Committee's experiences. Views data and the Guideline Committee's experiences indicate that good transitional care depends on the principles laid out across these first five recommendations.
Economic considerations	ES6
Evidence statements – numbered evidence statements from which the recommendation(s)	ES19 (RECs 1.1.1 and 1.1.2)(REC 1.1.1). ES4 (REC 1.1.2). ES11 (REC 1.1.2).

were developed	ES23 (REC 1.1.2). ES30 (REC 1.1.2). ES6 (RECs 1.1.1 and 1.1.3). ES8 (RECs 1.1.1 and 1.1.3). ES7 (REC 1.1.4). ES9 (REC 1.1.5).
Other considerations	These overarching principles reflect findings in the research literature, presentations by expert witnesses and experiences and expertise represented on the Guideline Committee. In particular, expert witness Julie Pointer stated that transition planning for young adults with additional needs is best conducted in a person-centred way, and this is supported by the Children and Families Act 2014 and the Code of Practice. Based on the expert witness presentation from Peter Winocour, the Guideline Committee agreed on the importance of involving people who use services in service design to ensure they are delivered in a way that is more likely to ensure young people use them, i.e. at the right times (not just evenings or weekends), in an informal way. When discussing the evidence on information-sharing, the Guideline Committee also talked about the importance of being able to share information appropriately about safeguarding concerns.

1

Topic/section heading	**Transition planning: Named worker**
Recommendations	1.2.1 Help the young person to identify a single named worker to coordinate their transition care and support. 1.2.2 The named worker: • could be, for example, a nurse, youth worker or another health or social care practitioner, depending on the young person's needs • should be someone with whom the young person has a meaningful relationship • should initially be someone in children's or young people's services but should hand over their responsibilities to someone in adult services when appropriate. 1.2.3 The named worker should: • be the link between the young person and the various practitioners involved in their support • help the young person navigate services

	• support the young person's family, if appropriate • act as a representative for the young person, if required (that is to say, someone who can provide advice, support or advocate for them) • proactively engage primary care in transition planning and direct the young person to other sources of support and advice, for example peer advocacy support groups provided by voluntary and community sector services • think about ways to help the young person to get to appointments, if needed • provide advice and information • ensure that the young person is offered support, as appropriate, with the following aspects of transition (which may include directing them to other services): • employment • community inclusion • health and wellbeing, including emotional health and independent living. 1.2.4 The named worker should support the young person for: • the time defined in relevant legislation, or • a minimum of 6 months before and after transfer (the exact length of time should be negotiated with the young person).
Research recommendations	Transition support for young adults • What approaches to providing transition support for those who move from children's to adults' services are effective and/or cost-effective?
Review questions	What are young people's experiences of transitions? What works well? What are the experiences of families and carers and in respect of young people's transitions? What works well? What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research? What is the effectiveness of interventions designed to improve transition from children's to adults' services? These interventions include any specific intervention which is there to support transition, for example keyworkers, transition clinics or information evenings, provided by any agency, statutory or voluntary.
Quality of evidence	The evidence on the effectiveness of a named worker is limited, but these recommendations respond to overwhelming evidence in regards to lack of information before, during and after transfer, as well as concerns by young people and carers on how to manage the transition on their own.
Relative value of different outcomes	Two of the studies from the supporting evidence statements evaluated outcomes from an intervention that included a named worker. One of these studies (Cadario et al 2009 -/++) found indications that having a transition co-ordinator in the last year of

	children's services improved the mean rate of HbA1c in young adults with type 1 diabetes. It also found improved attendance in adult services as a result of the co-ordinator, as well as attendance during transition. No change was found on service satisfaction. The other study (Prestidge et al 2012 -/++) evaluated a renal transplant transition clinic which included additional support from individual team members (nurse, dietician and youth worker). After the introduction of the clinic none of their transitioned young adults experienced graft loss.
Trade-off between benefits and harms	Evidence in support of a named worker during transition is primarily based on good quality views evidence and on expert witness evidence on the importance of coordinated support. It is worth noting one exception, Kelly 2013 (Internal validity ++, Relevance to guideline: Highly relevant). This study found that when some areas had designated transition coordinators and others had embedded the transition support function within the remit of the key worker role, this led to some confusion about roles. In this study young adults and their families reported varied experiences of key worker support during their transitional years. Good practice of key workers included building trusting relationships, regular contacts, prioritising of young people's and parents' views, signposting to other sources of support and advocacy. Poor practice was inconsistent contact, lack of follow up after a crisis in the family, and breaks in access workers at key transitional times.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES4 (REC 1.2.1 and REC 1.2.2). ES6 (REC 1.2.1 and REC 1.2.3) ES14 (RECs 1.2.3 and 1.2.4). ES16 (RECs 1.2.1, 1.2.2, 1.2.3 and 1.2.4). ES21 (RECs 1.2.1 and1.2.2). ES22 (RECs 1.2.1, 1.2.2, 1.2.3 and 1.2.4)
Other considerations	Expert witness Peter Winocour stated that a fully resourced multi-disciplinary team appears critical to implementation, including a named worker to support transition care and the actual transfer of care. Expert witness Robert Carr explained how their service users are often uncertain of who to contact in services. They have found it effective to have a named worker (lead nurse) who is accessible via text and who provides information and advice. Expert witness Janet McDonagh stated that: "The potential of a transitional care coordinator is obvious from the complex nature of health transition ... However it continues to be under-recognised in many who already undertake this role [Shaw 2014].

	It is important to state that this does not necessarily have to be a nurse or other health professional and may be a youth worker or indeed a more basic health navigator role [van Walleghem 2008]."

1

Topic/section heading	Transition planning: Timing and review
Recommendations	1.2.5 Ensure the transition planning is developmentally appropriate and takes into account each young person's capabilities, needs and hopes for the future. The point of transfer should not be based on a rigid age threshold. 1.2.6 Hold an annual meeting to review transition planning, or sooner if needed [26]. This should: • involve all professionals providing support to the young person and their family or carers • inform a plan that is linked to other plans the young person has in respect of their care and support. 1.2.7 Start transition planning early for young people in out-of-authority placements. 1.2.8 For groups not covered by legislation, health, social care and education, practitioners should start planning for adulthood from year 9 (age 13 or 14) at the latest[27] . For those entering the service close to transition age, planning should start immediately.
Research recommendations	Transition support for young adults • What approaches to providing transition support for those who move from children's to adults' services are effective and/or cost-effective?
Review questions	What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services?
Quality of evidence	The evidence on which these recommendations are based is primarily of moderate quality and not specifically focused on the impact of early planning. Overall, the lack of preparation was found to be a barrier to young adults experiencing a good transition into adult services.
Relative value of different outcomes	We did not identify any outcome studies which evaluated the impact of early planning. However, when reviewing literature on factors that help or hinder transition, views literature indicated that sudden and abrupt transfers were unhelpful.
Trade-off between benefits and harms	We did not find any studies which indicated that planning the transition was harmful.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.

[26] For young people with a child in need plan, an EHC plan or a care and support plan, local authorities **must** carry out a review, as set out in the Children Act 1989, the Children and Families Act 2014 and the Care Act 2014.

[27] For young people with education, health and care (EHC) plans, this **must** happen from year 9, as set out in the Children and Families Act 2014. For young people leaving care, this **must** happen from age 15-and-a-half.

Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES2 (REC 1.2.7) ES4. (REC 1.2.8). ES12 (REC 1.2.5, 1.2.6, 1.2.7 and 1.2.8) ES24 (REC 1.2.7) ES39 (REC 1.2.5) ES40 (REC 1.2.5) ES42 (REC 1.2.5) ES43 (RECs 1.2.5, 1.2.6, 1.2.7 and 1.2.8)
Other considerations	Expert witness Janet McDonagh spoke about the importance of developmentally appropriate care across all service. Developmentally appropriate care is care that which is responsive to the developmental needs of young people aged 10-24 years (citing Farre et al 2014). She argued that if healthcare is developmentally appropriate, much of the additional transitional support becomes redundant, because care will be similar irrespective of where it is delivered. The Guideline Committee also discussed the complexities of out-of-authority placements, in response to the evidence on this matter. They agreed that, most important in this respect was early planning, to take into account fully the wide range of factors potentially affecting young people and their families in this context.

1

Topic/section heading	**Transition planning: Involving young people**
Recommendations	1.2.9 Offer young people help to become involved in their transition planning. This may be through: • peer support • coaching and mentoring • advocacy • the use of mobile technology. 1.2.10 Service managers should ensure a range of tools are available to help young people communicate effectively with practitioners. These may include, for example, communication passports, communication boards, 1-page profiles and digital communication tools.
Research recommendations	Transition support for young adults • What approaches to providing transition support for those who move from children's to adults' services are effective and/or cost-effective?

Review questions	What are young people's experiences of transitions? What works well? What are the experiences of families and carers and in respect of young people's transitions? What works well?
Quality of evidence	These recommendations are derived from a combination of research evidence and the guideline committee's own expertise. A range of good quality studies informed different aspects of these recommendations. Two studies measured outcomes from interventions which included aspects of young people's involvement (Nesmith and Christophersen 2014 +/+, Huang et al, 2014, ++/+). Two systematic reviews (Kime et al 2013, + internal and ++ external validity, Jordan L et al 2013, + internal and + external validity) and 4 individual studies (Beresford B et al 2014, overall assessment +, Care Quality Commission 2014, overall assessment ++, Por J et al 2004, + internal and ++ external validity, Shaw KL et al 2004, + internal and ++ external validity) concluded transitions from children's to adults' services are hindered by insufficient information to young people and their parents/carers about what will happen during this period and after.
Relative value of different outcomes	Nesmith and Christophersen 2014 +/+ found that young people in the intervention where they were involved were slightly more satisfied with their care than those receiving foster care as usual (independent living skills training). Young people's relationship competencies decreased in the comparison group while remained the same in the intervention group. There was little difference between the groups in terms of their motivation for developing relationships with supportive adults, relationship-building skills, or in the identification of their most important supportive adult.
Trade-off between benefits and harms	We did not find any evidence of harm from involving young people in their transition planning. We found some evidence to suggest that in order to be person-centred, the transition planning needs to involve the young person.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES1 (REC1.2.9) ES5 (REC 1.2.9)
Other considerations	The involvement of young people reflects priorities in a raft of recent policy documents for specific groups covered by this guideline and overall for young people accessing health and social care.

1

Topic/section heading	Transition planning: Building independence
Recommendations	1.2.11 Consider opportunities for young people to have peer support and mentoring during transition from children's to adults' services. 1.2.12 Include support for young people to develop and sustain social, leisure and recreational networks in the transition plan. Put young people in touch with peer support groups if they want such contacts. This may be provided by voluntary- and community-sector organisations, such as specific support groups or charities. 1.2.13 Include information and signposting to alternative non-statutory services in transition planning. This may be particularly important for people who do not meet the criteria for statutory adult services. 1.2.14 Everyone working in health, social care and education should support all young people who continue to receive support from social services into adulthood. The support should help them to build autonomy in respect of their: • employment • community inclusion • health and wellbeing, including emotional health • independent living. 1.2.15 For young people with disabilities in education, the named worker should liaise with education practitioners to comprehensive student-focused transition planning is provided. This should involve peer advocacy, and friends and mentors as active participants. 1.2.16 If the young person has long-term conditions, ensure they are helped to manage their own condition as part of the overall package of transition support. This should include an assessment of the young person's ability to manage their condition, self-confidence and readiness to move to adult services. 1.2.17 For detailed recommendations on supporting looked-after children moving to independent living see 'Preparing for independence' in NICE's guideline on looked-after children.
Research recommendations	Support to carers and practitioners to facilitate young people's independence • What is the most effective way to help carers support young people's independence? Supporting people to manage their own conditions • What is the relationship between transition and subsequent self-management?
Review questions	What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research? What is the effectiveness of interventions designed to improve transition from children's to adults' services? These interventions include any specific intervention which is there to support transition, for example keyworkers, transition clinics or information

	evenings, provided by any agency, statutory or voluntary.
Quality of evidence	These recommendations are underpinned by a combination of different study designs and the studies speak to these recommendations in different ways. As for all other recommendations in this guideline there is no good quality evidence on the effect of particular transition support interventions. There is good quality qualitative evidence on young people's and parents' views and this has been combined with expert witnesses' statements and presentations, and the Guideline Committee's experiences and expertise.
Relative value of different outcomes	For young people transitioning out of foster care Powers et al (2012, +/+) found that a combination of coaching and mentoring can improve young people's quality of life, but did not find impact on their engagement in the transition planning. For disabled young people Cobb and Alwell (2009, +/+) found that student-focused planning increased their participation in planning meetings by a moderate degree (Cobb and Alwell, 2009, +/+). There is evidence from one small study of low quality (Hagner et al, 2012, -/+) that student-focused planning does not impact students' self-determination. There is evidence from one study of good quality that a particular type of reading technology (Rocket Reader) can have a small impact on students 'self-determination' in advance of transition (Lee et al, 2011, +/+). It is worth noting that two RCTs (Betz et al, 2010, +/+, Mackie et al, 2014, +/+) found no impact from one-off transition training interventions for young people.
Trade-off between benefits and harms	The reviewing for this guideline has focused on research on transition from children's to adults' services. This means that some relevant interventions, such as self-management of long-term conditions, have not been included unless they were specifically part of a transition programme and published as such. A consideration of the benefits and harms of these interventions is beyond the remit of this review but highly relevant to the recommendations provided here.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES1 (REC 1.2.11) ES2 (RECs 1.2.11 and 1.2.12). ES12 (RECs 1.2.14 and 1.2.15) ES14 (REC1.2.12 and 1.2.13) ES28 (REC 1.2.13)
Other considerations	Expert witness Robert Carr spoke of how Facebook had supported the development of a peer group among their service

	users. Their named worker (lead nurse) would facilitate and monitor this. Expert witness Janet McDonagh emphasised that both young people and carers need training to prepare for transition, and that training needs to be tailored to the kind of adult service they will be accessing.

1

Topic/section heading	Transition planning: Involving parents and carers
Recommendations	1.2.18 Ask the young person how they would like their parents or carers to be involved throughout their transition, including when they have moved to adult services. 1.2.19 Discuss the transition with the young person's parents or carers to understand their expectations about transition, recognising that the young person's preferences about their parents' involvement may be different and should be respected. 1.2.20 Help young people develop confidence in working with adult services by giving them the chance to raise concerns and queries separately from their parents. 1.2.21 Adult services should take into account the individual needs and wishes of the young person when involving parents or carers in assessment, planning and support[28].
Research recommendations	The role of families in supporting young adults discharged from children's services • What is most effective way of helping families to support young people who have been discharged from children's services (whether or not they meet criteria for adults' services)? Support to carers and practitioners to facilitate young people's independence • What is the most effective way to help carers support young people's independence?
Review questions	What are the experiences of families and carers and in respect of young people's transitions? What works well?
Quality of evidence	The role of carers/parents was discussed across several good quality studies.
Relative value of different outcomes	These recommendations are not based on any studies measuring outcomes.
Trade-off between benefits and harms	We did not identify any studies which identified carer involvement as harmful, although we did identify studies where carers/parents were seen as barriers to transition, and studies where young adults said that the lack of parental involvement was problematic after transfer to adult services.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.

[28] For young people with an EHC plan or a care and support plan, this **must** happen, as set out in the Children and Families Act 2014 and the Care Act 2014.

Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES19 (RECs 1.2.18 and 1.2.20)(RECs 1.2.19 and 1.2.20). ES20 (RECs 1.2.18, 1.2.19, 1.2.20 and 1.2.21) ES21 (RECs 1.2.19 and 1.2.20) ES24 (RECs 1.2.18, 1.2.19, 1.2.20 and 1.2.21).
Other considerations	There was a considerable amount of good quality review evidence on this topic, as summarised above which the Guideline Committee recognised from their own experience and supported. In particular, both evidence and examples provided by the Committee emphasised the need to: promote choice and control, recognise that there is no 'one size fits all' approach to involvement; keep both parents and young people informed; and, provide opportunity to work with both parents and young people separately.

1

Topic/section heading	**Support before transfer**
Recommendations	1.3.1 Service managers should ensure that a named worker from the nominated adult service meets the young person before they transfer from children's services. 1.3.2 Service managers should ensure that there is a contingency plan in place for how to provide consistent transition support if the named worker leaves their position. 1.3.3 Consider working in collaboration with the young person to create a personal folder that moves with the young person when they transfer from children's to adults' services. The folder should be in the young person's preferred format. The folder could contain: • a 1-page profile • information about their health condition • history of care interventions • preferences about parent and carer involvement • emergency care plans • unplanned admissions • their strengths, achievements, hopes for the future and goals. 1.3.4 All services should provide young people and their families or carers with information about what to expect from services and what support is available for them. This information should: • be in an accessible format, depending on the needs and preferences of the young person (this could include, for example, written information, computer-based reading programmes, audio and braille formats for people with disabilities) • describe the transition process

	• describe what support is available before and after transfer • describe where they can get advice about benefits and what financial support they are entitled to.
Research recommendations	Self-management • What is the relationship between transition and subsequent self-management?
Review questions	What are young people's experiences of transitions? What works well? What are the experiences of families and carers and in respect of young people's transitions? What works well? What is the effectiveness of interventions designed to improve transition from children's to adults' services? These interventions include any specific intervention which is there to support transition, for example keyworkers, transition clinics or information evenings, provided by any agency, statutory or voluntary. What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research?
Quality of evidence	The evidence for these recommendations is not about the effectiveness of providing information but draws on young people and their carers' experiences of not receiving information and how this impacted on their transition experiences. The evidence on this is of good quality.
Relative value of different outcomes	The evidence on which these recommendations are based did not measure outcomes.
Trade-off between benefits and harms	No evidence of harm was identified in any of the reviewed studies, in terms of providing information to people, providing them with a personal folder, or providing them with the opportunity to visit adult services in advance of the transfer.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES13 (RECs 1.3.1 and 1.3.4) ES24 (REC 1.3.4) ES26 (RECs 1.3.1, 1.3.2 and 1.3.4) ES27 (REC 1.3.1, 1.3.2, 1.3.3 and 1.3.4) ES33 (REC 1.3.1)
Other considerations	The recommendation about the personal folder is based on expert witnesses' statements and presentations, and members of the Guideline Committee's own expertise and experiences. In particular, the Guideline Committee was impressed by the description of a personal folder by expert witness Julie Pointer, including how this needs to capture how a young adult

	communicates, as well as being aspirational rather than deficit-oriented. Recommendation 1.3.2 about having a plan in place in case a named worker leaves their job, is based on findings from the study by Kelly (2013, Internal validity++, Relevance to guideline: Highly relevant) which found that inconsistent and fragmented support by keyworkers was unhelpful during transition. Expert witness Janet McDonagh also spoke about the importance of sustainability for transitional support: "Factors determining sustainability include committed teams rather than individuals, funding, institutional support and recognition, effective succession planning of key individuals" Expert witness Robert Carr described how their young adult team had effectively used Facebook to communicate with service users, and to facilitate peer support between service users. Feedback from young adults indicate that this was a highly successful and appreciated initiative.

1

Topic/section heading	**Support before transfer: Support from the named worker**
Recommendations	1.3.5 Consider ways to help the young person become familiar with adult services. This could be through the use of young adult support teams, joint or overlapping appointments, or visits to the adult service, with someone from children's services. 1.3.6 Support young people to visit adult services they may potentially use, so they can see what they are like first-hand and can make informed choices. 1.3.7 If a young person is eligible for adult social care services, the named worker: must make sure the young person is given information about different mechanisms for managing their care and support such as personal budgets. should give the young person the opportunity to test out different mechanisms for managing their care, in order to build their confidence in taking ownership of this over time. This should be done using a stepped approach. 1.3.8 If a young person is not eligible for statutory adult care and support services, make sure that they are given information about alternative support. 1.3.9 If a young person does not meet the criteria for specialist adult health services, involve the GP in their transition planning.
Research recommendations	Transition support for young adults • What approaches to providing transition support for those who move from children's to adults' services are effective and/or cost-effective?
Review questions	What are young people's experiences of transitions? What works well? What are the experiences of families and carers and in respect of young people's transitions? What works well?

	What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research? What is the effectiveness of interventions designed to improve transition from children's to adults' services? These interventions include any specific intervention which is there to support transition, for example keyworkers, transition clinics or information evenings, provided by any agency, statutory or voluntary.
Quality of evidence	No high quality evaluations of effectiveness or impact were identified in the search, and so all the recommendations are based primarily on suggestive studies and qualitative evidence. The qualitative evidence found was overall of good quality, although we did include some study reports which were of low quality but of very high relevance. A whole range of overall good quality studies support the recommendation that young people have the opportunity to meet with adult providers in advance of the transfer. The recommendation on the named workers role in providing information about self-directed care options and personal budgets is based on two good quality studies and is important because some young people will be offered personal budgets and/or self-directed care. There is good quality evidence to suggest that many young people fall short of the threshold of adult services, and that this is problematic. The role of GPs is less explored in the research literature.
Relative value of different outcomes	These recommendations are not based on outcome evaluations.
Trade-off between benefits and harms	No study was found that showed harm from meeting adult services in advance, or involving GPs in the transition. However, we did identify a whole range of studies which found a problematic situation where young people were not eligible for adult services, or where adult services were not available. This is particularly true for young people for conditions where the life expectancy has increased due to medical advancement, and young people with mental health problems.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	(REC 1.3.5 and 1.3.6). ES13 (REC 1.3.7). ES21 (REC 1.3.7). ES44 (REC 1.3.7). ES47 (REC 1.3.8).

	ES34 (REC 1.3.9).
Other considerations	Expert witness Janet McDonagh stated that it is essential that adult services recognise transition as their concern and responsibility. The Guideline Committee thought that joint appointments and joint training initiatives could enhance collaboration across services.

1

Topic/section heading	Support after transfer
Recommendations	1.4.1 If a young person has moved to adult services and does not attend meetings or appointments or engage with services, adult health and social care should: • follow up the young person • involve other relevant professionals, including the GP • try to contact the young person and their family. 1.4.2 If, after assessment, the young person does not engage with health and social care services, the relevant provider should refer back to the named worker with clear guidance on re-referral (if applicable). 1.4.3 If a young person does not engage with adult services and has been referred back to the named worker, the named worker should review the person-centred care and support plan with the young person to identify: • how to help them use the service, or • an alternative way to meet their support needs. 1.4.4 Ensure that the young person sees the same healthcare practitioner for the first 2 attended appointments after transition. 1.4.5 Ensure that the young person sees the same social worker throughout the assessment and planning process and until the first review of their care and support plan has been completed.
Research recommendations	Transition support for young adults • What approaches to providing transition support for those who move from children's to adults' services are effective and/or cost-effective?
Review questions	How can adult services support effective transition for young people in transition? What are young people's experiences of transitions? What works well? What are the experiences of families and carers and in respect of young people's transitions? What works well? What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research?
Quality of evidence	While there are a whole range of studies which have pointed out the risk of non-attendance as young people move from children's to adults' services, we did not identify any good quality studies which had evaluated interventions to reduce non-attendance.

	However, we did identify two good quality studies to support these recommendations, both of which found a relationship between attendance and the length of time before the adult appointment (Downing et al 2013 +/+, Garvey et al 2013 ++/+).
Relative value of different outcomes	Attendance levels are seen to be important in terms of long-term care.
Trade-off between benefits and harms	No harmful effects were identified in the included studies.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES35 (RECs 1.4.1, 1.4.2 and 1.4.3)
Other considerations	Overall, evidence on adult services was found to be limited and of poor quality. At meeting 6 the Guideline Committee discussed the papers presented then developed recommendations by consensus (also identifying that an expert witness should be invited to supplement the review evidence). They also referred to papers included in the review for ES6 although recognised limitations. They provide examples of where procedures or policies result in young people being discharged from adult services without having been seen. These recommendation seeks to remedy that. While this came from a discussion about health services, it was agreed that the recommendation is generalizable to other services (post-Guideline Committee 8 written feedback). This was further discussed and agreed at committee meeting 10.

1

Topic/section heading	**Training and development for staff**
Recommendations	1.5.1 Local authorities, local education and training boards and NHS trusts should ensure that everyone working with young people in transition up to the age of 25, in children's and adult services, understands: • young people's communication needs • young people's development (biological, cognitive, psychological, psychosocial, sexual, social) • the legal context and framework related to supporting young people through transition, including consent and safeguarding • special educational needs and disabilities • how to involve carers and families in a supportive, professional way.

	1.5.2Give all staff delivering direct care training that involves face-to-face interaction with young people, for example through shadowing. 1.5.3 Consider training or advice for staff not directly providing care. This could include, for example, listening to young people's views and experiences through e-learning or case study videos, or through case-based discussion.
Research recommendations	Training • What are the effects of different approaches to transition training for practitioners on outcomes for young people?
Review questions	What transition training is available for health and social care practitioners in children's and adult services? What is the effectiveness of transition training?
Quality of evidence	No good quality studies were identified for this question.
Relative value of different outcomes	This is not applicable to this question because we did not find any studies that met our inclusion criteria.
Trade-off between benefits and harms	We did not review any studies for this question.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	No studies were included for the question on training and so all recommendations were developed on the basis of consensus.
Other considerations	Expert witness Janet McDonagh stated that unmet training needs across staff in children's and adult services is a factor that hinder implementation of existing guidelines. She also stated that joint training with both children's and adult services professionals would enhance collaboration. This was supported by another expert witness, Peter Winocour, who referred to a recent survey confirming a major challenge in the access to training.

1

Topic/section heading	**Supporting infrastructure: Ownership**
Recommendations	1.6.1 Each health and social care organisation, in both children's and adult services, should nominate: • 1 senior executive to be accountable for transition strategies and policies • 1 operational champion to be accountable for transitions. 1.6.2 The senior executive should be responsible for championing transitions at a strategic level. 1.6.3 The operational-level champion should be responsible for: • liaising with the strategic level champion

	• implementing, monitoring and reviewing the effectiveness of transition strategy.
Research recommendations	Transition support for young adults • What approaches to providing transition support for those who move from children's to adults' services are effective and/or cost-effective?
Review questions	What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services? What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research?
Quality of evidence	These recommendations are supported by one good quality systematic review which included other systematic reviews and qualitative and quantitative individual studies. They are further supported by expert witnesses as described below.
Relative value of different outcomes	The evidence on which these recommendations are based did not measure specific outcomes.
Trade-off between benefits and harms	This section is not applicable to this recommendation on communication and joint working.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES8 (RECs 1.6.1, 1.6.2 and 1.6.3) ES9 (RECs 1.6.1, 1.6.2 and 1.6.3) ES25 (RECs 1.6.1, 1.6.2 and 1.6.3) ES31 (REC 1.6.3)
Other considerations	Several expert witnesses address the problem of implementing existing transition guideline. Janet McDonagh emphasised how individual champions of transitional care are still important in the implementation of guidelines and practices and therefore need to be supported in this work. Robert Carr stated that funding is a concern for transition services, in spite numerous guidelines outlining transitional care as essential. Peter Winocour stated that one factor that supports implementation of transition guidelines is a single integrated database information system, and another is the use of the best practice tariff. Local audits have shown that a major pressure point is after or at the time of transfer to adult services. There is anecdotal evidence that flexibility in transfer to young adult services helps the process.

1

Topic/section heading	**Supporting infrastructure: Developing transition services**

Recommendations	1.6.4 Local authorities should ensure there is independent advocacy available to support all young people after they transfer to adult care[29]. 1.6.5 Consider establishing local, integrated youth forums for transition to provide feedback on existing service quality and to highlight any gaps. These forums should meet regularly and should involve people with a range of care and support needs, such as those with physical and mental health needs, learning disabilities and people who use social care services. 1.6.6 Ensure that data from education, health and care plans are used to inform service planning. 1.6.7 Carry out a gap analysis to identify and respond to the needs of young people who have been receiving support from children's services, including child and adolescent mental health services (CAMHS), but who are not able to get support from adult services. 1.6.8 In undertaking the gap analysis: include young people who don't meet eligibility criteria for support from adult services and those for whom services are not available for another reason. • pay particular attention to young people: – with neurodevelopmental disorders – with cerebral palsy – with challenging behaviour, or – who are being supported with palliative care. 1.6.97 Jointly plan services for all young people making a transition from children's to adults' services[30]. 1.6.10 Consider: • developing pooled budgets across health and social care services • developing pooled budgets across children's and adult services. • incentivising adult services to invest in transitions, for example through the best practice tariffs, existing NHS transition CQUINs, or similar mechanisms.
Research recommendations	The role of primary care in supporting young people discharged from children's services • What are the most effective ways for primary care services to be involved in planning, implementing and following-up young people in transition (whether or not they meet criteria for adult services)? The consequences and costs of poor transition • What are the consequences and the cost of young people with ongoing need not being transitioned into adult services?

[29] This is in addition their statutory duty to provide advocacy under the Care Act 2014.

[30] For young people with EHC plans, local authorities and health commissioners **must** jointly commission services, as per the Children & Families Act 2014.

	Transition in special groups: Young Offenders Institutes • What is the most effective way of supporting young offenders transitioning from children's to adults' health and social care services? Transition in special groups: Looked after young people • What is the most effective way of supporting care leavers in transitioning from children's to adults' health services?
Review questions	What are the factors that help or prevent the implementation of effective transition strategies and practice in children's and adult services? How can the transition process (including preparing the young person, making the transfer and supporting them after the move) best be managed effectively for those receiving a combination of different services? What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research?
Quality of evidence	There is abundance of high quality research evidence to suggest that there are problems with how services are commissioned in terms of transition.
Relative value of different outcomes	This is not relevant for these recommendations.
Trade-off between benefits and harms	We did not identify any studies which found that joint commissioning or inter-agency working was harmful, but note that the recommendations are based on evidence that identify the problem. We did not find any studies that had specifically evaluated the outcomes of changed commissioning.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES8 (RECs 1.6.6 and 1.6.9) ES9 (RECs 1.6.4, 1.6.5, 1.6.9 and 1.6.10) ES10 (RECs 1.6.10) ES25 (RECs 1.6.4, 1.6.6 and 1.6.9) ES45 (REC 1.6.10) ES46 (RECs1.6.7, 1.6.5, 1.6.8, 1.6.9 and 1.6.10)
Other considerations	These recommendations are also based on expert witnesses' presentation and statement at committee meeting 9, Julie Pointer and Robert Carr. In particular, the Guideline Committee noted examples - also drawing on their own experience - of where the use of available levers, such as financial incentives, had led to increased adult services engagement in transition.

1

Topic/section heading	Supporting infrastructure: Developmentally-appropriate service provision
Recommendations	1.6.11 Service managers should ensure there are developmentally-appropriate services for both children and adults to support transition. This could include, for example: • running joint clinics where young people can meet their consultant from children's services and a new consultant from adult services, before they transfer to adult services • pairing a practitioner from children's services with one from adult services to encourage communication before, during and after the transfer.
Research recommendations	Training • What are the effects of different approaches to transition training for practitioners on outcomes for young people? Supporting people to manage their own conditions • What is the relationship between transition and subsequent self-management?
Review questions	What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research? What is the effectiveness of support models and frameworks to improve transition from children's to adults' services? These models include early transition planning, joint working or protocols between children's and adult services, and signposting young people to, or offering them support from, the voluntary and community sector. What is the effectiveness of interventions designed to improve transition from children's to adults' services? These interventions include any specific intervention which is there to support transition, for example keyworkers, transition clinics or information evenings, provided by any agency, statutory or voluntary.
Quality of evidence	There is no clear definition of what a transition clinic should consist of, and detail was lacking in some of the reporting upon which this recommendation is based. In addition, we did not find any randomised controlled trials of transition clinics. Comparison studies of various qualities, and good quality systematic reviews do support the recommendation, but note that clinics were provided in various forms and sometimes alongside additional support such as a named worker or self-management training.
Relative value of different outcomes	The evidence on outcomes is sketchy and highly uncertain. Bloom et al 2012 (++/+) draw on evidence from one cohort study with a comparison group which suggested that meeting adult providers in advance reduced service users' and carers' concerns about the transfer. They draw on one study without a comparison group to suggest that young adult clinics impacted positively on HbA1C and hospital admissions, but not on hospital readmissions. Another study suggested that meeting adult providers in advance resulted in more regular clinic attendance, but that the metabolic control remained unchanged. Prestidge et al (2012, -/++) found no graft loss in the sample that received

	support from a transition clinic team, but note the small sample.
Trade-off between benefits and harms	We did not identify any studies which had found harm from providing transition clinics. There was discussion in relation to one expert witness statement (Helen Krimlisk) however about the potential for an uneven approach to occur if use of transition clinics is by selection.
Economic considerations	No directly applicable economic evidence was identified. The Guideline Committee was mindful of potential costs and resource use when making recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	ES4 (REC 1.6.11)
Other considerations	The term 'developmentally appropriate' was not dominating the research literature, but introduced to the Guideline Committee by two members, including the topic advisor, as well as the expert witness Janet McDonagh. Developmentally appropriate care is care that is responsive to the developmental needs of young people aged 10-24 years (Farre et al, 2014). It includes children's services recognising the gradually evolving autonomy of the young person, and adult services recognising that many young people will still be relying on family or carer support after transfer to adult services. Expert witness Peter Winocour stated that within diabetes care, transition clinics that adhere to the principles outlined in the NHS Diabetes Transition document (2013) has improved condition-specific outcomes and clinic attendance. He stated that one of the key principles of these clinics was to see transition as a process over time with supported joint input from paediatric and adult services rather than handover at 1-2 consultations.

1

2

4 References

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. Great Britain: Department of Health: Research Initiative for Long Term Neurological Conditions [accessed 15 July 2015]

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. Diabetic Medicine 28: 994-1000

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. Journal of Health Services Research and Policy 17: 140-148

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. Pediatric Blood and Cancer 61: 697-701

Barn R, Andrew L, Mantovani N (2006) Review of Life after Care: The Experiences of Young People from Different Ethnic Groups. Child & Family Social Work 11: 85-6

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. Lancet 360: 1280-6

Beresford B, Cavet J (2009) Transitions to adult services by disabled young people leaving out of authority residential schools. York: University of York: Social Policy Research Unit

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). York: Social Policy Research Unit

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). York: Social Policy Research Unit [accessed 15 July 2015]

Betz CL, Lobo ML, Nehring WM et al. (2013) Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition. Nursing Outlook 61: 311-36

Betz CL, Smith K, Macias K. (2010) Testing the transition preparation training program: a randomized controlled trial. International Journal Of Child And Adolescent Health 3: 595-607

Bhaumik S, Watson J, Barrett M et al. (2011) Transition for teenagers with intellectual disability: Carers' perspectives. Journal of Policy and Practice in Intellectual Disabilities 8: 53-61

Binks JA, Barden WS, Burke TA et al. (2007) What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. Archives of Physical Medicine and Rehabilitation 88: 1064-73

Bloom SR, Kuhlthau K, Van Cleave J et al. (2012) Health care transition for youth with special health care needs. Journal of Adolescent Health 51: 213-20

Broadhurst S, Yates K, Mullen B. (2012) An evaluation of the My Way transition programme. Tizard Learning Disability Review 17: 124-34

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. Stirling: University of Stirling

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. Clinical Endocrinology 71: 346-50

Care Quality Commission. (2014) From the pond into the sea: children's transition to adult health services. Newcastle upon Tyne: Care Quality Commission [accessed 15 July 2015]

Certo NJ, Mautz D, Smalley K et al. (2003) Review and discussion of a model for seamless transition to adulthood. Education and Training in Developmental Disabilities. 38: 3-17

Cheak-Zamora NC, Yang X, Farmer JE et al. (2013) Disparities in transition planning for youth with autism spectrum disorder. Pediatrics. 131: 447-55

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? Leeds: Children's Workforce Development Council [accessed 15 July 2015]

Clarke S, Sloper P, Moran N, Cusworth L 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. Journal of Integrated Care 19: 30-41

Cobb R, Alwell M (2009) Transition planning/coordinating interventions for youth with disabilities: a systematic review. Career Development for Exceptional Individuals 32: 70-81.

Commission for Social Care Inspection (2007) Growing up matters: better transition planning for young people with complex needs. London: Commission for Social Care Inspection [accessed 15 July 2015]

Cowen A, Duffy S, Murray P. (2010) Personalised transition: innovations in health, education and support. Sheffield: Centre for Welfare Reform and IBK Initiatives [accessed 15 July 2015]

Craston M, Thom G, Spivack R et al. (2013) Impact evaluation of the SEND pathfinder programme research report. London: Department for Education [accessed: 15 July 2015]

Crowley R, Wolfe I, Lock K et al. (2011) Improving the transition between paediatric and adult healthcare: a systematic review. Archives of Disease in Childhood 96: 548-54

Day P, Turner J, Hollows A. (2007) Bridging the gap: transitioning from child to adult services. British Journal of School Nursing 2: 146

Donkoh C, Underhill K, Montgomery P. (2006) Independent living programmes for improving outcomes for young people leaving the care system. Cochrane Database of Systematic Reviews issue 3: CD005558

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. Archives of Diseases in Childhood 96: 78-84

Downing J, Gleeson HK, Clayton PE et al. (2013) Transition in endocrinology: the challenge of maintaining continuity. Clinical Endocrinology 78: 29-35

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. Child Care Health and Development 37: 767-79

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. Vulnerable Children and Youth Studies 7: 338-46

Farre, A., Wood, V., Rapley, T., Parr, J.R., Reape, D., McDonagh, J.E. (2014) 'Developmentally appropriate healthcare for young people: a scoping study', Archives of Diseases in Childhood [online]

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. International Journal Of Nursing Studies 51: 123-35

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. Endocrine Practice. 19: 946-52 [accessed 15 July 2015]

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. Psychiatric Services 63: 592-97

Hagner D, Kurtz A, Cloutier H et al. (2012) Outcomes of a family-centered transition process for students with autism spectrum disorders. Focus on Autism and Other Developmental Disabilities 27: 42-50

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. Journal of Pediatric Rehabilitation Medicine 7: 79-91

Heslop P, Abbott D. (2007) School's out: pathways for young people with intellectual disabilities from out-of-area residential schools or colleges. Journal of Intellectual Disability Research 51: 489-96

Hiles D, Moss D, Thorne L et al. (2014) “So what am I?”: multiple perspectives on young people's experience of leaving care. Children and Youth Services Review 41: 1-15

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. Children and Youth Services Review 35: 2059-71

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.

Huang JS, Terrones L, Tompane T et al. (2014) Preparing adolescents with chronic disease for transition to adult care: A technology program. Pediatrics 133: e1639-46

Jordan L, Swerdlow P, Coates T. (2013) Systematic review of transition from adolescent to adult care in patients with sickle cell disease. Journal of Pediatric Hematology/Oncology 35: 165-69

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. Advances in Mental Health and Intellectual Disabilities 5: 9-16

Kelly B (2013) Don't box me in: disability and transitions to young adult life. Belfast: Queens University Belfast in partnership with Barnardos

Kime N, Bagnall A-M, Day R. (2013) Systematic review of transition models for young people with long-term conditions: a report for NHS Diabetes. UK: NHS Diabetes.

Kingsnorth S, Lindsay S, Maxwell J et al. (2010) Implementation of the LIFE span model of transition care for youth with childhood onset disabilities. International Journal of Child and Adolescent Health 3: 547-60

Kipps S, Bahu T, Ong K et al. (2002) Current methods of transfer of young people with Type 1 diabetes to adult services. Diabetic Medicine 19: 649-54

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. Palliative Medicine 28 (4): 342-352

Lee Y, Wehmeyer ML, Palmer SB 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. The Journal of Special Education 45: 104-17

Lewis SA, 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. BMC Pediatrics. 13: 169-169.

Mackie AS, Islam S, Magill-Evans J (2014). Healthcare transition for youth with heart disease: a clinical trial. Heart. 128: doi: 10.1136/heartjnl-2014-305748

Marriott A, Townsley R, Ward L. (2009) Access to independent advocacy: an evidence review. Office for Disability Issues

Mills J, Cutajar P, Jones J et al. (2013) Ensuring the successful transition of adolescents to adult services. Learning Disability Practice 16: 26-8

Milner C. (2008) Experiences of health transition for young people with learning difficulties and complex health needs in Northumberland. Northumberland: NHS. [accessed 16 July 2015]

Mitchell F. (2012) Self-directed support and disabled young people in transition (part 2). Journal of Integrated Care 20: 223-30

Montano C, Young J. (2012) Discontinuity in the transition from pediatric to adult health care for patients with attention-deficit/hyperactivity disorder. Postgraduate medicine 124: 23-32

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

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

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. Pediatrics 124: (6) e1134 -1141

National Children and Young People's Diabetes Peer Review Programme (2014) Measures for Children and Young People's Diabetes 2014

Nesmith A, Christophersen K. (2014) Smoothing the transition to adulthood: creating ongoing supportive relationships among foster youth. Children and Youth Services Review 37: 1-8

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. International Journal of Transitions in Childhood 3: 45-55

Noyes D, Sax C. (2004) Changing systems for transition: students, families, and professionals working together. Education and Training in Developmental Disabilities 39: 35-44

Paul M, Street C, Wheeler N et al. (2014) Transition to adult services for young people with mental health needs: a systematic review. Clinical Child Psychology And Psychiatry doi: 10.1177/1359104514526603

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. Sociological Review 59 (2): 303-23

Pole JD, Alibhai SMH, Ethier MC et al. (2013) Adolescents with acute lymphoblastic leukemia treated at pediatric versus adult hospitals. Annals of Oncology 24: 801-6

Por J, Goldberg B, Lennox V et al. (2004) Transition of care: health care professionals' view. Journal of Nursing Management 12: 354-61

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. Children and Youth Services Review 34: 2179-87

Prestidge C, Romann A, Djurdjev O et al. (2012) Utility and cost of a renal transplant transition clinic. Pediatric Nephrology 27(2): 295-302

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. Child: Care, Health & Development 37(6): 852-61

Reid G, Irvine J, McCrindle B et al. (2004) Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. Pediatrics 113: e197-205

Richards M, Vostanis P. (2004) Interprofessional perspectives on transitional mental health services for young people aged 16-19 years. Journal of Interprofessional Care 18: 115-28

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. Journal of Crohn's and Colitis 6: 830-44 doi: http://dx.doi.org/10.1016/j.crohns.2012.01.010

Shaw KL, Southwood TR, McDonagh JE (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey. Rheumatology 43: 211-9

Shaw KL, Watanabe A, Rankin E et al. (2014) Walking the talk. Implementation of transitional care guidance in a UK paediatric and a neighbouring adult facility. Child: Care, Health And Development 40: 663-70 doi: 10.1111/cch.12110

Shropshire Parent and Carer Council; (2011) Transition Parent Consultation Findings. PACC [accessed 15 July 2015]

Singh SP (2009) Transition of care from child to adult mental health services: the great divide. Current Opinion in Psychiatry 22: 386–90

Singh SP, 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. Report for the National Institute for Health Research Service Delivery and Organisation Programme. Queen's Printer and Controller of HMSO

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. University of York: Social Policy Research Unit.

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

Stein M, Morris M. (2009) Increasing the number of care leavers in 'settled, safe accommodation': research review 3. Centre for Excellence and Outcomes in children and Young People's Services (C4EO) [accessed 15 July 2015]

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. BMC Psychiatry 13: 74 doi:10.1186/1471-244X-13-74

Swift K, Sayal K, Hollis C. (2013) ADHD and transitions to adult mental health services: a scoping review. Child: Care, Health And Development. 40:775-86. doi: 10.1111/cch.12107

Tierney S, Deaton C,Jones et al. (2013) Liminality and transfer to adult services: a qualitative investigation involving young people with cystic fibrosis. International Journal of Nursing Studies 50: 738-46

Thomas J, Brunton J, Graziosi S (2010) EPPI-Reviewer 4.0: software for research synthesis. EPPI-Centre Software. London: Social Science Research Unit, Institute of Education, University of London

van Staa A, van der Stege HA, Jedeloo S et al.(2011) Readiness to transfer to adult care of adolescents with chronic conditions: Exploration of associated factors. Journal of Adolescent Health 48: 295-302

Watson R, Parr J, Joyce C et al. (2011) Models of transitional care for young people with complex health needs: a scoping review. Child: care, health and development. 37: 780-91

van Walleghem N, MacDonald CA, Dean HJ (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. Canadian Journal of Diabetes 33 (3) doi: 10.1016/S1499-2671(09)33327-4

Van Walleghem, M., MacDonald, C.A., Dean H.J. (2008) Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. Diabetes Care 31: 1529-1530

Watson AR (2005) Problems and pitfalls of transition from paediatric to adult renal care. Paediatric Nephrology 20: 113–7

5 Related NICE guidance

Details of related guidance are correct at the time of consultation [amend to publication and update list] on the guideline (September 2015) [amend].

Published

- Antisocial behaviour and conduct disorders NICE quality standard 59 (2014)
- Children and young people with cancer NICE quality standard 55 (2014)
- Autism NICE quality standard 51 (2014)
- Antisocial behaviour and conduct disorders in children and young people NICE clinical guideline 158 (2013)
- Psychosis and schizophrenia in children and young people NICE clinical guideline 155 (2013)
- Depression in children and young people NICE quality standard 48 (2013)
- Looked-after children and young people NICE public health guidance 28 (2010)
- Methylphenidate, atomoxetine and dexamfetamine for the treatment of attention deficit hyperactivity disorder (ADHD) in children and adolescents NICE technology appraisal 98 (2006)
- Obsessive-compulsive disorder NICE clinical guideline 31 (2005)
- Self-harm NICE clinical guideline 16 (2004)
- Eating disorders NICE clinical guideline 9 (2004)

In development

NICE is developing the following guidance:

- Diabetes in children and young people NICE clinical guideline (publication expected August 2015)
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs NICE social care guideline (publication expected November 2015)

- Transition between inpatient mental health settings and community or care home settings for people with social care needs NICE social care guideline (publication expected August 2016)
- Child abuse and neglect NICE social care guideline (publication expected September 2017)
- Service models for people with learning disabilities and challenging behaviour. NICE social care guideline (publication expected September 2017).
- Service user and carer experience. NICE social care guideline (publication expected January 2018)

6 Glossary and abbreviations

Abbreviations

Abbreviation	Term
ADL	Activities of daily living
ASCOT	Adult Social Care Outcomes Toolkit
C	Comparison Group
DP	Direct payment
EQ-5D	EuroQol: a standard health measure that allows the calculation of quality-adjusted life years (QALYs)
GHQ	General Health Questionnaire
GP	General practitioner
IADL	Instrumental activities of daily living
IB	Individual budget
ICER	Incremental cost effectiveness ratio as a ratio of change in costs to change in benefits
I	Intervention group
N	Number of participants
p	p-value: a measure that indicates whether the change in outcome was due to chance; a p-value of less than 0.05 suggests that the change was not due to chance (statistically significant)
RCT	Randomised controlled trial
SCRQOL	Social care-related quality of life
SD	Standard deviation
SE	Standard error
wk	Week
WTP	Willingness-to-pay value: a threshold set by NICE that the government is prepared to pay for a year in perfect health; the threshold is set between £20,000 and £30,000

Please see the NICE glossary for an explanation of terms not described above.

About this guideline

What does this guideline cover?

The Department of Health (DH) asked the National Institute for Health and Care Excellence (NICE) to produce this guideline on Transition from children's to adults' services (see the scope).

The recommendations are based on the best available evidence. They were developed by the Guideline Committee– for membership see the NICE website.

For information on how NICE guidelines are developed, see Developing NICE guidelines: the manual.

The evidence

Further information about the evidence is available in Appendix A.

Other information

We will develop a pathway and information for the public and tools to help organisations put this guideline into practice. Details will be available on our website after the guideline has been issued.

Copyright

ISBN [add]