NICE National Institute for Health and Care Excellence

NICE guideline

Transition from children's to adults' services for young people using health or social care services

NICE guideline
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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

This guideline is the basis of QS140.

Overview

This guideline covers the period before, during and after a young person moves from children's to adults' services. It aims to help young people and their carers have a better experience of transition by improving the way it's planned and carried out. It covers both health and social care.

NICE has developed information for young people and their carers to help them to understand what good transition should include and look like. This information explains what care young people and their parents or carers should expect from children's and adults' services during transition. It suggests questions to ask, and where to find further help.

The Care Quality Commission uses NICE guidelines as evidence to inform the inspection process.

Who is it for?

- Health and social care providers
- Health and social care practitioners in children's and adult health, mental health and social care services
- Other practitioners working with young people who use health and social care services, for example, those working in education and employment agencies
- Young people using heath or social care services who may need support from adults' services in the future, and their parents or carers

Commissioners should ensure that any service specifications take into account the recommendations in this guideline and the NICE quality standard on transition from children's to adults' services.

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Overarching principles

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

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

1.1.2 Ensure transition support is developmentally appropriate, taking into account the person's:

- maturity
- cognitive abilities
- psychological status
- needs in respect of long-term conditions
- social and personal circumstances

- caring responsibilities
- communication needs.

1.1.3 Ensure transition support:

- 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.

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

- treats the young person as an equal partner in the process and takes full account of their views and needs
- involves the young person and their family or carers, primary care practitioners and colleagues in education, as appropriate
- 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:
  - education and employment
  - community inclusion
  - health and wellbeing, including emotional health
  - independent living and housing options
- involves agreeing goals with the young person
- includes a review of the transition plan with the young person at least annually or more often if their needs change.

1.1.5 Health and social care service managers in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people. This work 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.

  Note: For young people with education health and care 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.

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

1.1.7 Every service involved in supporting a young person should take responsibility for sharing safeguarding information with other organisations, in line with local information-sharing and confidentiality policies.

1.1.8 Check that the young person is registered with a GP.

1.1.9 Consider ensuring the young person has a named GP.

1.2 Transition planning

Timing and review

1.2.1 For groups not covered by health, social care and education legislation, practitioners should start planning for adulthood from year 9 (age 13 or 14) at the latest. For young people entering the service close to the point of transfer, planning should start immediately.

Note: For young people with education, health and care 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.

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

1.2.3 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
- take place at a time of relative stability for the young person.

1.2.4 Hold an annual meeting to review transition planning, or more frequently if needed. Share the outcome with all those involved in delivering care to the young person. This meeting should:

- involve all practitioners providing support to the young person and their family or carers, including the GP (this could be either in person or via teleconferencing or video)
- involve 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.

  Note: For young people with a child in need plan, an education, health and care 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.

A named worker

1.2.5 Help the young person to identify a single practitioner – who should act as a 'named worker' – to coordinate their transition care and support. This person could be supported by an administrator.

1.2.6 The named worker:

- could be, depending on the young person's needs:

  - a nurse, youth worker or another health, social care or education practitioner
  - an allied health professional
  - the named GP (see recommendation 1.1.9)
  - an existing keyworker, transition worker or personal adviser
- should be someone with whom the young person has a meaningful relationship.

1.2.7 The named worker should:

- oversee, coordinate or deliver transition support, depending on the nature of their role
- be the link between the young person and the various practitioners involved in their support, including the named GP
- arrange appointments with the GP where needed as part of transition
- help the young person navigate services, bearing in mind that many may be using a complex mix of care and support
- support the young person's family, if appropriate
- ensure that young people who are also carers can access support
- act as a representative for the young person, if needed (that is to say, someone who can provide support or advocate for them)
- proactively engage primary care in transition planning
- 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.

1.2.8 The named worker should ensure that the young person is offered support with the following aspects of transition, if relevant for them (which may include directing them to other services):

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

1.2.9 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)
- hand over their responsibilities as named worker to someone in adults' services, if they are based in children's services.

1.2.10 For disabled young people 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.

Involving young people

1.2.11 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.

1.2.12 Service managers should ensure a range of tools is available, and used, to help young people communicate effectively with practitioners. These may include, for example:

- ways to produce a written record of how a young person communicates, for example, communication passports or 1-page profiles
- ways to help the young person communicate, for example, communication boards and digital communication tools.

Building independence

1.2.13 Include information about how young people will be supported to develop and sustain social, leisure and recreational networks in the transition plan.

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

1.2.15 Put young people in touch with peer support groups if they want such contacts. This type of support:

- may be provided by voluntary- and community-sector organisations, such as specific support groups or charities
- should be provided in a way that ensures the safety and wellbeing of the young people involved.

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

1.2.17 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 adults' services.

1.2.18 For detailed recommendations on supporting looked-after children moving to independent living see the section on preparing for independence in NICE's guideline on looked-after children and young people.

Involving parents and carers

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

1.2.20 Discuss the transition with the young person's parents or carers to understand their expectations about transition. This should include:

- recognising that the young person's preferences about their parents' involvement may be different and should be respected
- taking into account the young person's capacity, following the principles of the Mental Capacity Act and other relevant legislation, as necessary.

1.2.21 Help young people develop confidence in working with adults' services by giving them the chance to raise any concerns and queries separately from their parents or carers.

1.2.22 Adults' services should take into account the individual needs and wishes of the young person when involving parents or carers in assessment, planning and support. For young people with an education, health and care 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.

1.3 Support before transfer

1.3.1 Children's and adults' service managers should ensure that a practitioner from the relevant adult services meets the young person before they transfer from children's services. This could be, for example, by:

- arranging joint appointments

- running joint clinics
- pairing a practitioner from children's services with one from adults' services.

1.3.2 Children's and adults' 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 with the young person to create a personal folder that they share with adults' services. This should be in the young person's preferred format. It should be produced early enough to form part of discussions with the young person about planning their transition (for example, 3 months before transfer). It could contain:

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

1.3.4 All children's and adults' services should give young people and their families or carers information about what to expect from services and what support is available to them. This information should be provided early enough to allow young people time to reflect and discuss with parents, carers or practitioners if they want to (for example, 3 months before transfer). It 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 or braille formats for disabled young people)
- 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 finding ways to help the young person become familiar with adults' services. This could be through the use of young adult support teams, joint or overlapping appointments, or visits to the adults' service with someone from children's services.

1.3.6 Support young people to visit adults' 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 adults' social care services, the named worker:

- must make sure the young person and their family or carers (if the young person wants them involved; see recommendations 1.2.20 to 1.2.21) are given information about different ways of managing their care and support, such as personal budgets
- should give the young person the opportunity to test out different ways of 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, and their family or carers, are given information about alternative support.

1.3.9 If a young person does not meet the criteria for specialist adult health services, recognise that involving the GP in transition planning is absolutely critical.

1.4 Support after transfer

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

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

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 adults' 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 in adults' services for the first 2 attended appointments after transfer.

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 Supporting infrastructure

Ownership

1.5.1 Each health and social care organisation, in both children's and adults' services supporting young people in transition, should nominate:

- 1 senior executive to be accountable for developing and publishing transition strategies and policies
- 1 senior manager to be accountable for implementing transition strategies

and policies.

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

1.5.3 The senior manager should be responsible for:

- liaising with the senior executive
- championing, implementing, monitoring and reviewing the effectiveness of transition strategies and policies.

Planning and developing transition services

1.5.4 Consider making independent advocacy available to support young people after they transfer to adults' services. This is in addition to the statutory duty to provide advocacy under the Care Act 2014.

1.5.5 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
- link with existing structures where these exist
- involve people with a range of care and support needs, such as:
  - people with physical and mental health needs
  - people with learning disabilities
  - people who use social care services.

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

1.5.7 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, but who are not able to get support from adult services. The gap analysis should inform local planning and commissioning of services.

1.5.8 When carrying out the gap analysis:

- take into account resources already available in primary care practices
- include young people who don't meet eligibility criteria for support from adults' 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.

1.5.9 Jointly plan services for all young people making a transition from children's to adults' services. For young people with education, health and care plans, local authorities and health commissioners **must** jointly commission services, as per the Children and Families Act 2014.

1.5.10 Consider joining up services for young people who are involved with multiple medical specialties. This might include a single physician, such as a rehabilitation consultant, taking a coordinating role.

Developmentally appropriate service provision

1.5.11 Service managers should ensure there are developmentally appropriate services for children, young people and adults to support transition, for example, age-banded clinics.

Terms used in this guideline

Developmentally appropriate

An approach to supporting young people that recognises them as a distinct group, subject to constantly changing circumstances. Developmentally appropriate care and support considers the young person as a whole, addressing their biological, psychological and social development in the broadest terms. This approach will need joined-up service provision, and for the young person to be informed about, and supported to play an active role in, their care and support (Farre et al. [2015] Developmentally appropriate healthcare for young people: a scoping study).

Gap analysis

An exercise carried out to understand the difference between the amount and type of services needed and the amount and type of services available. This could also be extended to understand the difference between the services people expect and those that are available.

Named worker

The named worker is a role rather than a job title. This should be 1 of the people from among the group of workers providing care and support to the young person, who has been designated to take a coordinating role. It could be, for example, a nurse, youth worker, an allied health professional or another health and social care practitioner. It could also be someone who already has the title keyworker, transition worker or personal adviser.

Person-centred

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

Pooled budget

A type of partnership arrangement whereby NHS organisations and local authorities contribute an agreed level of resource into a single 'pot' that is then used to commission or deliver health and social care services.

Strengths-based

Strengths-based practice involves the person who uses services and the practitioners who support them working together to achieve the person's intended outcomes, in a way that draws on the person's strengths. The quality of the relationship between those providing support and those being supported is particularly important, as are the skills and experience that the person using support brings to the process (Strengths-based approaches, Social Care Institute for Excellence).

Transfer

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

Transition

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

For other social care terms see the Think Local, Act Personal Care and Support Jargon Buster.

To find out what NICE has said on topics related to this guideline, see our webpage on service transition.

Implementation: getting started

This section highlights 4 areas of the transition from children's to adults' services for young people using health or social care services guideline that could have a big impact on practice and be challenging to implement, along with the reasons why change needs to happen in these areas. The reasons are given in the box at the start of each area. We identified these with the help of stakeholders and guideline committee members (see the section on resources to support putting the guideline into practice in NICE's developing NICE guidelines: the manual).

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

See recommendations 1.1.5 and 1.1.6, recommendation 1.3.1 and recommendations 1.5.9 to 1.5.11

Taking joint responsibility, as emphasised in the government's guidance supporting the Care Act and Children and Families Act, will help to ensure:

- greater continuity and higher quality of care for young people using, and transferring between, children's and adults' services
- better communication and more successful implementation of transition protocols
- better outcomes for young people.

Equal responsibility

Managers and practitioners across children's and adults' services need to recognise that the structural and cultural differences between their services can make transition more difficult and confusing for young people and their families. Differences in areas such as IT systems, approaches to practice and how the services are accessed, organised, managed and led can result in a lack of confidence in adults' services on the part of young people, their families and children's services practitioners. This can make them reluctant to fully engage in the transition process and with adults' services.

What can commissioners, managers and practitioners do to help?

- Jointly review current systems and practice to identify where changes are needed to support sharing responsibility. The Preparing for Adulthood programme's self-evaluation tools may be helpful.
- Involve young people and their families, together with professionals, to explore any concerns and assumptions that might limit the effectiveness of the transition process. These may include job roles and responsibilities, funding, understanding of the process and how it works, differing priorities and timescales, and issues with attachment or trust. The Participation Works resources may help.
- Jointly review service provision to identify where there is no equivalent adult service to refer young people to, or where young people may need to transfer to more than 1 adult service. Establish a protocol outlining what to do in such circumstances.
- Consider seconding people working in adults' services to children's services (and vice versa). Consider also creating a transitions team with workers from both services, to create a shared sense of responsibility for the process of transition and encourage the sharing of knowledge and experience.

The challenge: joint planning, development and commissioning of services involved in transition across children's and adults' health and social care

See recommendation 1.1.6, recommendation 1.5.1 and recommendations 1.5.5 to 1.5.11

Joint planning, development and commissioning can result in:

- the provision of developmentally appropriate support, and if necessary, services specifically tailored to young people up to the age of 25
- better communication and joint working between services, and a more coordinated approach
- better outcomes for young people.

A joint approach

Transition from children's to adults' services can be a complex process, spanning a range of agencies and specialisms. The absence of a coordinated approach to providing services across health, education and social care can result in ineffective communication, poor engagement, discontinuity of care and staff feeling unclear about the process and their role in it.

Adults' and children's services need to come together to pool funding, addressing the structural and cultural barriers that prevent them from achieving this. Transitional care should become a shared priority, despite the current pressures on public funds.

What can commissioners and managers do to help?

- Develop a locally shared vision and policy for transition. Consider using the 4 areas outlined in the 'Preparing for adulthood' chapter of the Department for Education and Department of Health and Social Care's Special educational needs and disability code of practice: 0 to 25 years (preparing for higher education or employment, independent living, participating in society and being as healthy as possible) to inform this process. Work with young people and their families to understand the impact of a poor transition and apply this knowledge to improve transition services.
- Review local practices, systems and policies to determine whether the current approach is developmentally appropriate. In reviewing policies it may be useful to pay particular attention to:
  - consulting with young people alone when they are over 18, while supporting

  parental involvement
  - admissions of young people to adult wards
  - parental visits on adult wards, and
  - managing non-attendance at clinics.

  The practice prompts in the Together for Short Lives' guide on making a difference for young adult patients may help.

- Develop joint commissioning arrangements and pooled budgets between children's and adults' services, across health, education and social care. Identify where there are barriers that prevent this from happening effectively. The Preparing for Adulthood programme's guide to joint commissioning may be useful, as may NHS England's Model specification for transitions from child and adolescent mental health services.
- Use existing systems, for example, hospital and social care IT and user record-keeping systems, to identify young people in transition (up to the age of 25). This could help the commissioning and allocation of resources for transition across both children's and adults' services. It will also support ongoing quality improvement.

The challenge: improving front-line practice with young people through training in developmentally appropriate services and person-centred practice

See recommendations 1.1.1 to 1.1.4 and recommendation 1.2.3

Improving front-line practice will ensure:

- each young person approaching or entering the transition phase receives person-centred and developmentally appropriate care and support
- young people are more likely to positively engage with services, and understand their own health and support needs
- each young person is more likely to achieve their goals and hopes for the next stage of their life.

Improved practice with young people

To provide effective support to young people during their transition, practitioners need to understand the concept of developmentally appropriate care and what it means within the context of their role and service. Managers should ensure that practitioners focus on improving practice and receive the support and training they need to do so.

What can managers and practitioners do to help?

- Ensure that everyone working with young people in transition up to the age of 25, in children's and adults' services, understands:
  - the principles of person-centred care
  - 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
  - supporting young people with special educational needs and disabilities
  - the need to support young people holistically, taking into account the outcomes to be achieved in respect of:
    - education and employment

        - community inclusion
        - health and wellbeing including emotional health
        - independent living and housing options
    - how to involve families and carers in a supportive, professional way.

- Give all staff delivering direct care training that involves face-to-face interaction with young people, for example, through shadowing.
- Offer 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.
- Review the local approach to assessments to ensure they:
    - are person-centred
    - consider the most appropriate communication methods
    - identify any mental capacity issues
    - identify and address any need for advocacy
    - share information with young people and their families
    - recognise and support the gradually evolving autonomy of young people, including self-management of any health condition.
- Plan and attend joint training in person-centred planning and developmentally appropriate health and social care. Ensure the sessions genuinely involve people from various agencies who are involved in transition. Consider involving professionals already trained to support people of all ages (for example, clinical psychologists) to help inform the sessions. National Voices' My life, my support, my choice gives examples of what is important to young people and their families. The Preparing for Adulthood's workforce development guide to supporting staff working with young people preparing for adult life may also be useful.
- Seek opportunities for reflecting on practice and sharing learning – for example, during team meetings, supervision or hand-overs.

The challenge: maximising opportunities for young people who have become disengaged or who are not eligible for adults' services to access care and support

See recommendations 1.2.14 and 1.2.15, recommendations 1.3.8 and 1.3.9, recommendations 1.4.1 to 1.4.3 and recommendations 1.5.7 and 1.5.8

Increasing opportunities for this group of young people to access services will:

- ensure all young people receive the health and social care support that they need
- reduce the likelihood that they will need a higher level of support in the future, and reduce the likelihood of further illness or increased risk of death
- provide valuable information for strategic planning.

Ongoing contact and support

Managers and practitioners in children's and adults' services need to recognise the risk of young people becoming disengaged from services during transition and understand the impact this may have in the future. Care leavers, young offenders and young carers may be at particular risk. This risk of disengagement can be reduced by ensuring that transition planning is tailored to the young person, addresses any lifestyle changes, involves their GP and includes information and signposting to non-statutory services.

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

- Use existing systems, for example, hospital and social care IT and user record-keeping systems, to identify young people in transition (up to the age of 25). Share this information, where possible, across all departments of all agencies involved in the young person's care. This should include young people in out-of-borough placements. The Social Care Institute for Excellence's guide to early and comprehensive identification may be useful.

- Build strong and sustainable links with special schools, looked-after children teams, and other local teams involved in supporting and protecting children to help identify young people who have disengaged, or may be disengaging, with services.
- Work with young people and their families to understand and address the impact of a lack of appropriate services or differing service thresholds that make some people ineligible for adult care.
- Ensure all young people have up-to-date information about the full range of care and support available to them. This should include support from primary care and pharmacy services. Ensure this is part of the information, advice and support provided to people in line with the Care Act. The Preparing for Adulthood guide to developing the preparation for adulthood section of the local offer may be helpful.
- Where there is no adult service for a young person to transfer to, or there is a risk they may not engage with the adult service, ensure a detailed discharge letter is sent to their GP. Give the young person information about known and trusted third sector organisations who could provide support.
- Explore the opportunities to work more flexibly with young people offered by technology. This could include consultations via Skype and sharing information using social media.

Need more help?

Further resources are available from NICE that may help to support implementation.

- Annual indicators for use in the Quality and Outcomes Framework (QOF) for the UK. See the process and the NICE menu of indicators.
- Uptake data about guideline recommendations and quality standard measures.

Context

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

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 Department of Health and Department for Education and Skills). But making this move can be difficult or provoke anxiety in young people and their carers.

There is a wealth of policy and guidance on agreed principles in respect of good transitional care, but there is also evidence that these principles are often not reflected in practice (for example, Beresford and Cavet [2009] Transitions to adult services by disabled young people leaving out of authority residential schools and the NHS Diabetes report Diabetes transition – assessment of current best practice and development of a future work programme to improve transition processes for young people). Without proper support, young people may not engage with services (Watson 2005, Singh 2009), leading to a loss of continuity in care. This can be disruptive for young people, particularly during adolescence when they are at a higher risk of psychosocial problems (Patten and Viner [2007] Pubertal transitions in health).

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

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

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

Recommendations for research

The committee has made the following recommendations for research.

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. Although there were gaps in effectiveness evidence across both children's and adults' services, the committee agreed that research could usefully focus in particular on transition interventions in adult services and on young adults receiving a combination of different services.

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 adults' services, which can cause them considerable distress and uncertainty. The young person may themselves ask for their family not to be involved so families may also undergo a 'transition' in their involvement in the care of the young person. Alternatively, the young person may want their family involved after they move to adults' services.

We need to understand how best to support and help families and carers through the transition period. A very important subgroup 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 adult healthcare services?

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 and implementing transition, and following-up young people after transfer (whether or not they meet criteria for adult services)?

Why this is important

Some young people leaving children's services will not have access to the support or 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 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.

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.

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 adults' 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 adults' services.

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. Although 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 can be built into transition planning and preparation for young people.

7 Transition in special groups: young offenders institutions

What is the most effective way of supporting young offenders in transition 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.

8 Transition in special groups: looked-after young people

What is the most effective way of supporting care leavers in transition 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 enabling inter-agency communication when this is agreed by the young person.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE topic page on service transitions.

For full details of the evidence and the guideline committee's discussions, see the full guideline. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting our guidelines into practice, see resources to help you put NICE guidance into practice.

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