Draft 0-25 special educational needs (SEN) Code of Practice: young disabled people’s views
When I used to have my reviews at school they never used to tell me what was actually going to happen in the meeting. Before I went in, the person who was actually taking me to the meeting would tell me what they were going to ask me, say 'don't be scared', just reassuring me that it'll be all right. Even though I was confident enough to say my opinion, it was so daunting to go in with these professionals from my school with all these different ideas on how my support should be.
Introduction

This report shares what young people think about the draft 0-25 special educational needs (SEN) Code of Practice. We spoke to 19 groups of children and young people from across England. The total number of young people we spoke to was 168.

This report looks at:

- Decision making
- Education, Health and Care Plans
- Taking control at 16
- Knowing what support is available where you live
- Challenging decisions
- Other issues
- Conclusion
- What happens next?
- Glossary

This report shares young people’s views on the draft Code of Practice and is not an explanation of the Code of Practice. To make this report easier to read we have picked out the key points that were raised by the children and young people we spoke with. If you would like more detailed information about what was said you can read the full report here.

The changes to special educational needs support will start in September 2014. Some of the changes include: moving from a Statement of SEN Support to an Education, Health and Care plan; having new support when you go to college or start a training programme; and disabled children and young people will get new rights to have a say in the support and services they receive.
Decision making

Disabled young people should be involved in making decisions about their education.

The young people we spoke to said they want to be more involved in making decisions about the SEN support they have. They said it was important for them to be involved in making decisions, but they also said they needed more information and support so they feel more confident making decisions.

Some of the things they said about making decisions included:

- More accessible and impartial information is needed to help young people understand their options and make choices
- A young person is an expert of their life and their views and opinions are the most important when it comes to deciding what support they need
- Young people would like to have support to build their confidence so they that they can make more decisions about their SEN support
- All young people would like to have opportunities to make decisions and to develop their skills

I find making decisions difficult when there are loads of people around asking questions. I like to be asked in private, and then things can be discussed in meetings.

Young people felt that gaining skills and confidence to make decisions was something they needed to learn as they grow up. The young people we spoke to felt very strongly that they should not suddenly have to make decisions without support.
Statements of SEN Support are going to be replaced with Education, Health and Care (EHC) plans. EHC plans are legal documents which say what support a young person needs at their school or college. Other young people with SEN who don’t get an Education, Health and Care plan but who still need support will get that help from their school or college, but it will not be written in a legal document.

Some of the young people we spoke to said the EHC plans might be confusing and they were worried about who would get an EHC plan.

Young people said they need more information about:

- When they will move to the new type of SEN support
- What assessments they need to take to get an EHC plan or to keep their plan when they finish school, and what happens if they need support but don’t have an EHC plan

The young people we spoke to also wanted more information to explain the support they are entitled to as they move into adulthood.

Young people also said they wanted to know what new rights they will have in deciding how they are supported. In all of the groups disabled young people said the information in their support plans should be kept private and young people should be able to decide who sees information about them.
I wasn’t involved in decisions until I hit transition and then everyone wanted me to make complicated decisions and I felt a lot of pressure and didn’t feel I had enough experience of making decisions.

Young people said they wanted to taking control of making decisions about their SEN support. During the focus groups young people said that to feel confident making decisions they needed:

- To be involved slowly and over time so that they can feel confident in making decisions about their support
- To know what taking control of their EHC plan means for them
- Access to an advocate or key worker if they need one
- Advice and support also needs to be available to help young people understand what will happen if they disagree with a decision
Young people said that access to information on the changes to their SEN support is important. They said information needs to be made available in a range of formats so that young people can understand what the changes are and how they will affect them. Some ways they’d like to have this information include:

- Leaflets and posters
- Websites
- Videos
- Face to face from professionals

They want the information to include how they can find out what support they are entitled to where they live.

“Yeah, where your options are clearly laid out, not your options, not necessarily your options, but what’s going to happen because you just need to understand, because if you don’t understand then you can’t really get anywhere.”

Young people were surprised to learn that local authorities have to provide accessible information that says what services are available to young people with SEN.

“I need to know all my options, and be aware of the consequences of my choices.”
Young people said they wanted to have information about:

- What it means to have control and make decisions
- What support a young person can get
- How a young person can make sure their rights are protected
- How to gain skills and gain employment
- What will change about the support they have now and when is it going to change

Young people felt very strongly that young adults need to receive support that is appropriate to their needs, including skills workshops, social events and support to find employment.
In many of the focus groups concerns were raised by the young people about the tribunal and appeals process for EHC plans. The young people we spoke to didn’t know what would happen now if they disagreed with decisions so want more information on how they would do that most of the young people we spoke with did not feel they would have the skills or confidence to challenge decisions after they turned 16 without the support of an advocate or parent.

Other issues

Other issues that young people brought up in the meeting were:

Being included in school

“I’m worried that plans are so complicated it could be used to force me into a special school.”

The young people felt that any changes to their SEN support should include help to make sure they can attend the school of their choice, and that they take part in all parts of school life.

Transport services

Transport was raised by lots of young people as something that worried them. Young people said that lack of accessible transport meant they wouldn’t be able to use services where they live.

“I can’t attend science club because transport is set at 3.30 and not flexible - I don’t like being excluded from activities.”

Challenging decisions

“The plan needs to say who's doing what so if they are not you can challenge them.”

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Conclusion

From talking to the groups of young people we know that young people want to be more involved in making decisions about their SEN support.

However, young people told us that they need more information about what support is available to them and they need to know more about what changes to their SEN support are going to happen in September 2014 so they can start to plan.

What happens next?

We will be asking some of the young people we have already spoken with to tell us what kind of information and advice they would like to have. We will use what they tell us to produce some materials for young people.

When we met with the groups of young people to write this report they asked lots of great questions about the changes to SEN support. We have given these questions to the government and they will be writing answers to all the questions. We will publish the answers in a separate document very soon.
Advocate or key worker: an independent person or organisation who will give you information or support to make a decision.

Assessment: looking at what you can and can’t do, and looking at the support available to help you do those things.

Draft 0-25 special educational needs (SEN) Code of Practice: A guide to tell local authorities what they need to do to work within the law and provide support for students with Special Educational Needs and Disabilities.

Education, Health and Care Plan: A new document that will set out what support disabled children and young people should get in school. This will replace a ‘statement’.

Government: The people who are in charge of the country and make the laws.

Impartial: information from a person, organisation that tells you all the facts and options available to you to help you make your own decision.

Local authority: The local government responsible for managing services in your area. It is sometimes call the local council.

Legal documents: a document that includes information and instructions that you must do to follow the law.

Special Educational Needs (SEN): Children and young people have special educational needs if they have a learning difficulty which means they need extra support to help them learn or take part in activities in school or college.

Statement of SEN Support: a legal document written by the local authority that tells schools what support they have to give you.

Tribunal and appeals: a place where you can go to talk about decisions that you don’t agree with. A group of people who are not involved will listen to all the people involved in the argument and make a decision.
About these documents

We know that this documents won’t be accessible to everybody, please use this documents or adapt the format in whatever way works for you. The quotes and content in this document reflect the views of young disabled people given to the Council for Disabled Children during the draft 0-25 SEN Code of Practice consultation and should not be amended or distorted.

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