NICE National Institute for Health and Care Excellence

NICE Pathways

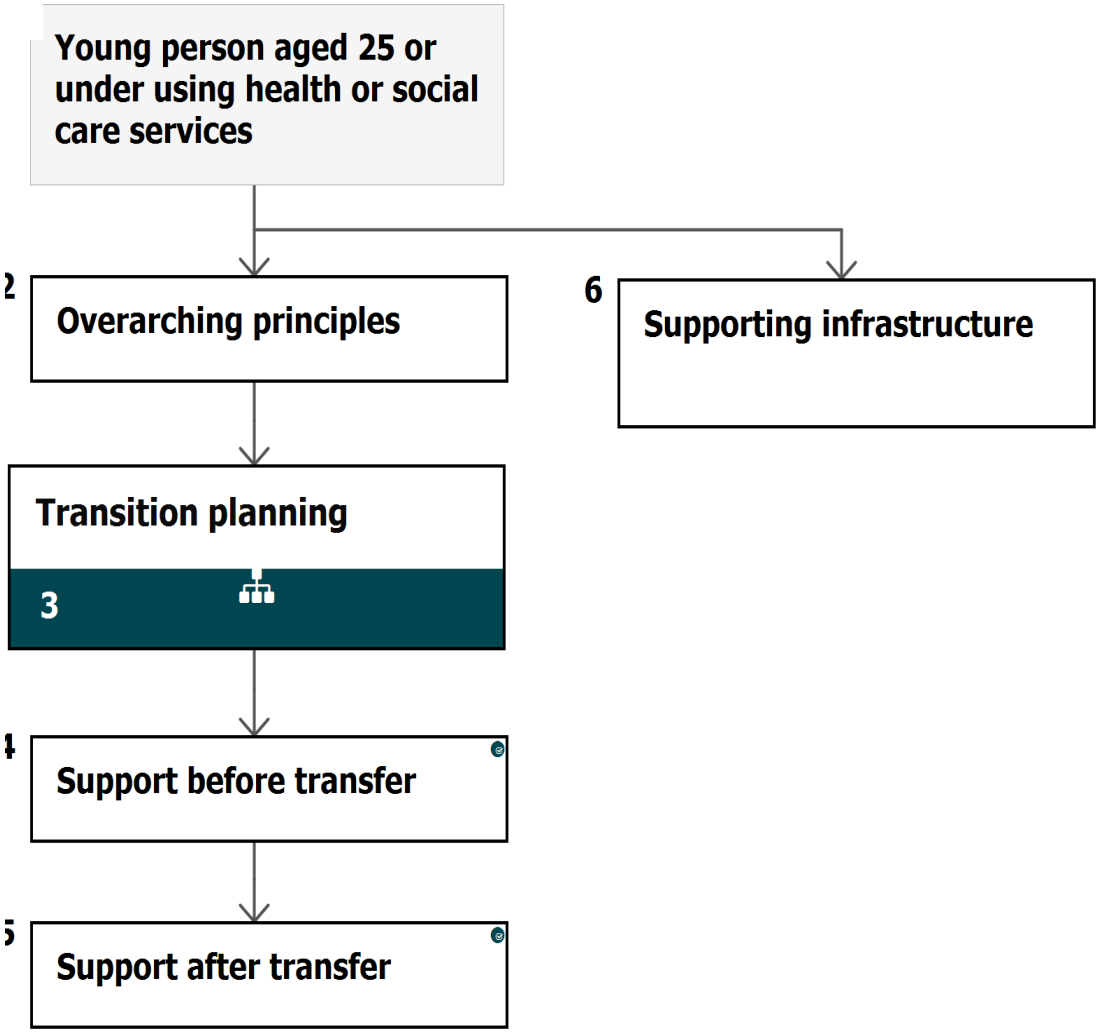
Transition from children's to adults' services overview

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/transition-from-childrens-to-adults-services
NICE Pathway last updated: 27 March 2018

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



1 Young person aged 25 or under using health or social care services

No additional information

2 Overarching principles

Involve young people and 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.

Ensure transition support is developmentally appropriate [See page 10], 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.

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.

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 review of the transition plan with the young person at least annually or more often if their needs change.

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 (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). 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.

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.

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.

Check that the young person is registered with a GP.

Consider ensuring the young person has a named GP.

For help with implementation: getting started see the NICE guideline on transition from children's to adults' services for young people using health or social care services.

3 Transition planning

See Transition from children's to adults' services / Transition planning for young people moving

from children's to adult services

4 Support before transfer

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.

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.

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.

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

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.

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.

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 involving parents and carers), 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.

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.

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.

For more information about the named worker, see named worker.

For help with implementation: getting started see the NICE guideline on transition from children's to adults' services for young people using health or social care services.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

4. Introduction to adults' services

5 Support after transfer

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.

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).

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.

Ensure that the young person sees the same healthcare practitioner in adults' services for the first 2 attended appointments after transfer.

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.

For help with implementation: getting started see the NICE guideline on transition from children's to adults' services for young people using health or social care services.

See what NICE says on patient experience and service user experience.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

5. Missed first appointments after transfer to adults' services

6 Supporting infrastructure

Ownership

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

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

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

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

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

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.

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

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.

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.

See what NICE says on attention deficit hyperactivity disorder, autism spectrum disorder, psychosis and schizophrenia, cerebral palsy in under 25s, spasticity in children and young people, and learning disabilities and behaviour that challenges.

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).

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

Service managers should ensure there are developmentally appropriate [See page 10] services for children, young people and adults to support transition, for example age-banded clinics.

For help with implementation: getting started see the NICE guideline on transition from children's to adults' services for young people using health or social care services.

This describes 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. Developmentally appropriate healthcare for young people: a scoping study 2015).

Glossary

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 one 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, for example, a nurse, a 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 – these recommendations 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

Sources

Transition from children's to adults' services for young people using health or social care services (2016) NICE guideline NG43

Your responsibility

Guidelines

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.

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.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so 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.

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.

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after

careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance 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.