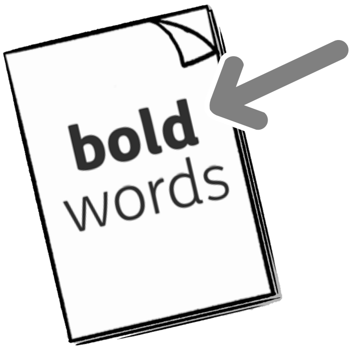
NICE
National Institute for
Health and Care Excellence

easy
read

Disabled children and young people with severe complex needs

Contents



In this easy read document, difficult words are in **bold**. We explain what these words mean in the sentence after they have been used.

Some words are blue and underlined. These are links which will go to another website which has more information.

Introduction

This guide is written by NICE, which is the short name for the National Institute for Health and Care Excellence.

We find out what works well in health and **social care** and write guides to give advice about it.

Social care is support you need to look after yourself. Social care workers include nurses, care home workers and social workers.

This guide is to make sure children and young people with **severe complex needs** get the support they need.

Severe complex needs is when a disabled person also needs social care and education support.

We want to know what you think about the guide.

About this guide

NICE
National Institute for Health and Care Excellence

easy read

Disabled children and young people with severe complex needs

What this guide is for

We have written this guide to make sure:

- disabled children and young people with severe complex needs get the right support from education, health and social care services

- children and young people are involved in decisions about their support

- staff think about each person’s wants and needs.

This guide will help:

- you to be more involved in decisions about your support

- staff and services to work together better, so they can provide the support you need.

SEND code of practice

SEND stands for Special Educational Needs and Disability.

A **code of practice** is a set of rules saying how something should be done.

The SEND code of practice explains:

- what support children and young people with special educational needs should have

- what councils, schools, colleges and the NHS have to do by law to support you.

This guide will help these organisations to follow the SEND code of practice.

The SEND code of practice is available here: www.gov.uk/government/publications/send-code-of-practice-0-to-25

There is also an easy read guide for parents available here: www.gov.uk/government/publications/send-support-easy-read-guide-for-parents

Involving you in decisions

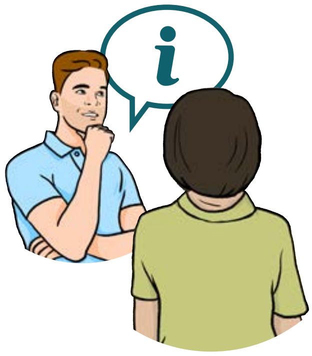
Staff should involve you in decisions about your support. To do this they should:

- get to know you, to understand your needs

- find out what your goals are in life

- learn how you like to **communicate.**

  Communicate means how you share information. It includes speaking and writing.



Staff should give you up-to-date information and advice about:

- your care and support

- any **assessments** you are having

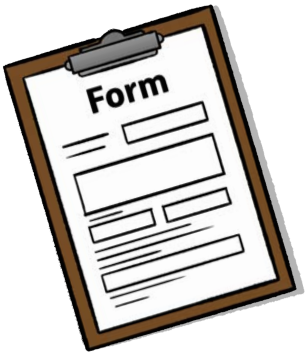
  An **assessment** is when staff check to see what care or support you might need.

- any meetings you are going to

- any staff or services who are involved in supporting you.

Staff should help you get involved at meetings. This means:

- finding out what you want to talk about and putting your wishes first



- helping you fill in forms and other paperwork before the meeting

- thinking about when to have the meeting, for example at a time of day when you are not normally tired

- making sure all the right people are at the meeting.

Severe complex needs

If staff think you have severe complex needs, they should:

- involve other services as soon as possible, so they can work together to provide you with support

- tell you about any support that is available before you have an education, health and care needs assessment.

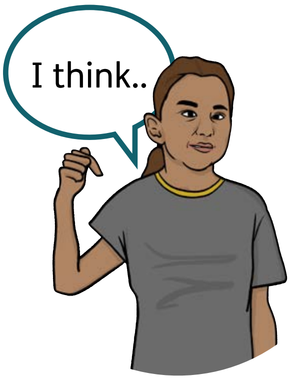
Education, health and care needs assessment

Staff should tell you how an education, health and care needs assessment can help you. They should also tell you:

- how to get an assessment

- what might happen because of the assessment

- how long the assessment will take



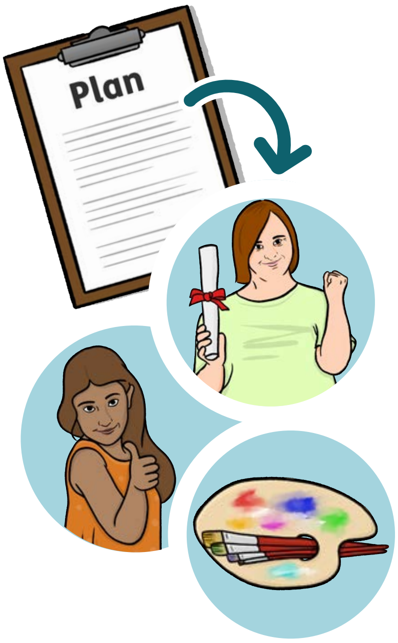
- how you can be involved in the assessment.

Staff should explain what services are available in your area and who can use them.

This will give you more of an idea of how an education, health and care plan could help.

Staff should make sure you get support while you are waiting for the assessment to be done.

Education, health and care plan



When writing a plan, staff should focus on:

- your goals in life
- what you are good at
- things you are interested in.

This will help to make sure the plan is right for you.

Staff should listen to your parents and carers when writing the plan.

All the staff involved should work together to write the plan, so it works as a whole and makes sense to everyone.

The important parts of the plan should be written so that you can understand them.

Staff should write what you have said about your wants and needs in the plan.

Staff should check that you know what is in the plan and agree with it.

The plan should be changed if your needs change, for example if you have a new health problem.

Types of support

Personal budgets and direct payments

Personal budgets and **direct payments** are money given to you to pay for your own care and support.

Staff should explain to you how personal budgets and direct payments can help you.

Support for parents and carers

Staff should explain what support they can give to your parents and carers.

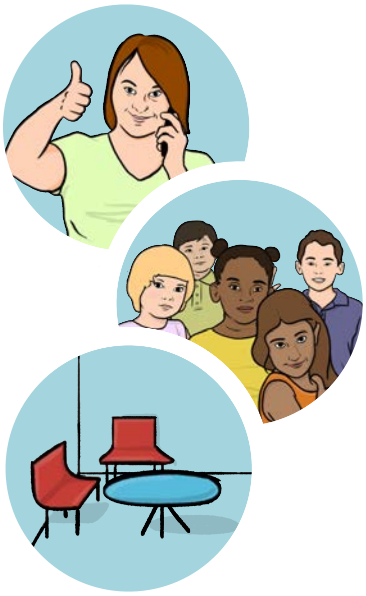
This should involve training, to help your parents and carers understand your particular needs.

The training should be:

- right for the needs of your family
- available when your family need it, not just at a certain time.

Joining in with other people

Staff should help you take part in group activities, like sport.



They could make the activities work for you by changing:

- how people communicate
- how people join in
- the place where you do the activity
- the equipment you use.

Staff should think about other ways to help you meet people, like helping you use community services and buildings.

Your healthcare team should work with other services to make sure that your health needs do not stop you from going to school or doing activities with other people.

Getting ready to become an adult

Staff should help you think about the different options when you become an adult, so you can decide what you want to do.

They should:

- look at your goals in life
- help you get ready
- help you be as independent as possible
- make sure there are no gaps in your support when you change to adult services.

Palliative and end of life care plans

End of life care is care that happens near the end of someone's life, and includes **palliative care**.

Palliative care is given to someone with a condition that can't be cured. It is to keep them feeling well.

If you need a palliative or end of life care plan, education and social care staff should continue to be involved.

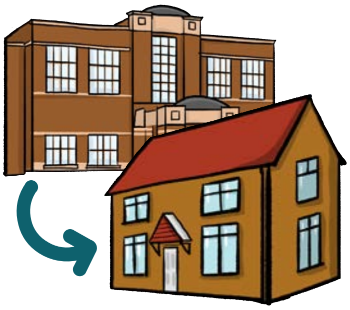
Staff should:

- help you to keep going to school or other activities if you want to
- check that your education, health and care plan still works for you
- find out what extra support your family and carers need.

Communication aids

Communication aids are things which help you communicate, like using symbols, or devices like phones and tablets.

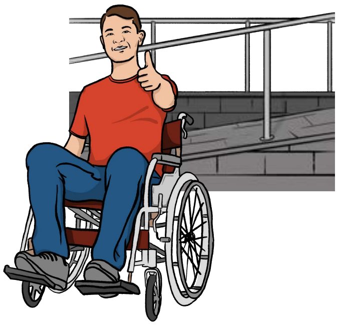
Staff should:



- make changes so that you can use your communication aid in more than one place, for example at home and at school

- train you and your family and carers in the best way to use your communication aid
- train other staff to help you use your communication aid.

Environmental changes



Environmental changes are changes to buildings or equipment to help you use them, like:

- ramps for people who use wheelchairs

- a switch to help you use computers.

Staff should train:

- you and your family and carers to use any equipment that has been given to you
- other staff to help you use this equipment.

Every year, services should look at:

- how **accessible** their buildings and equipment are

  Accessible means it is easy to use and suitable for people with different needs.

- how well their staff understand disability.

Using different kinds of transport

Services should offer you travel training to help you use different kinds of transport like the bus or train.

Looking for a job

Councils should make sure **supported internships** are available in your area.

Supported internships are when you learn how to do a job by practising in a real workplace.

Services should make sure you have 1 staff member working as your lead **employment practitioner**.

An **employment practitioner** is a person that will help the other people at your job to support you.

If you are offered a job at the end of your supported internship, staff should help to plan changes that will help you do your job.

Services working together

You should have 1 person who is in charge of all your support and helps you understand the different services that are involved.

They might be called a ‘key worker’.

This person should be someone who:

- is part of the team supporting you
- knows you and understands your needs.

Services should ask you how well they have:

- supported you
- worked with the other services involved.

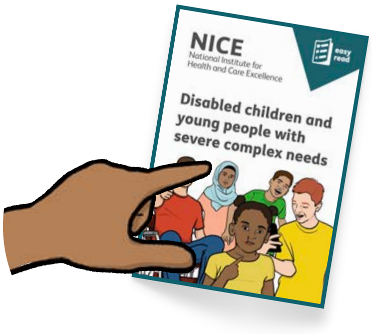
When councils and health commissioners set up new services, they should make sure these services are supporting you as soon as possible, before any serious problems can happen.

Councils and health commissioners should involve disabled children and young people and their parents and carers in planning local services.

What do you think?

We would like to know what you think about this guide:

- How could this guide make a difference in your life?



- Are there parts of the guide you would like to know more about?