

1 **Transition from children’s to adults’**
2 **services for young people using health or**
3 **social care services**

4 **NICE guideline: short version**

5 **Draft for consultation, September 2015**

This guideline covers principles and practice of good transition from children's to adults' services. Although there are agreed principles of good transitional care, there is evidence that these principles are often not reflected in practice, and that transition support is often patchy and inconsistent. This guideline covers both health and social care services. It aims to improve the planning, delivery and experience of care of young people in their transition (move) from children’s to adults’ services.

Who is it for?

- Providers of care and support in health and social care services
- Front-line practitioners and managers in children’s and adult health, mental health and social care services
- All young people using health or social care services at the time when they are due to make a transition into adult health or social care services, and their families or carers.

Commissioners should ensure that any service specifications take into account the recommendations in this guideline and associated [quality standard](#).

This version of the guideline contains the recommendations, context and recommendations for research. The Committee’s discussion and the evidence reviews are in the [full guideline](#).

Other information about how the guideline was developed is on the NICE website on the [page about this guideline](#). This includes the scope, and details

of the Guideline Committee and any declarations of interest.

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16 **Recommendations**

People using services have the right to be involved in discussions and make informed decisions about their care, as described in [Your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength of our recommendations, and has information about safeguarding, consent and prescribing medicines.

17 **1.1 Overarching principles**

18 1.1.1 Involve young people and carers in all aspects of service design,
19 delivery and evaluation related to transition by:

- 20 • considering co-producing transition policies and strategies with
21 them (co-production means involving people who use health and

- 1 social care services as equal partners in designing the services
2 and support they receive)
- 3 • asking them whether the services helped them achieve agreed
4 outcomes
 - 5 • considering co-producing, planning and piloting materials and
6 tools
 - 7 • feeding back to them about the effect their involvement has had.

8 1.1.2 Use person-centred approaches to ensure that transition support:

- 9 • takes full account of the young person's views and needs
- 10 • is strengths-based and focuses on what is positive and possible
11 for the young person rather than on a pre-determined set of
12 transition options
- 13 • identifies the support available to the young person, which
14 includes but is not limited to their family or carers
- 15 • is developmentally appropriate, taking into account their
16 maturity, cognitive abilities, needs in respect of long-term
17 conditions, social and personal circumstances and psychological
18 status
- 19 • treats the young person as an equal partner in the process
- 20 • supports the young person to make decisions and builds their
21 confidence to direct their own care and support over time
- 22 • fully involves the young person in terms of the way it is planned,
23 implemented and reviewed
- 24 • addresses all relevant outcomes, including those related to
25 employment, community inclusion, health and wellbeing
26 including emotional health, and independent living
- 27 • involves agreeing goals with the young person
- 28 • includes review of the transition plan with the young person at
29 least annually or more often if their needs change.

30 1.1.3 Health and social care service managers should work together in
31 an integrated way, involving colleagues in education to ensure a

1 smooth and gradual transition for young people moving from
2 children's to adults' services¹. This could involve, for example,
3 developing:

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

7 1.1.4 Service managers in both adults and children's services, across
8 health and social care, should proactively identify and plan for
9 young people in their locality with transition support needs.

10 1.1.5 Every service involved in supporting a young person should take
11 responsibility for sharing safeguarding information with other
12 organisations.

13 **1.2 Transition planning**

14 **Named worker**

15 1.2.1 Help the young person to identify a single named worker to
16 coordinate their transition care and support.

17 1.2.2 The named worker:

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

26 1.2.3 The named worker should:

¹ 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 • be the link between the young person and the various
- 2 practitioners involved in their support
- 3 • help the young person navigate services
- 4 • support the young person's family, if appropriate
- 5 • act as a representative for the young person, if required (that is
- 6 to say, someone who can provide advice, support or advocate
- 7 for them)
- 8 • proactively engage primary care in transition planning and direct
- 9 the young person to other sources of support and advice, for
- 10 example peer advocacy support groups provided by voluntary
- 11 and community sector services
- 12 • think about ways to help the young person to get to
- 13 appointments, if needed
- 14 • provide advice and information
- 15 • ensure that the young person is offered support, as appropriate,
- 16 with the following aspects of transition (which may include
- 17 directing them to other services):
- 18 – employment
- 19 – community inclusion
- 20 – health and wellbeing, including emotional health and
- 21 – independent living.

22 1.2.4 The named worker should support the young person for:

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

26 **Timing and review**

27 1.2.5 Ensure the transition planning is developmentally appropriate and

28 takes into account each young person's capabilities, needs and

29 hopes for the future. The point of transfer should not be based on a

30 rigid age threshold.

1 1.2.6 Hold an annual meeting to review transition planning, or sooner if
2 needed². This should:

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

7 1.2.7 Start transition planning early for young people in out-of-authority
8 placements.

9 1.2.8 For groups not covered by legislation, health, social care and
10 education, practitioners should start planning for adulthood from
11 year 9 (age 13 or 14) at the latest³. For those entering the service
12 close to transition age, planning should start immediately.

13 **Involving young people**

14 1.2.9 Offer young people help to become involved in their transition
15 planning. This may be through:

- 16 • peer support
17 • coaching and mentoring
18 • advocacy
19 • the use of mobile technology.

20 1.2.10 Service managers should ensure a range of tools are available to
21 help young people communicate effectively with practitioners.
22 These may include, for example, communication passports,
23 communication boards, 1-page profiles and digital communication
24 tools.

² 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](#).

³ 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.

1 **Building independence**

2 1.2.11 Consider opportunities for young people to have peer support and
3 mentoring during transition from children's to adults' services.

4 1.2.12 Include support for young people to develop and sustain social,
5 leisure and recreational networks in the transition plan. Put young
6 people in touch with peer support groups if they want such
7 contacts. This may be provided by voluntary- and community-
8 sector organisations, such as specific support groups or charities.

9 1.2.13 Include information and signposting to alternative non-statutory
10 services in transition planning. This may be particularly important
11 for people who do not meet the criteria for statutory adult services.

12 1.2.14 Everyone working in health, social care and education should
13 support all young people who continue to receive support from
14 social services into adulthood. The support should help them to
15 build autonomy in respect of their:

- 16 • employment
- 17 • community inclusion
- 18 • health and wellbeing, including emotional health
- 19 • independent living.

20 1.2.15 For young people with disabilities in education, the named worker
21 should liaise with education practitioners to ensure comprehensive
22 student-focused transition planning is provided. This should involve
23 peer advocacy, and friends and mentors as active participants.

24 1.2.16 If the young person has long-term conditions, ensure they are
25 helped to manage their own condition as part of the overall
26 package of transition support. This should include an assessment
27 of the young person's ability to manage their condition, self-
28 confidence and readiness to move to adult services.

1 1.2.17 For detailed recommendations on supporting looked-after children
2 moving to independent living see 'Preparing for independence' in
3 NICE's guideline on [looked-after children](#).

4 **Involving parents and carers**

5 1.2.18 Ask the young person how they would like their parents or carers to
6 be involved throughout their transition, including when they have
7 moved to adults' services.

8 1.2.19 Discuss the transition with the young person's parents or carers to
9 understand their expectations about transition, recognising that the
10 young person's preferences about their parents' involvement may
11 be different and should be respected.

12 1.2.20 Help young people develop confidence in working with adults'
13 services by giving them the chance to raise concerns and queries
14 separately from their parents.

15 1.2.21 Adults' services should take into account the individual needs and
16 wishes of the young person when involving parents or carers in
17 assessment, planning and support⁴.

18 **1.3 Support before transfer**

19 1.3.1 Service managers should ensure that a named worker from the
20 nominated adult service meets the young person before they
21 transfer from children's services.

22 1.3.2 Service managers should ensure that there is a contingency plan in
23 place for how to provide consistent transition support if the named
24 worker leaves their position.

25 1.3.3 Consider working in collaboration with the young person to create a
26 personal folder that moves with the young person when they

⁴ 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](#).

1 transfer from children's to adults' services. This folder should be in
2 the young person's preferred format. The folder could contain:

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

10 1.3.4 All services should provide young people and their families or
11 carers with information about what to expect from services and
12 what support is available for them. This information should:

- 13 • be in an accessible format, depending on the needs and
14 preferences of the young person (this could include, for
15 example, written information, computer-based reading
16 programmes, audio and braille formats for people with
17 disabilities)
- 18 • describe the transition process
- 19 • describe what support is available before and after transfer
- 20 • describe where they can get advice about benefits and what
21 financial support they are entitled to.

22 **Support from the named worker**

23 1.3.5 Consider ways to help the young person become familiar with
24 adults' services. This could be through the use of young adult
25 support teams, joint or overlapping appointments, or visits to the
26 adult service with someone from children's services.

27 1.3.6 Support young people to visit adult services they may potentially
28 use, so they can see what they are like first-hand and can make
29 informed choices.

- 1 1.3.7 If a young person is eligible for adult social care services, the
2 named worker:
- 3 • must make sure the young person is given information about
4 different mechanisms for managing their care and support, such
5 as personal budgets
 - 6 • should give the young person the opportunity to test out different
7 mechanisms for managing their care, in order to build their
8 confidence in taking ownership of this over time. This should be
9 done using a stepped approach.
- 10 1.3.8 If a young person is not eligible for statutory adult care and support
11 services, make sure that they are given information about
12 alternative support.
- 13 1.3.9 If a young person does not meet the criteria for specialist adult
14 health services, involve the GP in their transition planning.
- 15 **1.4 Support after transfer**
- 16 1.4.1 If a young person has moved to adults' services and does not
17 attend meetings or appointments or engage with services, adult
18 health and social care should:
- 19 • follow up the young person
 - 20 • involve other relevant professionals, including the GP
 - 21 • try to contact the young person and their family.
- 22 1.4.2 If, after assessment, the young person does not engage with health
23 and social care services, the relevant provider should refer back to
24 the named worker with clear guidance on re-referral (if applicable).
- 25 1.4.3 If a young person does not engage with adults' services and has
26 been referred back to the named worker, the named worker should
27 review the person-centred care and support plan with the young
28 person to identify:

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

3 1.4.4 Ensure that the young person sees the same healthcare
4 practitioner for the first 2 attended appointments after transition.

5 1.4.5 Ensure that the young person sees the same social worker
6 throughout the assessment and planning process and until the first
7 review of their care and support plan has been completed.

8 **1.5 *Training and development for staff***

9 1.5.1 Local authorities, local education and training boards and NHS
10 trusts should ensure that everyone working with young people in
11 transition up to the age of 25, in children's and adults' services,
12 understands:

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

21 1.5.2 Give all staff delivering direct care training that involves face-to-
22 face interaction with young people, for example through shadowing.

23 1.5.3 Consider training or advice for staff not directly providing care. This
24 could include, for example, listening to young people's views and
25 experiences through e-learning or case study videos, or through
26 case-based discussion.

1 **1.6 Supporting infrastructure**

2 **Ownership**

3 1.6.1 Each health and social care organisation, in both children's and
4 adults' services, should nominate:

- 5 • 1 senior executive to be accountable for transition strategies and
6 policies
7 • 1 operational champion to be accountable for transitions.

8 1.6.2 The senior executive should be responsible for championing
9 transitions at a strategic level.

10 1.6.3 The operational-level champion should be responsible for:

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

14 **Developing transition services**

15 1.6.4 Local authorities should ensure there is independent advocacy
16 available to support all young people after they transfer to adult
17 care⁵.

18 1.6.5 Consider establishing local, integrated youth forums for transition to
19 provide feedback on existing service quality and to highlight any
20 gaps. These forums should meet regularly and should involve
21 people with a range of care and support needs, such as those with
22 physical and mental health needs, learning disabilities and people
23 who use social care services.

24 1.6.6 Ensure that data from education, health and care plans are used to
25 inform service planning.

⁵ This is in addition their statutory duty to provide advocacy under the [Care Act 2014](#).

1 1.6.7 Carry out a gap analysis to identify and respond to the needs of
2 young people who have been receiving support from children's
3 services, including child and adolescent mental health services
4 (CAMHS), but who are not able to get support from adult services.

5 1.6.8 In undertaking the gap analysis:

- 6 • include young people who don't meet eligibility criteria for
7 support from adults' services and those for whom services are
8 not available for another reason
- 9 • pay particular attention to young people:
 - 10 – with neurodevelopmental disorders
 - 11 – with cerebral palsy
 - 12 – with challenging behaviour, or
 - 13 – who are being supported with palliative care.

14 1.6.9 Jointly plan services for all young people making a transition from
15 children's to adults' services⁶.

16 1.6.10 Consider:

- 17 • developing pooled budgets across health and social care
18 services
- 19 • developing pooled budgets across children's and adults'
20 services
- 21 • incentivising adults' services to invest in transitions, for example
22 through the best practice tariffs, existing NHS transition CQUINs
23 or similar mechanisms.

24 **Developmentally appropriate service provision**

25 1.6.11 Service managers should ensure there are developmentally
26 appropriate services for both children and adults to support
27 transition. This could include, for example:

⁶ For young people with EHC plans, local authorities and health commissioners **must** jointly commission services, as per the [Children & Families Act 2014](#).

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

7 **Terms used in this guideline**

8 **Named worker**

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

13 **Person-centred**

14 This means seeing the person using care and support as an individual and an
15 equal partner who can make choices about their own care and support. The
16 recommendations in this guideline seek to ensure that all of a young person's
17 needs are supported, including those related to their wider context (such as
18 employment, community inclusion, health and wellbeing including emotional
19 health, and independent living).

20 **Pooled budgets**

21 Partnership arrangements whereby NHS organisations and local authorities
22 contribute an agreed level of resource into a single 'pot' that is then used to
23 commission or deliver health and social care services.

24 **Transfer**

25 The actual point at which the responsibility for providing care and support to a
26 person moves from a children's to an adult provider.

1 **Transition**

2 The process of moving from children's to adults' services. It refers to the full
3 process including initial planning, the actual transfer between services, and
4 support throughout.

5 For other social care terms see the Think Local, Act Personal [Care and](#)
6 [Support Jargon Buster](#).

To find out what NICE has said on topics related to this guideline, see our web page on service transitions .

7 **Implementation: getting started**

8 NICE has worked with the Guideline Committee to identify 4 areas in this draft
9 guideline that may have a big impact on practice and could be challenging to
10 implement.

11 During consultation we want stakeholders to let us know whether you agree
12 with the 4 areas identified below. Or do you think other areas in this guideline
13 will have a bigger impact, or be more difficult to implement?

14 To help us complete this section, please use the comments form to give us
15 your views on these questions:

- 16 • Which areas will have the biggest impact on practice and be challenging to
17 implement? Please say for whom and why.
- 18 • What would help users overcome any challenges? (for example, existing
19 practical resources or national initiatives, or examples of good practice.)

20 Please use the [stakeholder comments form](#) to send us your comments and
21 suggestions.

1 ***Challenges for implementation***

2 **The challenge: adults' services taking joint responsibility with children's**
3 **services for transition**

4 See recommendations 1.1.3–4, 1.6.9–11.

This will ensure that transition is seen as a joint responsibility of both children's and adults' services. It will enable greater continuity and higher quality of care for young people using, and transferring between, children's and adults' services. It will enable effective use of education, health and care plans and should increase the likelihood of young people achieving their goals.

5

6 The structural and cultural differences between adults and children's services
7 can make transition more challenging and confusing for young people and
8 their families. The differences include clinical practice, IT systems, and how
9 the service is organised, managed and led.

10 ***What can commissioners, managers and practitioners do to help?***

- 11 • Jointly review systems and practice to identify any changes needed to
12 support the provision of developmentally appropriate care.
- 13 • Involve young people and their parents, together with professionals, to
14 explore any assumptions that might be limiting the effectiveness of the
15 transition process. These may include job roles and responsibilities,
16 funding, understanding of the process, differing priorities and timescales.

17 **The challenge: joint investment in transition support services up to age**
18 **25 across the local authority and health service**

19 See recommendations 1.6.9, 1.6.6, 1.6.10–11.

Joint investment in services for young people up to the age of 25 will ensure services are appropriate, and if necessary specific to, this particular age group. Ultimately this should increase young people's chances of achieving

their desired outcomes.

1

2 Adults' and children's services across health, education and social care will
3 need to come together to pool funding, overcoming the structural and cultural
4 barriers that exist between them. Transition support services cover a wide age
5 span, creating an additional challenge to ensure appropriate services are
6 available.

7 ***What can commissioners and managers do to help?***

- 8 • Recognise young people, and their transfer between children's and adults'
9 services, as a priority for funding.
10 • Develop joint commissioning arrangements between children's and adults'
11 services and between health, education and social care services.

12 **The challenge: improving front-line practice with young people through**
13 **training in developmentally appropriate health and social care and**
14 **person-centred practice**

15 See recommendations 1.5.1–2.

This will ensure each young person approaching or entering the transition phase receives person-centred care and support, and developmentally appropriate interventions that take account of any underlying health conditions. It should also mean that each young person is more likely to achieve their goals.

16

17 Managers need to ensure that practitioners focus on improving practice and
18 receive the support and training they need. Transitional care needs to become
19 a priority, especially in the context of current pressures on public services.

20 ***What can managers and practitioners do to help?***

- 21 • Review the approach to assessments to ensure they are person-centred,
22 consider the most appropriate communication methods, identify any

1 advocacy needs and ensure information is shared with young people and
2 their families

- 3 • Undertake training in person-centred planning and developmentally
4 appropriate healthcare
- 5 • Make effective use of the education, health and care plans.

6 **The challenge: sharing information about young people who have**
7 **become disengaged, or who are not eligible for adults' services, to**
8 **maximise the opportunities to provide care and support.**

9 See recommendations 1.4.1–3, 1.3.8–9.

This will ensure as many young people get support as possible and may help avert an increased need for support in the future. It will also be valuable information for strategic planning.

10

11 Managers and practitioners in children's and adults' services will need to
12 recognise and understand the risk of young people becoming disengaged
13 during the process of transition, and ensure accurate shared records are
14 maintained. Looked-after children, care leavers and young carers may be at
15 particular risk.

16 ***What can managers and practitioners across health, education and***
17 ***social care do to help?***

- 18 • Maintain an up-to-date database, shared across all departments and
19 including young people in out-of-borough placements. Build good links with
20 special schools, looked-after children teams and children in need/child
21 protection teams to identify young people who have disengaged, or may be
22 disengaging, with services.
- 23 • Share information and maintain up-to-date knowledge about the full range
24 of care and support available, including from primary care and pharmacy
25 services.

1 **Context**

2 This guideline covers both health and social care services. It aims to improve
3 the planning and delivery of care, and young people's experience as they
4 move from children's to adults' services. It focuses on all young people aged
5 up to 25 who are going through a planned transition, including those who have
6 mental health problems, disabilities or who are looked after.

7 Transition is defined as a purposeful and planned process of supporting
8 young people to move from children's to adults' services ([Transition: getting it
9 right for young people](#), DfES & DH). But making this move can be difficult or
10 provoke anxiety in young people and their carers. There is a wealth of policy
11 and guidance on agreed principles in respect of good transitional care, but
12 there is also evidence that these principles are often not reflected in practice
13 (for example, as illustrated in [Transitions to adult services by disabled young
14 people leaving out of authority residential schools](#) Beresford and Cavet 2009
15 and [Diabetes transition – assessment of current best practice and
16 development of a future work programme to improve transition processes for
17 young people](#) NHS Diabetes). Without proper support, young people may not
18 engage with services (Watson 2005⁷, Singh 2009⁸), leading to a loss of
19 continuity in care. This can be disruptive for young people, particularly during
20 adolescence when they are at a higher risk of psychosocial problems
21 ([Pubertal transitions in health](#) Patten and Viner 2007).

22 Although this guideline does not cover adolescent care more generally, it
23 should be noted that transition from children's to adults' services takes place
24 within the context of broader cultural and developmental changes that lead a
25 young person into adulthood. As a result, young people may be experiencing
26 several changes simultaneously ([Lost in transition? Between paediatric and
27 adult services](#) McDonagh and Viner 2006).

⁷ Singh SP (2009) Transition of care from child to adult mental health services: the great divide. *Current Opinion in Psychiatry* 22: 386–90

⁸ Watson AR (2005) Problems and pitfalls of transition from paediatric to adult renal care. *Paediatric Nephrology* 20: 113–7

1 This guideline has been developed in the context of a complex and rapidly
2 evolving landscape of guidance and legislation, most notably the Children and
3 Families Act 2014 and the [Care Act 2014](#). While the Care Act and other
4 legislation describe what organisations must do, this guideline is focused on
5 ‘what works’ in terms of how to fulfil those duties. It is relevant to young
6 people using health and social care services, their families and carers, care
7 providers (including independent and voluntary sector providers), health and
8 social care practitioners and commissioners (including people who purchase
9 their own care). It is particularly aimed at professionals and managers in
10 health and social care services, in both children’s and adults’ services.

11 The guideline will also be relevant to all people working with young people
12 who are receiving health and social care services, in particular those working
13 in education and employment agencies, youth justice and housing support.

14 **Recommendations for research**

15 The Committee has made the following recommendations for research.

16 ***1 Transition support for young adults***

17 What approaches to providing transition support for those who move from
18 children’s to adults’ services are effective and/or cost-effective?

19 **Why this is important**

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

1 ***2 The role of families in supporting young adults discharged***
2 ***from children's services***

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

6 **Why this is important**

7 Families and carers often feel left out once the young person moves to adults'
8 services, which can cause them considerable distress and uncertainty. The
9 young person may themselves ask for their family not to be involved and so
10 families also undergo a 'transition' in their involvement in the care of the
11 young person. Alternatively, the young person may want their family involved
12 after their move to adults' services. We need to understand how best to
13 support and help families and carers through the transition period. A very
14 important sub-group in this regard is young people with long-term conditions
15 who are leaving care, and who are therefore less likely to have consistent and
16 long-term support from parents or carers. How can foster carers, social
17 workers or personal advisers in leaving care services best support young
18 people transitioning from children's to adults' healthcare services?

19 ***3 The role of primary care in supporting young people***
20 ***discharged from children's services***

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

24 **Why this is important**

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

1 ***4 The consequences and costs of poor transition***

2 What are the consequences and the costs of young people with ongoing
3 needs not making a transition into adults' services, or being poor supported
4 through the process?

5 **Why this is important**

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

11 ***5 Support to carers and practitioners to help young people's
12 independence***

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

15 **Why this is important**

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

20 ***6 Supporting young people to manage their conditions***

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

23 **Why this is important**

24 Self-management is part of being independent, and so is a part of
25 developmental transition to adulthood. The most effective models of self-
26 management and whether these are generic or disease-specific still need to
27 be established. Some transition programmes include training in self-
28 management, others do not. While growing independence is part of the
29 transition into adulthood, personalised healthcare and helping people self-

1 manage tends to be variable. Further research is needed to understand how
2 self-management training and planning can be built into transition planning
3 and preparation for young people.

4 ***7 Transition in special groups: young offenders institutions***

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

7 **Why this is important**

8 Young offenders tend to be vulnerable, with multiple problems. There are
9 concerns that they tend to undergo particularly poor transitions into adults'
10 services. There is a lack of evidence for this group, despite documented high
11 need and poor outcomes.

12 ***8 Transition in special groups: looked-after young people***

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

15 **Why this is important**

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

27 ***9 Outcome measures***

28 What indicators are most important for evaluating transition effectiveness?

1 **Why this is important**

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

9 **10 Training**

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

12 **Why this is important**

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

19