



Transition from children's to adults' services

Quality standard

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This standard is based on NG43.

This standard should be read in conjunction with QS152, QS41, QS39, QS168, QS175, QS25, QS182, QS81, QS48, QS188, QS191 and QS194.

Quality statements

<u>Statement 1</u> Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

<u>Statement 2</u> Young people who will move from children's to adults' services have an annual meeting to review transition planning.

<u>Statement 3</u> Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.

<u>Statement 4</u> Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.

<u>Statement 5</u> Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

Quality statement 1: Planning transition

Quality statement

Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Rationale

Starting to plan their transition as early as possible can lead to a better experience for young people moving from children's to adults' services. Early planning allows a more gradual process. A sudden move to adults' services with no time for preparation or support can lead to young people and their families losing confidence and disengaging with services. Early planning, led by the health and social care practitioners but with full involvement from the young person, allows young people more time to be involved in decisions and to adjust to changes to their future care. It is recognised that for some young people, those covered by health and social care or education legislation, early transition planning is already a legal requirement.

Quality measures

Structure

Evidence of local arrangements to ensure that young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Data source: Local data collection.

Process

a) Proportion of young people in school year 9 (aged 13 to 14 years) who will move from children's to adults' services who have started planning their transition.

Numerator – the number in the denominator who have started planning their transition.

Denominator – the number of young people in school year 9 (aged 13 to 14 years) who will move

from children's to adults' services.

Data source: Local data collection.

b) Proportion of young people entering children's services after school year 9 and who will move to adults' services who started planning their transition immediately.

Numerator – the number in the denominator who started planning their transition immediately.

Denominator – the number of young people entering children's services after school year 9 and who will move to adults' services.

Outcome

a) Satisfaction with planning for transition and transfer as reported by young people and their carers.

Data source:Local data collection.

b) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services (for measurement purposes this could be engagement at 1-year after transfer).

Data source:Local data collection.

c) Proportion of young people who have transferred from children's services, who do not attend their first meeting or appointment with each adults' service.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (children's and adults' health, mental health and social care providers) ensure that systems are in place to identify young people who will move from children's to adults' services and to start planning their transition by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Health and social care practitioners (such as hospital consultants, nurses, social workers and mental health workers) involve children and young people in planning their transition from children's to adults' services by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Commissioners (clinical commissioning groups, local authorities and NHS England) ensure that they commission services that identify young people who will move from children's to adults' services and start planning their transition by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9. Commissioners should ensure that the planning involves the young person and their parents and carers, as well as the practitioner.

Young peoplewho will move from children's to adults' services work with their health or social care practitioners to start planning for the move by school year 9. For young people who enter children's services after year 9, planning for the move should start immediately. Early planning gives young people time to be involved in decisions and to understand and adapt to changes in their future care.

Parents and carers of young peoplewho will move from children's to adults' services are involved from the start in planning for the move. This gives them time to understand and to adapt to changes in the young person's future care. Their level of involvement will depend on the needs and preferences of the young person.

Source guidance

<u>Transition from children's to adults' services for young people using health or social care services</u> (2016) NICE guideline NG43, recommendation 1.2.1

Quality statement 2: Annual meeting

Quality statement

Young people who will move from children's to adults' services have an annual meeting to review transition planning.

Rationale

Transition is a lengthy process that starts early, by school year 9 (aged 13 to 14 years), and continues past the point of transfer. Regular review of transition planning ensures that a young person's changing needs are taken into account. Transition planning should be reviewed at least annually, but for some young people the meetings may need to be more frequent, depending on their individual needs.

Quality measures

Structure

Evidence of local arrangements to ensure that young people who will move from children's to adults' services have an annual meeting to review transition planning.

Data source: Local data collection.

Process

Proportion of young people, older than school year 9, who will move from children's to adults' services who have had a meeting in the previous 12 months to review transition planning.

Numerator – the number in the denominator who have had a meeting in the previous 12 months to review transition planning.

Denominator – the number of young people older than school year 9 who will move from children's to adults' services.

Data source: Local data collection.

Outcome

a) Satisfaction with planning for transition and transfer as reported by young people and their carers.

Data source:Local data collection.

b) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services (for measurement purposes this could be engagement at 1-year after transfer).

Data source:Local data collection.

c) Proportion of young people who have transferred from children's services, who do not attend their first meeting or appointment with each adults' service.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (children's and adults' health, mental health and social care providers) ensure that systems are in place for young people who will move from children's to adults' services to have an annual meeting to review transition planning.

Health and social care practitioners supporting transition (such as the lead clinician, care coordinator or named worker) take part in an annual meeting to review transition planning for young people who will move from children's to adults' services.

Commissioners (clinical commissioning groups, local authorities and NHS England) ensure that they commission services that arrange an annual meeting to review transition planning for young people who will move from children's to adults' services.

Young people who will move from children's adults' services have a meeting each year to talk about planning for the move and check that the plans are still suitable for them. The meeting should involve practitioners supporting the young person, and parents and carers.

Parents and carers of young people who will move from children'sto adults' services are involved in

a meeting each year to review planning for the move. The meeting ensures that parents and carers feel involved and know about future changes to services and care that the young person will receive.

Source guidance

Transition from children's to adults' services for young people using health or social care services (2016) NICE guideline NG43, recommendation 1.2.4

Definitions of terms used in this quality statement

Annual meeting

The annual meeting should involve the young person, their parents or carers and input from the lead practitioners providing support.

The meeting can take place either in person or via teleconferencing or video.

The meeting should identify what is working well in the transition planning and what can be improved. The young person should be treated as an equal partner and their views taken into account. At the meeting there should be a review of the young person's current:

- clinical needs
- psychological status
- social and personal circumstances
- caring responsibilities
- educational and vocational needs
- cognitive abilities, and
- communication needs.

[NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.1.2, 1.1.4, 1.2.4 and expert opinion]

Quality statement 3: Named worker

Quality statement

Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.

Rationale

Transition can be a difficult time for young people and their families, because it is a lengthy process and involves various professionals and services. A single point of contact – preferably a person that the young person knows and trusts – can coordinate care and signpost to appropriate support. This can increase attendance in adult services and lead to a better experience of care and better outcomes.

Quality measures

Structure

Evidence of local arrangements to ensure that all young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.

Data source: Local data collection.

Process

Proportion of young people who are moving from children's to adults' services who have a named worker to coordinate care and support before, during and after transfer.

Numerator – the number in the denominator who have a named worker to coordinate care and support before, during and after transfer.

Denominator – the number of young people who are moving from children's to adults' services.

Data source: Local data collection.

Outcome

a) Satisfaction with planning for transition and transfer as reported by young people and their carers.

Data source:Local data collection.

b) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services (for measurement purposes this could be engagement at 1-year after transfer).

Data source:Local data collection.

c) Proportion of young people who have transferred from children's services, who do not attend their first meeting or appointment with each adults' service.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (children's and adults' health, mental health and social care providers) ensure that systems are in place for young people who are moving from children's to adults' services to have a named worker to coordinate care and support before, during and after transfer.

Health and social care practitioners (such as hospital consultants, nurses, youth workers, social workers, mental health workers and transition workers) work with the young person who is moving from children's to adults' services to identify a named worker and then work with this practitioner to coordinate care and support before, during and after transfer.

Commissioners (clinical commissioning groups, local authorities and NHS England) ensure that they commission services that work with young people who are moving from children's to adults' services to identify a named worker to coordinate care and support before, during and after transfer.

Young peoplewho are moving from children's to adults' services should be helped to choose a single worker – preferably someone that they know and trust – to act as a named worker who coordinates care before, during and after transfer. The named worker acts as a link with staff providing support,

including the young person's GP. The named worker should arrange appointments, as well as providing support to the young person and their family.

Parents and carers of young peoplewho are moving from children's to adults' services can contact the named worker for information and support for themselves. If appropriate, they can also ask the named worker for extra support for the young person to help with the move.

Source guidance

<u>Transition from children's to adults' services for young people using health or social care services</u> (2016) NICE guideline NG43, recommendations 1.2.5 and 1.2.9

Definitions of terms used in this quality statement

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. The young person should help decide who this person should be. It could be, for example, a support planner, a nurse, a youth worker, an allied health professional or another health or social care practitioner. It could also be someone who already has the title keyworker, transition worker or personal adviser. The transition process is lengthy and it would be expected that the named worker may change over time.

A named worker should oversee, coordinate and deliver transition support. They should be the main link with other practitioners, particularly if a young person receives care from more than one service. They should arrange appointments for the young person, act as their representative, direct them to other services and sources of support, and support the young person's family if appropriate.

The named worker should be involved throughout transition, supporting the young person before and after transfer until a time agreed with the young person and their family. The named worker should hand over responsibilities to a practitioner in adults' services (if they are based in children's services).

[NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.2.5, 1.2.6, 1.2.7 and 1.2.9]

Quality statement 4: Introduction to adults' services

Quality statement

Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.

Rationale

Young people may feel unsure about moving to adults' services, especially if they have been with children's services for a while. Meeting a practitioner who will take a lead role in their future care, at least once, from each of the adults' services they will move to can help build a young person's confidence, reduce their concerns and increase their willingness to have new practitioners involved in their care. This can lead to a smoother transition for the young person and more regular attendance at appointments in adults' services, with better outcomes.

Quality measures

Structure

Evidence of local arrangements to ensure that young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.

Data source: Local data collection.

Process

Proportion of young people who moved from children's to adults' services who met a practitioner from each adults' service they moved to before they transferred.

Numerator – the number in the denominator who met a practitioner from each adults' service they moved to before they transferred.

Denominator – the number of young people who moved from children's to adults' services.

Data source: Local data collection.

Outcome

a) Satisfaction with planning for transition and transfer as reported by young people and their carers.

Data source:Local data collection.

b) Proportion of young people attending adults' services after transfer from children's services who continue to engage with services (for measurement purposes this could be engagement at 1-year after transfer).

Data source:Local data collection.

c) Proportion of young people who have transferred from children's services, who do not attend their first meeting or appointment with each adults' service.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (children's and adults' service managers) ensure there are systems in place for young people to meet a practitioner from each adults' service they will move to before they transfer from children's to adults' services. These may include joint appointments, joint clinics, and pairing of a practitioner from adults' services with one from children's services.

Health and social care practitioners from adults' services (such as hospital consultants, nurses, social workers and mental health workers) meet the young people who will move into their service before they transfer.

Commissioners (clinical commissioning groups, local authorities and NHS England) ensure that they commission adults' services in which practitioners meet young people before they transfer from children's services.

Young peoplewho will move from children'sto adults' services meet someone from each of their new adults' services before they transfer, to help them feel more confident about the move.

Source guidance

<u>Transition from children's to adults' services for young people using health or social care services</u> (2016) NICE guideline NG43, recommendation 1.3.1

Quality statement 5: Missed first appointments after transfer to adults' services

Quality statement

Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

Rationale

Young people need to engage with adults' services so that they continue to receive the care and support they need. When young people disengage from services during transition it can affect their future health, mental health and social care needs.

Quality measures

Structure

Evidence of local protocols in adults' services about follow-up arrangements for young people who have moved from children's to adults' services but do not attend their first meeting or appointment.

Data source: Local data collection.

Process

Proportion of young people who have moved from children's to adults' services but did not attend their first meeting or appointment who were contacted by adults' services and given further opportunities to engage.

Numerator – the number in the denominator who were contacted by adults' services and given further opportunities to engage.

Denominator – the number of young people who have moved from children's to adults' services but did not attend their first meeting or appointment.

Data source: Local data collection.

Outcome

Proportion of young people who have transferred from children's services, who are discharged from each adults' services without attending a meeting or appointment.

Data source:Local data collection.

What the quality statement means for different audiences

Service providers (adult health, mental health and social care services) ensure that systems are in place so they know who is transferring from children's services, and that a young person is contacted and given further opportunities to engage if they do not attend their first meeting or appointment in adults' services.

Health and social care practitioners from adults' services (such as hospital consultants, social workers, mental health workers) ensure that they work with children's services to identify young people who have moved to adults' services but did not attend their first meeting or appointment. They ensure that the young people are contacted and given further opportunities to engage.

Commissioners (clinical commissioning groups, local authorities and NHS England) ensure that they commission adults' services that contactyoung people who have moved to their services but do not attend the first meeting or appointment and give them further opportunities to engage (for example, other appointments).

Young peoplewho have moved from children'sto adults' services but do not attend their first meeting or appointment are contacted by someone from adults' services. They will check if the young person's care and support plan is still right and whether they need any other help to get back in touch with the service.

Parents and carers of young peoplewho have moved from children'sto adults' services but do not attend their first meeting or appointment are contacted by someone from adults' services to try to help the young person keep in touch with adults' services.

Source guidance

Transition from children's to adults' services for young people using health or social care services (2016) NICE guideline NG43, recommendations 1.4.1 and 1.4.2

Definitions of terms used in this quality statement

Opportunities to engage

If a young person does not attend meetings and appointments in adults' services the adults' service should try to contact them and their family and follow up with the young person, then involve other relevant professionals (including children's services and their GP) if need be. If there is still no contact then the relevant provider should refer back to the named worker with clear guidance on re-referral, if applicable. If the young person does not want to engage in services they should be offered alternative ways to meet their support needs.

[NICE's guideline on transition from children's to adults' services for young people using health or social care services, recommendations 1.4.1, 1.4.2 and 1.4.3].

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Information about how NICE quality standards are developed is available from the NICE website.

See <u>quality standard advisory committees</u> on the website for details of standing committee 3 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the <u>quality standard's webpage</u>.

This quality standard has been incorporated into the NICE pathway on <u>transition from children's to</u> adults' services.

NICE has produced a <u>quality standard service improvement template</u> to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- young person's experience of transition
- parents' and carers' experience of transition

- health-related quality of life
- social care-related quality of life
- engaging with adults' services
- unplanned care following transfer from children's to adults' services.

It is also expected to support delivery of the Department of Health's outcome frameworks:

- Adult social care outcomes framework 2015–16
- NHS outcomes framework 2016-17.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the <u>resource impact report</u> for the NICE guideline on transition from children's to adults' services to help estimate local costs.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and <u>equality</u> <u>assessments</u> are available. When implementing the statements some adjustments may need to be made to ensure young people can be fully involved in their transition process and take part in its planning. These adjustments involve ensuring the principles of the <u>Mental Capacity Act 2005</u> and other relevant legislation are followed, that treatment, care and support and the information given about it, is both developmentally appropriate and culturally appropriate. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard 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 quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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Endorsing organisation

This quality standard has been endorsed by Department of Health and Social Care, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Association of Paediatric Anaesthetists of Great Britain and Ireland
- National Paediatric Respiratory and Allergy Nurses Group
- Royal College of Anaesthetists
- Royal College of General Practitioners (RCGP)
- Royal College of Physicians (RCP)
- Together for Short Lives