

1.0.7 DOC EIA (2019)

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

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?

Disability

Communication needs

Stakeholders raised that children with the most complex needs (for example those with profound and multiple learning disabilities) may not be able to actively participate in planning and decision making. A recommendation was added that in such instances the views of those who know the child or young person best should be taken into account (1.1.2; Evidence report M) to ensure that the perspective of the child or young person is fully represented. Another recommendation to engage with those who know the young person best if they lack capacity to plan for adulthood (1.8.4; Evidence report J).

Stakeholders raised that those with communication needs may require specialist support to participate in discussions and decisions and express their views. A recommendation was added to highlight this (1.1.9; Evidence report B).

Stakeholders raised that communication aids need to capture equity, diversity and inclusion information relevant to young person. This was added to recommendation 1.1.17 (Evidence report B).

Stakeholders highlighted that the parents and carers of disabled children and young people with severe complex needs may also have communication needs that affect their ability to participate in discussions and understand information that is provided to them. A recommendation was added to highlight this (1.1.22; Evidence report K).

Accessibility

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

Stakeholders highlighted that not all disabled children and young people with severe complex needs will want to or be able to attend meetings as they may find them overwhelming or distressing. Recommendation 1.1.4 (Evidence report B) was amended to focus on getting input in the way that is most effective for the individual, including physical and virtual options to attend meetings and other accessible options to input (for example providing video presentations). Recommendation 1.1.32 (Evidence report B) was amended to include consideration of virtual attendance options.

Stakeholders highlighted that it was important to check that meetings are physically and financially accessible to the family. This was added to recommendation 1.1.29 (Evidence report B).

One stakeholder highlighted that attendance at group social activities would require consideration of equipment that was needed to make the activity accessible. This was added to recommendation 1.7.3 (Evidence report F).

One stakeholder commented that workplaces often need to adapt environments or provide additional equipment to ensure young people have the opportunity to perform in the same way as their peers. This was added to recommendation 1.13.7 (Evidence report H).

Race

One stakeholder requested recommendation 1.4.23 consider how communication and processes around SEND and EHC plans cater for different communities and whether additional support to counter stigma or different cultural views around SEND is needed to ensure that families are able to access support for their child. The committee added assumptions and cultural beliefs as things that should be discussed if the family disagree with the EHC plan (1.4.23; Evidence report M).

Socio-economic factors

Stakeholders raised that it is important to be aware of issues related to digital exclusion and not to assume that all families have access to laptops, iPads or a reliable internet connection (or feel confident in using these). Recommendation 1.1.4 (Evidence report B) was amended to focus on getting input in the way that is most effective for the individual, including physical and virtual options to attend meetings and other accessible options to input (for example providing video presentations). Other recommendations were checked to ensure that they did not exclusively recommend things that were only accessible online.

One stakeholder highlighted that it was important to check that meetings are physically and financially accessible to the family. This was added to recommendation 1.1.29 (Evidence report B).

Living in a rural area

One stakeholder commented that particular regard was required to families living in

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rural areas, where there is no workable public transport system. The committee did not make any changes based on this as they are not able to influence funding for public transport.

Mental health needs

Stakeholders highlighted that the guideline needed to include consideration of emotional and mental health needs at an early stage. A recommendation was added to be aware that children and young people may have emotional and mental health needs that can be obscured by their severe complex needs (1.2.1; Evidence report C).

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?

No

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?

No

4.4 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 question 4.2, or otherwise fulfil NICE's obligations to advance equality?

N/A

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

The committee's considerations have been included in the recommendations, and the committee discussion sections of the evidence reports as outlined in the sections above.

Updated by Developer: Angela Bennett

Date: 16.11.21

Approved by NICE quality assurance lead: Kay Nolan

Date: 20.01.2022