

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Transition from children's to adult services

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Scope: before consultation (To be completed by the developer and submitted with the draft scope for consultation)

1.1 Have any potential equality issues been identified during the development of the draft scope, before consultation, and, if so, what are they?

(Please specify if the issue has been highlighted by a stakeholder)

Young people: This guideline will cover young people in transition from children's to adult services in health and social care. This transition will be only one of many that young people go through during their teenage years and early adulthood. In addition to undergoing physiological transition, many will also be at risk of psycho-social illness, increased peer pressure, onset of mental health problems and other important transitions such as starting paid work, moving out of the family home and becoming a parent themselves.

Diversity in population: Young people are as diverse as the entire population. Transition support should be sensitive and accommodating to different cultural, religious and LGBT requirements. Young people of ethnic minority background, recent migrants and those who do not speak English as their first language are likely to have less access to information and advice, and hence i) reduced access to health and social care services; ii) may be more likely to drop out from services during transition.

Young people with disabilities, including those arising from traumatic injury: Young people with physical and mental disabilities are affected by a range of issues

which limit their ability to lead independent lives. For example, they may have low care aspirations and expectations, or attitudes of families and professionals working with them may be discriminatory. This can lead to poor outcomes in their care. .

Young people with life-limiting conditions: support and co-ordination of palliative care, and involvement of parents and carers are important areas of concern for this group. This group might also experience a gap in service, for example, because of a lack of appropriate adult services, as more young people are growing up into adulthood, with conditions previously only seen in childhood.

People with communication difficulties, and/or sensory impairment: Effective communication strategies, quality of services, choice and control, and moving on to independence are important issues for all the equalities groups in this document, and even more challenging for this group. Young people moving out of special education residential schools will have particular needs such as communication difficulties and sensory impairments, which may lead to their preferences being ignored.

Young people in complex and/or unstable living situations: Young people who are homeless, or in foster care, or who have difficult relationships with their family or carers, are less likely to make successful transitions into adult services. They are also more likely to undergo multiple and unsupported transitions in other areas of their lives.

Socioeconomic status: Evidence suggests that lower socio-economic status is associated with increased difficulty in (a) accessing information about care options; and (b) ability to pay for alternative care when no adult provision is available, or when they do not meet the threshold for adult services.

Informal carers' gender and ethnicity: Evidence suggests that women and ethnic minority carers are sometimes expected to provide informal care more than their male/white counterparts.

Plans for dealing with these aspects include sensitivity to equality and diversity issues, and to consider these in particular when analysing findings. Search strategies will be focused on the intervention 'transition' and the population of 'young people'. Adding inequalities filters has been shown to potentially exclude relevant

studies on the groups the filters are meant to identify, since authors use a very wide range of terms to describe a population. The guidance will address the organisation and delivery of services that take account of these issues, including the provision of advice and information to support access to personalised services for both the young person and carer. The Guidance Development Group may also make recommendations specifically in relation to particular service users and carers. Recommendations from the Guidance will also be subjected to an Equality Impact Assessment before being finalised.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

Adults who are under 25 but who are accessing services for the first time are excluded. This is in order to maintain focus on the transition between children's and adult services.

Young people who do not receive health or social care services are excluded. This is to retain the focus of the guideline on the transition from young people's to adult services in health and social care, and to provide action-oriented recommendations for good practice in these and related services. There is a risk that this will exclude important groups who do not engage with services even though they are eligible to receive them. Important groups in this regard will be travelers, refugees and asylum seekers, and homeless young people. However, the focus of this guidance is on transition, not on the lack of service for particular groups.

Transition between children's to adult health and social care services is tightly linked to transitions in other parts of a young person's life such as leaving school and starting work. Separating these out is not ideal, but the rationale for focusing solely on transitions between services rather than service transitions and other transitions that young people may face during adolescence is to ensure that the guidance is

focused and that there is time and resource to address the most relevant evidence.

We recognise that a number of other services (including those provided, for example, by education, housing or youth justice sectors) can often be involved in supporting young people included in the scope of this guidance. The way that health and social care services relate to other agencies as part of transition planning and management will, therefore, be included.

Completed by Developer: Swaran Singh (GC Chair)

Date: 24/02/14

Approved by NICE quality assurance lead: Jane Silvester

Date: 18/03/14

2.0 Scope: after consultation (To be completed by the developer and submitted with the final scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

Young people commenting on the scope asked that we use the term 'long-term conditions' instead of 'chronic conditions'.

Young offenders were identified as a highly vulnerable group to transition and although the guideline remit remained focused on health and social care, the research team included any studies which focused on the transition of young offenders from children's and adolescent to adult services. Only one study was identified for this group.

For care leavers, who are in scope, it became necessary to include studies on housing because housing form an essential part of their transition.

For disabled young people it became necessary to include some studies on education, because education is now the lead agency for their transitions.

None of these changes impacted on the search strategy.

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

No changes were made to the scope.

2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?

If so, is an alternative version of the 'Information for the Public' document recommended?

If so, which alternative version is recommended?

The alternative versions available are:

- large font or audio versions for a population with sight loss;
- British Sign Language videos for a population who are deaf from birth;
- 'Easy read' versions for people with learning disabilities or cognitive impairment.

The primary focus of the guideline is not essentially a population with a specific disability, because it includes young people leaving care without a disability, and young people with a physiological long-term condition which is not disabling. However, the guideline covers all possible childhood-onset disabilities because it is about any young person's transition from children's to adult services.

The relevant guideline documents should be published in formats for people with disabilities, including learning disabilities.

Updated by Developer: Swaran Singh (GC Chair)

Date: 09/05/14

Approved by NICE quality assurance lead: Jane Silvester

Date: 15/05/14

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

It is recognised that all young people using children's services are at risk during the transfer to adult services, if their transition is not purposeful and planned. Because of this, the guideline recommendations are primarily focused on all health and social care services, for all young people.

Particular groups identified as being vulnerable to a poor transition were:

Young people placed out of their local authority area and residing there at the point of transfer of services. Recommendation 1.2.2 mentions this group and the need for early transition planning for them.

Recommendation 1.5.8 asks that commissioners pay particular attention to the needs of young people for whom adult services are often not available:

- with neurodevelopmental disorders
- with cerebral palsy
- with challenging behaviour, or
- who are being supported with palliative care.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

Young people: The literature indicated how young people go through multiple transitions around the time of service transitions from children's to adult care, and how important it is that service providers recognize this. The guideline therefore emphasizes the importance of developmentally appropriate care: taking into account young people's maturity, cognitive abilities, needs in respect of long-term conditions, social and personal circumstances and psychological status.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

Diversity in population: The guideline emphasizes the importance of person-centred transitions which are based on individual needs. Recommendation 1.2.3 says that transitions should not be based on a rigid age threshold.

Young people with disabilities, including those arising from traumatic injury: The person-centred approach recommended by the guideline focuses on the importance of involving young people in the transition planning.

Young people with life-limiting conditions: Young people receiving palliative care are mentioned as a particularly important group for whom services need to be commissioned.

People with communication difficulties, and/or sensory impairment: Recommendation 1.2.12 emphasises the need to ensure that providers understand young people's communication needs and provide tools that can support communication.

Young people in complex and/or unstable living situations: Young people in the criminal justice system and young people in care were identified as groups where there is need for more research, and a research recommendation was developed for these two groups.

Socio-economic status: None of the recommendations specifically mentions lower socio-economic groups.

Informal carers' gender and ethnicity: None of the recommendations specifically mentions gender or ethnicity of carers, but they are included in the recommendations throughout, in particular in terms of the importance of involving them. One of the research recommendations is specifically aimed at carers and parents.

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?

Where equalities issues were discussed, they are reported in the LETR tables under 'other considerations'.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

In developing the draft recommendations the Committee was careful to ensure that it would not be more difficult for a group of people to access support during transitions. Examples of this are given above (3.1)

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

The Committee took care in developing recommendations to ensure they would not have an adverse impact on people with disabilities.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

The Committee has focused on all groups vulnerable to poor care during and after transfer from children's to adult services. Examples of particular groups are provided in 3.1.

Completed by Developer: Swaran Singh (GC Chair)

Date: 29/07/15

Approved by NICE quality assurance lead: Jane Silvester

Date: 14/08/15

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

There were a number of stakeholder comments that related to young people with specific conditions (e.g. congenital heart disease, eating disorders) or aspects of care (e.g. orthoptics).

The Guideline Committee considered again the scope of the work and agreed that, in order to be as inclusive as possible, the guideline should not list all relevant conditions and needs separately. The Committee were concerned that the Guideline sets out the broad principles to follow with respect to care and support before, during and after transition. This was intended to ensure that it is relevant to the very wide range of young people it covers.

The Committee reviewed the recommendations in the context of young people with mental health needs, in particular recognising the need to ensure that young people with mental health needs do not “fall through the gap” between CAMHS and Adult Mental Health Services. To this end, they agreed that the recommendations already referenced this issue sufficiently well (recommendations 1.5.5 and 1.5.7).

There were also a number of comments in relation to the needs of young carers being insufficiently represented in the guideline. Following discussion about stakeholder comments at Guideline Committee meeting 12, the Committee agreed that young carers were an important group to reference, and therefore they have been highlighted explicitly in one of the over-arching recommendations (1.1.2) as well as in 1.2.7.

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

In reviewing and finalising the recommendations the Committee was careful to ensure that it would not be more difficult for a group of people to access support during transitions. Section 3.1 provides examples of the recommendations that explicitly seek to address access which remained in the guideline following consultation.

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

The Committee took care in reviewing and finalising recommendations to ensure they would not have an adverse impact on people with disabilities. The Committee also discussed and agreed the most appropriate terminology to use in reference to disabled young people at Committee meeting after consultation. Two recommendations reference disabled young people explicitly, to help ensure the guideline speaks to their needs appropriately. These are:

1.2.16 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.

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

- be in an accessible format, depending on the needs and preferences of the young person (this could include, for example, written information, computer-based reading programmes, audio and braille formats for disabled young people)

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

- 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.

1.3 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

The Committee has focused on all groups vulnerable to poor care during and after transfer from children's to adult services. Examples of particular groups are provided in 3.1.

1.4 Have the Committee's considerations of equality issues been described in the final guideline document, and, if so, where?

Reference to specific issues has been included in LETR tables and evidence statements.

Updated by Developer: Swaran Singh (GC Chair)

Date: 21/12/15

Approved by NICE quality assurance lead: Jane Silvester

Date: 06/01/16