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2 **NATIONAL INSTITUTE FOR HEALTH AND CARE**
3 **EXCELLENCE**

4 **Guideline scope**

5 **Children and young people with disabilities**
6 **and severe complex needs: integrated**
7 **health and social care support and service**
8 **guidance**

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

12 The guideline will be developed using the methods and processes outlined in
13 [developing NICE guidelines: the manual](#).

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

16 **1 Why the guideline is needed**

17 **Key facts and figures**

18 Disabled children and young people are entitled to the same access to health
19 and social care as other children and young people. They may have severe
20 complex needs that require health and social care support from a range of
21 providers. This requires a joint, integrated, inter-agency approach at the point
22 of delivery of both health and social care.

23 With advances in medicine, more disabled children and young people with
24 severe complex needs are surviving to adulthood. However, they may remain
25 dependent on their gradually aging parents (and carers) to navigate health
26 and social care systems and coordinate provision of services. Survival with
27 physical disability, cognitive impairment, behavioural and social

1 communication disorders, learning disability or sensory impairment, in
2 combination with a health condition may lead to increasingly severe and
3 complex ongoing needs. It is important that health and social care services
4 work together to meet these. When a young person over 16 lacks capacity to
5 make a particular decision, the best interests process under the Mental
6 Capacity Act 2005 should be followed, involving the young person as far as
7 possible in decisions made on their behalf.

8 **Current practice**

9 Challenges faced in the care of disabled children and young people with
10 severe complex needs include the following examples:

- 11 • schools not allowing access to places because they feel they cannot meet
12 children and young people's needs
- 13 • lack of local service provision meaning that children and young people
14 sometimes have to travel long distances for support, such as respite care
- 15 • discrimination in day-to-day life, including accessing mainstream services,
16 such as transport, housing and social activities
- 17 • children and young people's voices not being heard because, for example,
18 carers may be overly protective and so they may not have the same
19 experiences as other children or young people
- 20 • development of health conditions such as epilepsy or complications of
21 enteral feeding — this may mean prolonged periods in hospital, often
22 without education or recreation, because safe discharge requires providing
23 equipment and training of carers, as well as meeting other new needs
- 24 • respiratory failure in children and young people with neuromuscular
25 conditions requiring ventilatory support — these children and young people
26 need review of changing health needs, re-engagement with statutory
27 agencies and reintegration into the community (which can be delayed while
28 provision and funding responsibilities are resolved between health and
29 social care)
- 30 • parents coordinating multiple health and social care appointments.

1 Providing improved, individually tailored and integrated health and social care
2 for disabled children and young people with severe complex needs, and
3 providing support for their families and carers, will improve health and enable
4 the children and young people to live more fulfilled lives with greater potential
5 to be involved in decisions about their health and care.

6 **Policy, legislation, regulation and commissioning**

7 While legislation (see below) describes what organisations must do, this
8 guideline is focused on 'what works' in terms of how to fulfil those duties.

9 Legislation and statutory guidance that will be taken into account in
10 developing the guideline includes:

- 11 • Children and Families Act 2014
- 12 • Equality Act 2010
- 13 • Mental Capacity Act 2005
- 14 • Health and Social Care Act 2012
- 15 • Care Act 2014.

16 Other national policy and guidance relevant to this guideline includes:

- 17 • [Good intentions, good enough?](#) (2017) Department for Education
- 18 • [These are our children](#) (2017) Department of Health and Social Care
- 19 • [Special educational needs and disability \(SEND\) code of practice: 0 to 25](#)
20 [years](#) (2015) Department for Education and Department of Health and
21 Social Care
- 22 • [Aiming high for disabled children: better support for families](#) (2007)
23 Department for Education and Skills
- 24 • [Better care, better lives](#) (2008) Department of Health
- 25 • [Services for disabled children and families](#) (2003) Audit Commission
- 26 • [Healthcare for disabled children and young people](#) (2012) Care Quality
27 Commission
- 28 • [Children and young people's health outcome strategy](#) (2012) Children and
29 Young People's Health Outcomes Forum

1 **2 Who the guideline is for**

2 This guideline is for:

- 3 • social workers and other social care practitioners working with disabled
- 4 children and young people with severe complex needs
- 5 • health professionals working with disabled children and young people with
- 6 severe complex needs
- 7 • allied health professionals working with disabled children and young people
- 8 with severe complex needs
- 9 • practitioners working with disabled children and young people with severe
- 10 complex needs in education services
- 11 • special educational needs and disability teams in local authorities
- 12 • providers of care and support for disabled children and young people with
- 13 severe complex needs (including third sector and voluntary organisations)
- 14 • commissioners of health and social care and support for disabled children
- 15 and young people with severe complex needs
- 16 • disabled children and young people with severe complex needs, their
- 17 families and carers, and the public.

18 NICE guidelines cover health and care in England. Decisions on how they

19 apply in other UK countries are made by ministers in the [Welsh Government](#),

20 [Scottish Government](#), and [Northern Ireland Executive](#).

21 ***Equality considerations***

22 NICE has carried out [an equality impact assessment](#) [add hyperlink in final

23 [version](#)] during scoping. The assessment:

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

26 The guideline will look at inequalities related to physical disabilities, cognitive

27 impairment, behavioural and social communication disorders, learning

28 disability and sensory impairment. Additionally, the following protected

29 characteristics may be relevant for this guideline: having a long-term mental

1 health condition; having an ‘invisible’ disability (where the disability or
2 impairment is not immediately apparent); being less able to communicate
3 verbally; and race, religion or belief (these might be associated with particular
4 attitudes [positive or negative] or sensitivities towards disability).

5 The following additional characteristics associated with vulnerability, and
6 possibly stigma, may be relevant for this guideline: looked-after children
7 status; homelessness; traveller status; English not being the first language;
8 having poor literacy; being in a family with a low income; not attending school;
9 child abuse and neglect. Living in a rural area may also mean inequality in
10 access to services.

11 **3 What the guideline will cover**

12 This guideline will focus on general principles across all services. However,
13 where evidence is available, recommendations may also be made for specific
14 subgroups.

15 **3.1 Who is the focus?**

16 **Groups that will be covered**

- 17 • Disabled children and young people from birth to 25 years, with disability as
18 defined by the Equality Act 2010, and severe complex needs and their
19 families or carers. Severe complex needs refers to an ongoing requirement
20 for integrated health and social care support and services.

21 **Groups that will not be covered**

- 22 • Disabled children and young people who do not have ongoing severe
23 complex needs.

24 **3.2 Settings**

25 **Settings that will be covered**

26 All settings in which health and social care is provided for disabled children
27 and young people with severe complex needs, including educational settings.

1 **3.3 Activities, services or aspects of care**

2 **Key areas that will be covered**

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

5 ***Integrated health and social care support for individual children and*** 6 ***young people and their families and carers***

7 1 Identifying, assessing and monitoring combined health and social care
8 needs, including changing needs, of disabled children and young people
9 with severe complex needs.

10 2 Ensuring children and young people are involved in planning, and know
11 about, their combined health and social care.

12 3 Managing health and social care needs, including changing and evolving
13 needs.

14 4 Promoting and maintaining independence and wellbeing.

15 5 Facilitating the role of families and carers.

16 6 Ensuring suitability and accessibility of accommodation.

17 7 Enabling education, social and leisure activities and preparation for
18 employment.

19 ***Service delivery and organisation***

20 8 Ensuring effective commissioning, integration and joint working between
21 practitioners across health and social care services.

22 **Areas that will not be covered**

23 1 Interventions that relate exclusively to healthcare.

24 **Related NICE guidance**

- 25 • [Transition between inpatient mental health settings and community or care](#)
26 [home settings](#) (2016) NICE guideline NG53
- 27 • [Transition from children's to adults' services for young people using health](#)
28 [or social care services](#) (2016) NICE guideline NG43

- 1 • [Challenging behaviour and learning disabilities: prevention and](#)
2 [interventions for people with learning disabilities whose behaviour](#)
3 [challenges](#) (2015) NICE guideline NG11
- 4 • [Looked-after children and young people](#) (2015) NICE guideline PH28
- 5 • [Social and emotional wellbeing in secondary education](#) (2009) NICE
6 guideline PH20
- 7 • [Social and emotional wellbeing in primary education](#) (2008) NICE guideline
8 PH12

9 ***In development***

- 10 • [Carers: provision of support for adult carers.](#) NICE guideline. Publication
11 expected January 2020
- 12 • [Infant, children and young people's experience of healthcare.](#) NICE
13 guideline. Publication expected April 2021

14 **NICE guidance about the experience of people using NHS and social** 15 **care services**

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

- 20 • [People's experience in adult social care services](#) (2018) NICE guideline
21 NG86
- 22 • [Medicines optimisation](#) (2015) NICE guideline NG5
- 23 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 24 • [Service user experience in adult mental health](#) (2011) NICE guideline
25 CG136
- 26 • [Medicines adherence](#) (2009) NICE guideline CG76

27 **3.4 Economic aspects**

28 We will take economic aspects into account when making recommendations.
29 We will develop an economic plan that states for each review question (or key
30 area in the scope) whether economic considerations are relevant, and if so

1 whether this is an area that should be prioritised for economic modelling and
2 analysis. We will review the economic evidence and carry out economic
3 analyses, using an NHS, individual or societal perspective, as appropriate.

4 **3.5 Key issues and draft questions**

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

7 Please note that the wording of the following review questions is provisional.

8 The guideline developers intend to use a mixed-methods approach to
9 evidence reviews in this guideline. This will allow consideration of both
10 quantitative evidence of effectiveness and qualitative evidence describing
11 views and experiences of people using services for at least some of the
12 review questions.

13 ***Integrated health and social care support for individual children and*** 14 ***young people and their families and carers***

15 1 Identifying, assessing and monitoring combined health and social care
16 needs, including changing needs, of disabled children and young people
17 with severe complex needs

18 1.1 What interventions are effective and acceptable in early identification
19 of combined health and social care needs, including changing needs, of
20 disabled children and young people with severe complex needs?

21 1.2 What interventions are effective and acceptable in assessing
22 combined health and social care needs, including changing needs, of
23 disabled children and young people with severe complex needs?

24 1.3 What interventions are effective and acceptable in monitoring
25 combined health and social care needs, including changing needs, of
26 disabled children and young people with severe complex needs?

27 2 Ensuring children and young people are involved in planning, and know
28 about, their combined health and social care

29 2.1 What strategies, including communication, are effective and
30 acceptable in involving disabled children and young people with and

- 1 severe complex needs in planning and understanding their combined
2 health and social care?
- 3 3 Managing health and social care needs, including changing and evolving
4 needs
- 5 3.1 What combinations of health and social care interventions are
6 effective and acceptable in addressing changing and evolving health and
7 social care needs of disabled children and young people with severe
8 complex needs?
- 9 4 Promoting and maintaining independence and wellbeing
- 10 4.1 What combinations of health and social care interventions, including
11 provision of equipment and assistive technologies, are effective and
12 acceptable in promoting and maintaining independence and wellbeing of
13 disabled children and young people with severe complex needs?
- 14 5 Facilitating the role of families and carers
- 15 5.1 What interventions, such as support and communication strategies,
16 are effective and acceptable in enabling families and carers to be
17 involved in the care of disabled children and young people with severe
18 complex needs?
- 19 5.2 How can health and social services work together to facilitate short
20 breaks (respite care) for families and carers of disabled children and
21 young people with severe complex needs?
- 22 6 Ensuring suitability and accessibility of accommodation
- 23 6.1 What combinations of health and social care interventions are
24 effective and acceptable in promoting suitability and accessibility of
25 accommodation for disabled children and young people with severe
26 complex needs?
- 27 7 Enabling education, social and leisure activities and preparation for
28 employment
- 29 7.1 What combinations of health and social care interventions are
30 effective and acceptable in promoting inclusion and learning for disabled
31 children and young people with severe complex needs?
- 32 7.2 What combinations of health and social care interventions are
33 effective and acceptable in promoting social and leisure activities for
34 disabled children and young people with severe complex needs?

1 7.3 What combinations of health and social care interventions are
2 effective and acceptable in preparing disabled children and young
3 people with severe complex needs for employment?

4 ***Service delivery and organisation***

5 8 Ensuring effective commissioning, integration and joint working between
6 practitioners across health and social care services

7 8.1 What factors would enable strategic oversight of and clear
8 accountability in integrated health and social care?

9 8.2 What is the effectiveness and acceptability of specific service models
10 involving key workers and case managers for facilitating access to
11 disparate services and coordinating support across health, social care,
12 education and other services?

13 8.3 What communication strategies are effective and acceptable for
14 sharing information across health, social care, education and other
15 services?

16 8.4 What strategies are effective and acceptable for ensuring continuity
17 of care across health, social care, education and other services for
18 disabled children and young people with severe complex needs?

19 8.5 What are the barriers to and facilitators of continuity of care across
20 health, social care, education and other services for disabled children
21 and young people with severe complex needs?

22 8.6 What models of timing and location of service delivery across health,
23 social care, education and other services, including geographical or
24 virtual co-location of services, are effective and acceptable for disabled
25 children and young people with severe complex needs?

26 **3.6 *Main outcomes***

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

- 29 • quality of life (both health- and social-related quality)
- 30 • wellbeing
- 31 • independence

- 1 • experience of services
- 2 • participation and inclusion
- 3 • self-efficacy
- 4 • social capital (range of social contact that provides access to social,
- 5 emotional or practical support)
- 6 • communication
- 7 • learning or educational attainment
- 8 • morbidity
- 9 • mortality
- 10 • economic outcomes (including resource use and impact on other services).

11 **4 NICE quality standards and NICE Pathways**

12 **4.1 NICE quality standards**

13 **NICE quality standards that will use this guideline as an evidence source** 14 **when they are being developed**

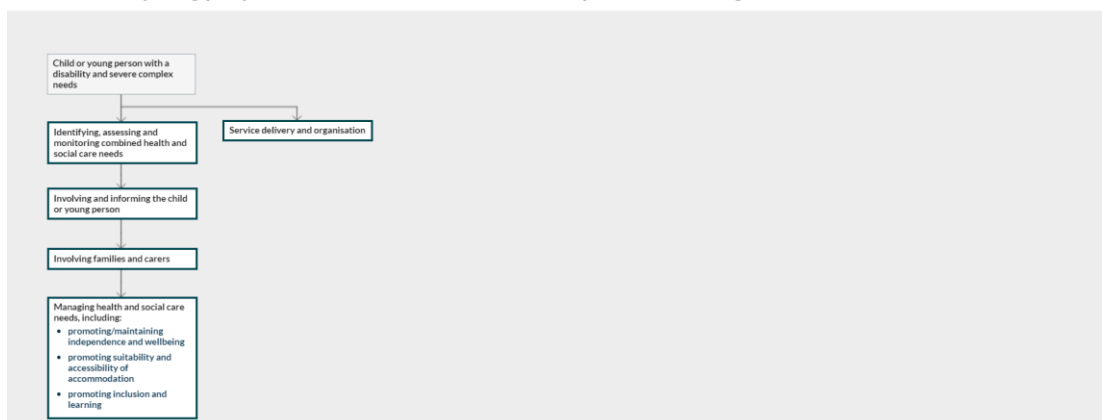
- 15 • Children and young people with disabilities and complex needs NICE
16 quality standard. Publication date to be confirmed

17 **4.2 NICE Pathways**

18 [NICE Pathways](#) bring together everything we have said on a topic in an
19 interactive flowchart. When this guideline is published, the recommendations
20 will be included in the NICE Pathway on children and young people with
21 disabilities and severe complex needs: integrated health and social care (in
22 development).

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

Children and young people with disabilities and severe complex needs: integrated health and social care overview



2 **5 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 8 January to 5 February 2019.

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.

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