

NICE guidelines

Equality impact assessment

Children and young people with disabilities and severe complex needs: integrated health and social care support and service guidance

2.0 Checking for updates and scope: after consultation (to be completed by the Developer and submitted with the revised scope)

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

Yes, the stakeholders commented on a number of issues through the consultation on the draft scope. These covered the following aspects.

- The distinction and importance of both mental health and physical health considerations, both as underlying conditions (comorbidities) and in giving rise to disabilities that might result in severe complex needs.
- The importance of several specific health conditions and areas of disability that would be of relevance in this guideline.
- The importance of ensuring equality of access to services related to: transition from children's to adults' services; sexual health; and palliative and end of life care for children and young people with degenerative or life-limiting conditions.
- The relevance of family breakdown and bullying as additional vulnerabilities that might affect children and young people with disabilities and severe complex needs.
- The importance of consistency of access to services regardless of geographical location.

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

Yes, the section in the scope that summarises equalities considerations has been revised to refer to the specific conditions, disabilities and issues highlighted by the stakeholders as being of relevance. This section now states that the guideline will

look at inequalities related to physical disabilities, cognitive impairments, communication problems and disorders (including behavioural and social communication disorders), learning disability and sensory impairments. The section emphasises that these disabilities may manifest through, or occur in combination with, mental health and behavioural conditions or physical health conditions. The following examples of conditions and disorders highlighted by stakeholders as being of relevance when considering principles that should be applied to integrate health, social care and education services for children and young people with severe complex needs are listed in the scope for future reference:

- autism spectrum disorder
- attention deficit hyperactivity disorder
- anxiety and depression
- challenging behaviour
- attachment disorder
- neurological conditions (such as epilepsy)
- allergic conditions (such as asthma)
- genetic conditions (including rare genetic conditions such as Norrie disease)
- myalgic encephalomyelitis.

Further specific considerations that may be relevant for this guideline in relation to equalities are also noted as follows:

- having a disability or impairment that is not immediately apparent (this might occur with several of the mental health and behavioural conditions mentioned above, and with physical disabilities such as continence problems)
- gender, sexual orientation, race, religion or belief (these might be associated with particular attitudes [positive or negative] or sensitivities towards disability).

The revised scope lists the following as additional characteristics associated with vulnerability, and possibly stigma, that may be of relevance in this guideline:

- looked-after children status
- traveller status
- family breakdown
- homelessness
- English not being the first language
- having poor literacy
- being in a family with a low income
- being unable to attend school
- child abuse and neglect
- being bullied.

This section of the scope explains that living in a rural area might mean inequality in access to services, while the earlier section explaining why the guideline is needed highlights the importance of consistency in the delivery of care and services,

regardless of geographical location, which was raised as an issue by stakeholders.

The section of the scope that summarises equalities considerations concludes by stating that the following additional areas will be important when considering integration of health, social care and education services from an equalities perspective:

- transition from children's to adults' services
- sexual health
- palliative or end of life care for children and young people with degenerative or life-limiting conditions.

Other areas of the scope that have been revised in response to stakeholder comments (noted here to reflect the context for the changes documented with regard to equalities considerations) are:

- emphasising the overall focus on general principles in the integration of health, social care and education services (the addition and prominence of education services was an important area in stakeholder feedback)
- emphasising that the guideline will not lead to recommendations specific to particular disabilities or health conditions, although the contexts raised by stakeholders as being of relevance to this guideline, and documented in the equalities considerations section, will be kept in mind
- amending the guideline title to emphasise person-centred care and emphasising that people aged 25 are included in the guideline population, which is consistent with the age range for access to an education, health and care (EHC) plan
- defining the guideline population with reference to the need for support across all 3 sectors (health, social care and education services), which was highlighted as being of relevance to the guideline in several stakeholder comments.

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

If so, do the key messages for the public need to be produced in an alternative version?

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 deaf from birth
- 'Easy read' versions for people with learning disabilities or cognitive impairment.

As described in the pre-consultation version of the equality impact assessment, this guideline is intrinsically focused on children and young people with severe complex needs associated with having a disability. As noted above, in the post-consultation version of the scope, children and young people with disabilities and complex needs are defined through reference to the need for support across all 3 sectors (health, social care and education services). Since the disabilities of relevance in the guideline include cognitive impairments, communication problems and disorders (including behavioural and social communication disorders), learning disability and sensory impairments, an alternative version to share key messages for the public is likely to be needed, although the disabilities are so wide-ranging it might be challenging to identify a universal alternative format. Current thinking is that augmented and alternative communication aids will be needed. This might include preparing a summary of key messages in video format. Additionally, as part of the guideline development process, involvement of children and young people with personal experience of living with a disability and severe complex needs is being explored. It is anticipated that this will go beyond involving children and young people as committee members, for example, by conducting focus groups at key stages during the guideline development process to elicit views and experiences of a larger group of children and young people.

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