NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

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

The Department of Health and Social Care and the Department for Education have asked NICE to develop a service guideline for disabled children and young people with severe complex needs.

The guideline will be developed using the methods and processes outlined in developing NICE guidelines: the manual.

This guideline will also be used to develop the NICE quality standard for children and young people with disabilities and complex needs.

1 Why the guideline is needed

Disabled children and young people who also have a mental health or behavioural condition or a physical health condition, may have increasingly severe, complex and changing needs. It is important that health, social care and education services work together to meet these. This guideline will focus on integrating health, social care and education services for disabled children and young people with severe complex needs, and their families and carers. Whereas 'integration of services' can relate to unifying service infrastructure at a national, regional or local level, the aim of this guideline is to deliver seamless provision of services from the perspective of the child or young person and their families and carers. The terms 'integrated', 'joined-up' and 'joint' are used synonymously throughout this document.

Current practice

Examples of challenges to delivering integrated health, social care and education services for disabled children and young people with severe complex needs include the following.

- Ensuring the voice of the child or young person is heard. This means that:
  - they are able to influence how and where their care is provided
  - they are involved in their care
  - communication focuses on them, rather than their parents or carers (although parents and carers might act as advocates for the child or young person's interests), and is adapted appropriately in terms of skills and technology used.
- Making reasonable adjustments to support and promote access to and joined-up delivery of health, social care and education services.
- Overcoming barriers related to attitudes to service provision among professionals, and setting expectations that support the child or young person's involvement and independence.
- Considering the impact on families and carers, and the training and support they might need (while giving due consideration to potential safeguarding issues). This includes helping parents and carers to coordinate multiple health, social care and education appointments.
- Planning and managing multi-professional and volunteer-led input across organisations, sectors and geographical areas. This includes:
  - joint commissioning and coordination of services
  - communication between services
  - avoiding the need for disabled children and young people to travel long distances to access care and services, such as residential services, education or short breaks (respite care).
- Providing training and development opportunities for professionals involved in delivering joined-up health, social care and education services, including aspects related to the interface between services (such as access to medicines in schools).

- Managing the consequences of planned or unplanned health procedures in terms of delivering joined-up health, social care and education services, including the location of services and coordinating care across the interface between hospital and community services.
- Considering the relevance of mental health conditions and/or behaviour that challenges, including aspects that affect communication with the child or young person.
- Considering changing, evolving and emerging needs and their impact on the joint delivery of health, social care and education services.
- Ensuring access to education services, overcoming barriers to offering school places and activities, and considering the impact of part-time attendance patterns due to health and care needs.
- Eliminating discrimination in day-to-day life, including ensuring appropriate access to services related to accommodation, transport, state benefits, and social and physical activities.
- Providing transparency and consistency in arrangements for transition between children's and adults' services, in terms of integration of services.
- Meeting the needs of children and young people with life-limiting conditions, including provision of palliative or end of life care, in terms of integration of services.

The lives of disabled children and young people with severe complex needs can be improved by health, social care and education services that:

- are joined-up
- are tailored to the needs of the individual child or young person
- involve children and young people in decisions about their health and social care and education
- incorporate support for families and carers.

Policy, legislation, regulation and commissioning

While legislation describes what organisations must do, this guideline is focused on 'what works' in terms of how to fulfil those duties. Legislation and statutory guidance that will be taken into account in developing the guideline includes:

- Care Act 2014
- Children Act 1989
- Children and Families Act 2014
- Chronically Sick and Disabled Persons Act 1970
- Equality Act 2010
- Health and Social Care Act 2012
- Mental Capacity Act 2005
- Statutory visits to children with special educational needs and disabilities or health conditions in long-term residential settings 2017
- Supporting pupils at school with medical conditions 2015
- Working together to safeguard children 2018.

Other national policy and guidance relevant to this guideline includes:

- Better care, better lives (2008) Department of Health
- Care and support for deafblind children and adults policy guidance (2014) Department of Health
- Children and young people's health outcome strategy (2012) Children and Young People's Health Outcomes Forum
- Good intentions, good enough? (2017) Council for Disabled Children
- Healthcare for disabled children and young people (2012) Care Quality Commission
- Short breaks for carers of disabled children (2011) Department for Education
- Services for disabled children and families (2003) Audit Commission
- Special educational needs and disability (SEND) code of practice: 0 to 25 years (2015) Department for Education and Department of Health
- The NHS long term plan (2018) NHS England
- These are our children (2017) Council for Disabled Children

2 Who the guideline is for

This guideline is for:

- health professionals working with disabled children and young people with severe complex needs
- allied health professionals working with disabled children and young people with severe complex needs
- social workers and other social care practitioners working with disabled children and young people with severe complex needs
- teaching and support staff, including special educational needs coordinators (SENCOs), working with disabled children and young people with severe complex needs in education settings and services
- special educational needs and disability teams in local authorities
- providers of health and social care and education for disabled children and young people with severe complex needs (including third sector and voluntary organisations)
- commissioners of health and social care services for disabled children and young people with severe complex needs
- disabled children and young people with severe complex needs, their families and carers, and the public.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

Equality considerations

NICE has carried out an equality impact assessment during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities related to physical disabilities, cognitive impairments, communication needs and disorders (including behavioural and social communication disorders), learning disability and sensory impairments. These may manifest through, or occur in combination with, mental health and behavioural support needs or physical health conditions.

When considering principles that should be applied to the delivery of joined-up health, social care and education services for children and young people with severe complex needs, relevant conditions and disorders include:

- autism spectrum disorder
- attention deficit hyperactivity disorder
- anxiety and depression
- behaviour that challenges
- attachment disorder
- neurological conditions
- allergic conditions
- genetic conditions
- myalgic encephalomyelitis (chronic fatigue syndrome).

Further specific considerations that may be relevant for this guideline in relation to equalities include:

- 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
- family origin
- religion or belief (these might be associated with particular attitudes [positive or negative] or sensitivities towards disability).

The following additional characteristics associated with vulnerability, and possibly stigma, may be relevant for this guideline:

- looked-after children status

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

Living in a rural area may also mean inequality in access to services.

There may be specific equalities considerations relating to children and young people who are transitioning from children’s to adults’ services, or who have degenerative or life-limiting conditions and palliative or end of life care needs.

3 What the guideline will cover

NICE guidelines use the best available evidence to develop recommendations that guide decisions. This guideline will focus on general principles in the delivery of joined-up health, social care and education services. We will not be able to formulate recommendations specific to particular disabilities or health conditions, although we will keep in mind the contexts raised by stakeholders as being of relevance to this guideline. The guideline will be developed using the approaches described in appendix A of developing NICE guidelines: the manual.

3.1 Who is the focus?

Groups that will be covered

- Disabled children and young people from birth to 25 years with severe complex needs, who require health, social care and education support.

Groups that will not be covered

- Children and young people who do not have needs in all 3 areas of health, social care and education.

3.2 Settings

Settings that will be covered

All settings in which health, social care and education is provided for disabled children and young people from birth to 25 years with severe complex needs.

3.3 Activities, services or aspects of care

Key areas that will be covered

We will look at evidence in the areas below when developing the guideline, but it may not be possible to make recommendations in all the areas.

Ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services, taking into account the following factors:

1. strategic planning, timely access, location of services, types of service provision and service capacity
2. identifying, assessing and monitoring combined health, social care and education needs (including changing needs) of disabled children and young people with severe complex needs
3. ensuring children and young people are involved in planning and reviewing, and know about, their combined health and social care and education
4. meeting health, social care and education needs, including changing and evolving needs
5. promoting and maintaining independence and wellbeing
6. supporting the role of families and carers
7. ensuring that the environments in which disabled children and young people with severe complex needs receive health and social care and education are suitable and accessible (for example, what accommodation is needed and what equipment [including assistive technology] could help)
8. enabling education, social and leisure activities and preparation for employment

9 planning and managing transition from children's to adults' services

10 planning and managing palliative and end of life care for children and young people with life-limiting conditions

11 views and experiences of service users and providers.

Areas that will not be covered

1 Interventions and approaches that do not relate to health, social care and education in combination.

Related NICE guidance

- End of life care for infants, children and young people with life-limiting conditions: planning and management (2016) NICE guideline NG61
- Transition between inpatient mental health settings and community or care home settings (2016) NICE guideline NG53
- Transition from children's to adults' services for young people using health or social care services (2016) NICE guideline NG43
- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (2015) NICE guideline NG11
- Looked-after children and young people (2015) NICE guideline PH28
- Social and emotional wellbeing in secondary education (2009) NICE guideline PH20
- Social and emotional wellbeing in primary education (2008) NICE guideline PH12

In development

- Supporting adult carers. NICE guideline. Publication expected January 2020
- Babies, children and young people's experience of healthcare. NICE guideline. Publication expected April 2021

NICE guidance about the experience of people using NHS and social care services

NICE has produced the following guidance on the experience of people using the NHS and social care services. This guideline will not include additional recommendations on these topics unless there are specific issues related to children and young people with disabilities and severe complex needs:

- People’s experience in adult social care services (2018) NICE guideline NG86
- Medicines optimisation (2015) NICE guideline NG5
- Patient experience in adult NHS services (2012) NICE guideline CG138
- Service user experience in adult mental health (2011) NICE guideline CG136
- Medicines adherence (2009) NICE guideline CG76

3.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS, individual or societal perspective, as appropriate.

3.5 Key issues and draft questions

While writing this scope, we have identified the following key issues and draft review questions related to them.

Please note that the wording of the following review questions is provisional. The guideline developers intend to use a modified mixed-methods approach to evidence reviews in this guideline. This will allow consideration of both quantitative evidence of effectiveness and qualitative evidence describing views and experiences of people using, commissioning and providing services for at least some of the review questions.

For questions 9 and 10, this guideline will not duplicate or replace existing NICE guidelines. Instead, it will focus specifically on effective joint commissioning, integration and joint working across health, social care and education services for disabled children and young people with severe complex needs.

Ensuring effective joint commissioning, integration and joint working between practitioners across health, social care and education services, taking into account the following factors:

1 Strategic planning, timely access, location of services, types of service provision and service capacity
  1.1 What are the most effective commissioning and practice models to deliver joined-up health, social care and education services for disabled children and young people with severe complex needs?
  1.2 What are the most effective practices (for example, communication and training) to enable health, social care and education professionals to meet the combined health, social care and education needs of disabled children and young people with severe complex needs?

2 Identifying, assessing and monitoring combined health, social care and education needs (including changing needs) of disabled children and young people with severe complex needs
  2.1 What are the most effective combined approaches to identifying, assessing and monitoring the health, social care and education needs (including changing needs) of disabled children and young people with severe complex needs?

3 Ensuring children and young people are involved in planning and reviewing, and know about, their combined health and social care and education
  3.1 What are the most effective practices (for example, communication and information management) to enable health, social care and education services to work together to involve disabled children and young people with severe complex needs in understanding, planning and reviewing their care and education?

4 Meeting health, social care and education needs, including changing and evolving needs

4.1 What combined service delivery models are most effective in meeting the health, social care and education needs (including changing and evolving needs) of disabled children and young people with severe complex needs?

5 Promoting and maintaining independence and wellbeing

5.1 What are the most effective approaches for health, social care and education services to work together to promote inclusion, independence and wellbeing of disabled children and young people with severe complex needs?

6 Supporting the role of families and carers

6.1 What interventions, such as combined support, communication strategies and short breaks, are effective in enabling families and carers to be involved in the planning and delivery of care for disabled children and young people with severe complex needs?

7 Ensuring that the environments in which disabled children and young people with severe complex needs receive health, social care and education support are suitable and accessible (for example, what accommodation is needed and what equipment [including assistive technology] could help)

7.1 What are the most effective practices (for example, environmental assessments and use of equipment such as assistive technology across different contexts) to ensure the suitability and accessibility of the environments in which disabled children and young people with severe complex needs receive health and social care and education?

8 Enabling education, social and leisure activities and preparation for employment

8.1 What are the most effective ways that health, social care and education services can work together to support disabled children and young people with severe complex needs to participate in and benefit from education and social activities?

8.2 What are the most effective models of health, social care and education services working together to prepare disabled children and young people with severe complex needs for employment?

9 Planning and managing transition from children's to adults' services

9.1 What is the impact of including education with combined health and social care support models and frameworks on transition from children's to adults' services for disabled children and young people with severe complex needs?

10 Planning and managing palliative and end of life care for children and young people with life-limiting conditions

10.1 What combined health, social care and education service delivery arrangements can best provide for the needs of disabled children and young people with severe complex needs on a palliative or advance care plan, and for the needs of their families and carers?

11 Views and experiences of service users and providers

11.1 What is the experience of disabled children and young people with severe complex needs and their families and carers of joint delivery of health, social care and education services?

11.2 What is the experience of commissioners and providers of joint working of health, social care and education services for disabled children and young people with severe complex needs?

11.3 What are the barriers and facilitators perceived or experienced by users and providers of joined-up care across health, social care, education and other services for disabled children and young people with severe complex needs?

3.6 Main outcomes

The main outcomes that may be considered when searching for and assessing the evidence are:

- person focused:
  - quality of life (both health- and social-related quality)
  - wellbeing
  - independence

  - experience of services
  - participation and inclusion (including progress into employment)
  - self-efficacy
  - social capital (range of social contact that provides access to social, emotional or practical support)
  - communication
  - progress in learning
  - educational achievement or attainment
  - morbidity
  - mortality
- service focused:
  - availability, capacity and timeliness of health, social care and education services
  - use of health, social care and education services
  - availability, access and uptake of local services
  - accessibility of joined-up services
  - extent to which general and severe mental and physical health and educational needs are met
  - geographical variation in service provision (locally, regionally and nationally)
  - setting of services (for example, hospital or community)
  - extent of joined-up support
  - effective cross-sector planning.

4 NICE quality standards and NICE Pathways

4.1 NICE quality standards

NICE quality standards that will use this guideline as an evidence source when they are being developed

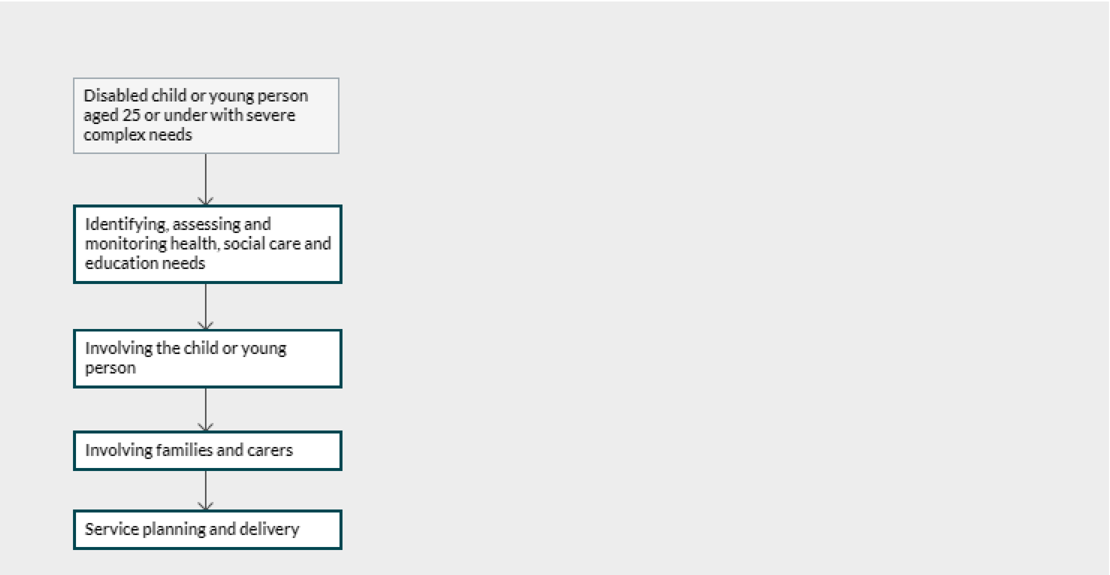
- Children and young people with disabilities and complex needs. NICE quality standard. Publication date to be confirmed

4.2 NICE Pathways

NICE Pathways bring together everything we have said on a topic in an interactive flowchart. When this guideline is published, the recommendations will be included in the NICE Pathway on disabled children and young people with severe complex needs (in development).

An outline based on this scope is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

Disabled children and young people with severe complex needs



5 Further information

This is the final scope, which takes into account comments from registered stakeholders during consultation.

The guideline is expected to be published in February 2021.

You can follow progress of the guideline.

Our website has information about how NICE guidelines are developed.