

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

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

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

Because of the nature of the severe complex needs of this population, there are multiple subgroups who might require equalities consideration. Particular subgroups or conditions have not necessarily been mentioned in the recommendations. However, all of the recommendations in the guideline are intended to improve the delivery of joined-up education, health and social care services and reduce inequalities across all characteristics.

Physical disabilities

In order to participate in social activities some adaptations to the physical environment may be needed to facilitate attendance and participation of children and young people with severe complex needs. A recommendation was made (1.7.4; Evidence report F) for services to make these adaptations.

Section 1.11 (recommendations 1.11.1 – 1.11.12; Evidence report I) makes recommendations about:

- training staff and families/carers to use environmental adaptations that children or young people are provided with
- signposting relevant support groups
- how to refer children and young people to local specialised environmental control services
- services conducting regular accessibility assessments and making these publicly available
- ensuring accessibility assessment are available for key places the child or young person needs to access

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- providing equipment to the child or young person rather than to a service that they use

Although these recommendations do not cite any specific equalities considerations, they should all help to reduce inequalities for those with physical disabilities.

A recommendation was made (1.12.4; Evidence report I) for what travel training could cover to help all disabled children and young people with severe complex needs to use transport. This included assessing their mobility skills and identify problems they will have using public transport, which is particularly relevant for those with physical disabilities.

Cognitive impairments

Existing NICE guidance on babies, children and young people's experience of healthcare (In development) and patient experience in adult NHS services (CG138) makes recommendations about communicating and discussing complex information and tailoring information to individual's needs (including use of accessible formats). So a recommendation was made (1.1.19; Evidence report A) cross referencing to these guidelines.

Given the central importance of obtaining the views of children and young people with severe complex needs and their being involved in decision making about their support, recommendations were made about establishing the child or young persons preferred communication format (1.1.13; Evidence reports B and M), using this during meetings (1.1.27; Evidence report B) and enabling them to communicate their views in a way that is appropriate for their age, developmental level and communication skills (1.1.12; Evidence report M) in order to ensure they are able to participate in decisions as much as possible.

A recommendation was made (1.1.20; Evidence reports B and M) on how to help children and young people prepare for discussions and meetings. Adequate preparation time will be particularly important in facilitating meaningful participation for those with cognitive impairments.

A recommendation was made (1.1.28; Evidence report B) that children and young people are given plenty of time to express their views during discussions and meetings. This would be particularly relevant for those with cognitive impairments as they may need extra time to communicate their views and process what is being discussed.

A recommendation was made (1.1.29; Evidence report K) that actions from meetings

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and discussions which directly affect the child or young person need to be recorded in a format that the child or young person and their family and carers can understand.

Young people with cognitive impairments may lack capacity to make some decisions about their support and education so a recommendation was made (1.1.41; Evidence report B) to involve them as much as possible in decisions made on their behalf and that the principles in the Mental Capacity Act (2005) should be followed.

A recommendation was made (1.3.10; Evidence report C) that the child or young person's level of understanding and communication needs are taken into account during the EHC needs assessment process.

A recommendation was made (1.4.8; Evidence report M) that the views of children and young people should be recorded in their EHC plans and it needs to be made clear which parts of the plan contain their contributions.

A recommendation was made (1.4.16; Evidence report B) that EHC plans should be checked with the child or young person during the planning process to ensure they understand the plan outcomes, what these will mean in practice and that the plan makes sense to them and they agree with it. The recommendation acknowledges this may be difficult to do for some individuals but emphasises that it should still be done.

A recommendation was made (1.12.4; Evidence report I) for what travel training could cover to help all disabled children and young people with severe complex needs to use transport. This included travelling with parents and carers for those who will not be able to travel on their own, which is particularly relevant for those with cognitive impairments.

Communication needs and disorders

Existing NICE guidance on babies, children and young people's experience of healthcare (In development) and patient experience in adult NHS services (CG138) makes recommendations about communicating and discussing complex information and tailoring information to individual's needs (including use of accessible formats). So a recommendation was made (1.1.19; Evidence report A) cross referencing to these guidelines.

Given the central importance of obtaining the views of children and young people with severe complex needs and their being involved in decision making about their

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support, recommendations were made about establishing the child or young persons preferred communication format (1.1.13; Evidence reports B and M), using this during meetings (1.1.27; Evidence report B) and enabling them to communicate their views in a way that is appropriate for their age, developmental level and communication skills (1.1.12; Evidence report M) in order to ensure they are able to participate in decisions as much as possible. Recommendations were also made (1.4.14; Evidence report M) about preserving the voice of the child or young person when recording their views, using their preferred communication format and in their own words (or equivalent format).

A recommendation was made (1.1.14; Evidence report K) that the most effective way of communicating with families should be established.

A recommendation was made (1.1.20; Evidence reports B and M) on how to help children and young people prepare for discussions and meetings. Adequate preparation time will be particularly important in facilitating meaningful participation for those with communication disorders.

A recommendation was made (1.1.21; Evidence report B) for chairs of meetings to establish the age and communication abilities of the child or young person in advance of meetings. This information can be used to plan meetings and will be particularly relevant to helping children and young people with communication difficulties to meaningfully participate in discussions.

A recommendation was made (1.1.28; Evidence report B) that children and young people are given plenty of time to express their views during discussions and meetings. This would be particularly relevant for those with communication needs and disorders as they may have difficulty communicating their views and it is important that they are not rushed.

A recommendation was made (1.1.29; Evidence report K) that actions from meetings and discussions which directly affect the child or young person need to be recorded in a format that the child or young person and their family and carers can understand.

A recommendation was made (1.3.10; Evidence report C) that the child or young person's level of understanding and communication needs are taken into account during the EHC needs assessment process.

A recommendation was made (1.4.8; Evidence report M) that the views of children

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and young people should be recorded in their EHC plans and it needs to be made clear which parts of the plan contain their contributions.

A recommendation was made (1.4.15; Evidence reports B and M) that the outcomes and support provision sections of EHC plans need to be written in language that is understandable to the child or young person. This should ensure children and young people, and their families and carers with communication needs know what support they are supposed to receive.

A recommendation was made (1.4.16; Evidence report B) that EHC plans should be checked with the child or young person during the planning process to ensure they understand the plan outcomes, what these will mean in practice and that the plan makes sense to them and they agree with it. The recommendation acknowledges this may be difficult to do for some individuals but emphasises that it should still be done.

In order to participate in social activities some adaptations to communication formats may be needed to facilitate attendance and participation of children and young people with severe complex needs. A recommendation was made (1.7.4; Evidence report F) for services to make these adaptations.

Section 1.10 (recommendations 1.10.1 – 1.10.7; Evidence report I) makes recommendations about:

- training staff and families/carers to use communication aids that children or young people are provided with
- signposting relevant support groups
- how to refer children and young people to local augmentative and alternative communication services

Although these recommendations do not cite any specific equalities considerations, they should all help to remove inequalities for those with communication needs and disorders.

A recommendation was made (1.12.4; Evidence report I) for what travel training could cover to help all disabled children and young people with severe complex needs to use transport. This included how communication aids can help, which is particularly relevant for those communication needs.

A recommendation was made (1.13.7; Evidence report H) about things that need to be considered when planning employment support. Developing communication

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passports/communication plans and providing training for employers to help them communicate with the young person at work were included as examples.

A recommendation was made (1.15.20; Evidence report M) that services should develop joint training for all practitioners on how to adapt communication for children and young people with communication difficulties and the use of communication aids.

Learning disability

A recommendation was made (1.1.20; Evidence reports B and M) on how to help children and young people prepare for discussions and meetings. Adequate preparation time will be particularly important in facilitating meaningful participation for those with learning disabilities.

A recommendation was made (1.1.21; Evidence report B) for chairs of meetings to establish the age and communication abilities of the child or young person in advance of meetings. This information can be used to plan meetings and will be particularly relevant to helping children and young people with learning disabilities to meaningfully participate in discussions.

A recommendation was made (1.1.28; Evidence report B) that children and young people are given plenty of time to express their views during discussions and meetings. This would be particularly relevant for those with learning disability as they may need extra time to communicate their views and process what is being discussed.

A recommendation was made (1.3.10; Evidence report C) that the child or young person's level of understanding and communication needs are taken into account during the EHC needs assessment process.

A recommendation was made (1.4.16; Evidence report B) that EHC plans should be checked with the child or young person during the planning process to ensure they understand the plan outcomes, what these will mean in practice and that the plan makes sense to them and they agree with it. The recommendation acknowledges this may be difficult to do for some individuals but emphasises that it should still be done.

In order to participate in social activities some adaptations to activities, communication format and participation methods may be needed to facilitate attendance and participation of children and young people with severe complex needs. A

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recommendation was made (1.7.4; Evidence report F) for services to make these adaptations.

Sensory impairments

Given the central importance of obtaining the views of children and young people with severe complex needs and their being involved in decision making about their support, recommendations were made about establishing the child or young persons preferred communication format (1.1.13; Evidence reports B and M), using this during meetings (1.1.27; Evidence report B) in order to ensure they are able to participate in decisions as much as possible. Recommendations were also made (1.4.14; Evidence report M) about preserving the voice of the child or young person when recording their views, using their preferred communication format and in their own words (or equivalent format).

A recommendation was made (1.1.21; Evidence report B) for chairs of meetings to establish the age, communication abilities and circumstances of the child or young person in advance of meetings. This information can be used to plan meetings and will be particularly relevant to helping children and young people with sensory impairments to meaningfully participate in discussions.

In order to participate in social activities some adaptations to the physical environment, activities and participation methods may be needed to facilitate attendance and participation of children and young people with severe complex needs. A recommendation was made (1.7.4; Evidence report F) for services to make these adaptations.

Mental health conditions

A recommendation was made (1.15.19; Evidence report K) that practitioners should be trained to be better able to recognise social, emotional and mental health needs and internalising symptoms.

Specific conditions and disorders

A recommendation was made (1.11.7; Evidence report I) that services should be aware of best-practice and statutory guidance on environmental accessibility. Examples of adaptations were given including lighting and acoustic adaptations to avoid distractions of distress.

A recommendation was made (1.1.23; Evidence report B) to consider the child or young person's preferences when planning meetings by holding the meeting in a place where they feel comfortable or scheduling it at a time of day when they are not

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usually tired. These considerations would be important for those individuals with sensory processing needs or who may experience difficulty with sleeping and fatigue due to their conditions.

A recommendation was made (1.1.28; Evidence report B) that children and young people are given plenty of time to express their views during discussions and meetings. This would be particularly relevant for those with social and communication needs that impact on the time required to communicate information and they may be asked something unexpected which they will need time to process.

A recommendation was made (1.4.4; Evidence report K) that when deciding on outcomes for EHC plans, expectations for a child or young person should be based on their own life goals and ambitions, rather than on their condition or needs.

A recommendation was made (1.4.6; Evidence report C) to remind practitioners not to assume that all children and young people with a particular diagnosis need the same support

A recommendation was made (1.11.8; Evidence report I) that services conduct regular accessibility assessments, which include sensory aspects of the physical environment).

Race

A recommendation was made (1.3.13; Evidence report C) that practitioners should consider any cultural or communication challenges when parents or carers decline any assessments.

A recommendation was made (1.4.6; Evidence report C) to remind practitioners not to assume that all children and young people with a particular diagnosis need the same support.

Religion or belief

A recommendation was made (1.3.13; Evidence report C) that practitioners should consider any cultural or communication challenges when parents or carers decline any assessments.

A recommendation was made (1.4.6; Evidence report C) to remind practitioners not to assume that all children and young people with a particular diagnosis need the same support.

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Characteristics associated with vulnerability (and possibly stigma)

A recommendation was made (1.1.3; Evidence report B) that at meetings, consideration was needed about which members of the child or young person's family should be involved to take into account situations of family breakdown.

A recommendation was made (1.1.14; Evidence report K) that the most effective way of communicating with families should be established. Providing information in different languages or involving an interpreter may be needed to effectively communicate with families and carers, especially if English is not their first language.

A recommendation was made (1.1.20; Evidence reports B and M) on how to help children and young people prepare for discussions and meetings. Adequate preparation time will be particularly important in facilitating meaningful participation for those with poor literacy. The same recommendation includes providing support for parents and carers if they need help completing any documents.

A recommendation was made (1.2.6; Evidence report C) that barriers to engaging with healthcare services, for example families on low income who have difficulty attending appointments should be included in the referral for a social care assessment for family support.

A recommendation was made (1.2.7; Evidence report K) highlighting that parents and carers may be anxious about involving social care services and so it is important to explain areas they do not understand, address any misconceptions and clarify the difference between safeguarding, child protection, social care and broader family support services. This would be particularly relevant to those with traveller status.

A recommendation was made (1.2.8; Evidence report C) about referral if a safeguarding concern is identified as the population of this guideline. This would be of particular relevance to those who are being bullied and also where there is child abuse or neglect.

A recommendation was made (1.3.13; Evidence report C) that practitioners should consider any cultural or communication challenges when parents or carers decline any assessments. This would be particularly relevant to those with traveller status, those who are homeless and those with poor literacy.

A recommendation was made (1.4.6; Evidence report C) to remind practitioners not to assume that all children and young people with a particular diagnosis need the same support. This is particularly relevant to those with traveller status, those who

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are homeless, situations of family breakdown, families with low income, looked after children, and cases of bullying and abuse/neglect.

A recommendation was made (1.4.15; Evidence reports B and M) that the outcomes and support provision sections of EHC plans need to be written in language that is understandable to the child or young person. This should ensure children and young people, and their families and carers with poor literacy know what support they are supposed to receive.

A recommendation was made (1.4.17; Evidence report B) that local authorities must follow the SEND code of practice guidance on issuing draft EHC plans, giving people time to propose changes to the plan and making its officers available to meet with children and young people and their families and carers. This will be particularly important for those who may be isolated, have English as a second language or have other barriers to accessing information.

A recommendation was made (1.6.8; Evidence report D) to consider using different teaching styles when providing training to parents and carers to take into account different learning styles. This would be particularly relevant for those where English is not their first language or who have poor literacy

A recommendation was made (1.7.1; Evidence report F) highlighting the importance of social participation in maintaining and improving the quality of life of children and young people and that social participation may be more difficult for those who are not able to attend school.

A recommendation was made (1.7.2; Evidence report F) that a range of different options for group social activities should be developed to accommodate different cultural backgrounds and family circumstances, which would include those with traveller status, family breakdown, looked after children status.

In order to participate in social activities, adaptations may be needed to facilitate attendance and participation of children and young people with severe complex needs. A recommendation was made (1.7.4; Evidence report F) for services to make these adaptations. Although not specified in the recommendation, these adaptations could relate to English not being the first language.

A recommendation was made (1.15.5; Evidence report N) that the level of key working support provided needs to take into account family circumstances. This would be relevant to those with looked after children status, traveller status, family

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breakdown, homelessness

Living in a rural area

A recommendation was made (1.7.2; Evidence report F) that local authorities need to think about access to group social activities for those living in rural areas.

Transitioning from children's to adults' services

Section 1.8 (recommendations 1.8.1 – 1.8.13; Evidence reports A, G, J, K, M) makes recommendations about:

- focussing on the young person's goals for adulthood; including making short term goals as well as long term goals
- helping young people to understand all the different options available
- improving consistency across services in the age at which young people transfer to adults' services
- providing information about what will happen
- having a named worker to oversee and coordinate transition

Although these recommendations do not cite any specific equalities considerations, they should all help to remove inequalities for those transitioning from children's to adult's services.

A recommendation was made (1.10.2; Evidence report I) that support should be provided during transition to those children or young people who have been provided with a communication aid, so that they are able to continue to use this in the new environment.

Palliative or end of life care needs

Section 1.9 (recommendations 1.9.1 – 1.9.9; Evidence report E) makes recommendations about:

- reviewing the EHC plan
- finding out what support families and carers need
- implementing new support for children and young people soon as possible
- continued involvement of education and social care practitioners
- providing training in palliative and end of life care and parallel planning

Although these recommendations do not cite any specific equalities considerations, they should all help to remove inequalities for those with palliative or end of life care needs.

Physical health conditions, those with hidden disabilities or impairments, gender; sexual orientation

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

No recommendations have been made explicitly about these equalities considerations. However, all of the recommendations in the guideline are intended to improve the delivery of joined-up education, health and social care services and reduce inequalities across all characteristics.

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?

Families who move areas frequently were identified as an additional group with potential equality issues. Frequently moving area can cause difficulties with effective coordination of care and support and timely transfer of information resulting in a detriment to the care and support received by the child or young person.

A recommendation was made (1.15.13; Evidence report K) for the practitioner providing key working support to identify practitioners in the families new area to share relevant information with, to ensure continuity of care and support and to give a copy of this information to the child or young person and their family and carers.

3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, 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.

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?

No, the recommendations do not make it more difficult for specific groups to access services

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?

No, the recommendations do not have the potential to 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 box 3.4, or otherwise fulfil NICE's obligation to advance equality?

N/A

Completed by Developer: Angela Bennett

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Approved by NICE quality assurance lead: Kay Nolan

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