

Draft 0-25 special educational needs (SEN) Code of Practice: disabled young 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.”



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¹ EPIC (Equality, Participation, Influencing Change) is the only young people's group advising the Government on current special educational needs reform outlined in the Children and Families Bill. Formed in October 2012, EPIC currently has 14 members aged 15-23 years. EPIC is supported by the Council for Disabled Children and funded by the Department for Education.

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We Have a Voice, Changing our Lives

Young Campaigners, SENSE

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Young Voices, Changing our Lives

1. Introduction

This report presents the combined findings and key messages arising from 19 focus groups involving 168 children and young people. The groups were delivered during November-December 2013 and were focused on the draft special educational needs (SEN) Code of Practice. Outlined in this introduction is a brief overview of the consultation process and its context.

1.1. Background and context

CDC was asked by the Department for Education to carry out a programme of wider consultation with disabled children and young people on the draft 0-25 special educational needs (SEN) Code of Practice. As strategic reform partner to the Department for Education, CDC welcomes the opportunity to support the participation of disabled young people in the special educational needs reform process.

This report presents data from 19 focus groups carried out with young people to enable them to feed into the draft 0-25 special educational needs (SEN) Code of Practice consultation published in November 2013. It details the views of 168 young people who will be directly affected by the special educational needs reforms to be implemented from September 2014.

You can read CDC's response to the draft 0-25 special educational needs (SEN) Code of Practice consultation [here](#).

1.2. Language used in this report

Throughout this report we have referred to special educational needs by its acronym **SEN**.

This report includes the views of disabled young people and those with special educational needs aged 5-25 years old, but to make it easier to read we have referred to them as **disabled young people** or **young people** throughout the report.

Where we have used the term **accessible** or **accessibility**, we mean not only physical access but also documents and information presented in a format that is suitable to a young person's disability and uses language that is easy for them to understand.

The groups who participated in submitting views to this report were drawn from across a range of settings, including school councils and student unions from both non-maintained special

schools and mainstream schools, youth groups supported by national and local charities and a group formed specifically to discuss SEN reform, we refer to them all in this report as **young people's groups**.

Disabled young people's views on the **draft 0-25 special educational needs (SEN) Code of Practice** is the focus of this report. For ease of reading we have also referred to this document as both the **Code of Practice** and the **Code**.

The draft 0-25 special educational needs (SEN) Code of Practice is draft statutory guidance relating to the SEN reforms outlined in the Children and Families Bill. These reforms are referred to in this report as **SEN reform** or the **reforms**.

This report was commissioned by the **Department of Education**, also referred to in the report as the **Department**.

1.3. Disabled young people working with the draft 0-25 special educational needs (SEN) Code of Practice

The draft Code of Practice is a document intended for professionals. The technical nature and length of the Code means that it is not universally accessible to disabled young people. Therefore in order to get a wide spectrum of views both a young person's consultation and face to face focus groups were needed to give disabled young people the opportunity to give their views on policy reform to Government.

In preparation for delivering this series of focus groups CDC produced two young people's guides to the draft Code of Practice, however we acknowledged that these themselves were not accessible to all disabled young people and, therefore, encouraged those working with disabled young people to adapt them as necessary. There is a high demand from disabled young people and those supporting them for information on the SEN reforms. Although these documents were well received and resulted in a much increased response to the consultation than the Department had previously achieved, it is clear that there is a need for a wider suite of materials which reflects the diverse access needs of this group.

Overall young people's awareness and understanding of the SEN reforms was limited, in part because of the lack of accessible information available to them. During the focus groups young people and the professionals we worked with responded positively to the opportunity to learn

more about the reforms and what these changes directly mean for them. The lack of accessible information is creating considerable anxiety for many disabled young people.

The lack of available information underscores the need for supported participation as a platform to enable disabled young people to engage with issues that will directly affect their lives. The young people's limited awareness and understanding of SEN reforms also highlights the need for accessible information to be available earlier in the process. More accessible information needs to be produced for young disabled people and all available information needs to be distributed more widely through a variety of sources, including schools, youth groups and public libraries.

Lack of awareness and understanding of SEN reform is not the only barrier to disabled young people sharing their views. Insufficient understanding of what they are entitled to under the current system of SEN assessment and support means many of the young people we spoke with were unable to give context to the reforms or compare and contrast the two systems, making it hard for many to evaluate what the changes may mean for them personally both short and long term.

It was important to include disabled young people across the 0-25 age range when seeking views on the draft Code of Practice, including young people from the lower part of the age range, to fully represent disabled young people's views. Some of the concepts raised in the draft Code of Practice too complex for the understanding of many aged under 11 years. To support younger children to engage with talking about the reforms, we adapted the language and activities in the focus groups to make them more accessible, focussing on their immediate experiences. These adaptations enabled those in the lower age range to share their views and give valuable contributions to this report.

1.4. Diversity within participation

Recognising the need to encourage disabled young people to be more involved in influencing decisions and policy, the Department has used the opportunity of the draft Code of Practice consultation to adapt their response mechanisms, of which this report is an example. CDC welcomes this approach and looks forward to continuing to work with the Department to develop ways for young people to participate and feedback their views.

CDC is aware that whilst 168 disabled young people were able to participate in the focus group

stage of this report they are by no means able to represent all disabled young people in England. Given the time constraints of the consultation period the number of young people who took part in contributing to this report reflects disabled young people's desire to be more involved in making decisions about their SEN support. The young people taking part in the focus groups said they enjoyed being involved and valued the opportunity to participate in a constructive and effective way.

The opportunity to submit an expression of interest to participate in the focus groups was an open process and we went on to work with several groups who CDC had not previously worked with before.

In order to gain as wide a range of views as possible, the following criteria were considered when selecting the young people's groups:

- Young people from across England
- From across the 0-25 years age range
- Of diverse ethnic background
- Experience of different academic settings
- Who live in a range of settings, for example towns, cities and villages
- With a range of impairments

Despite trying to recruit as diverse a range of young people as possible disabled young people from black and minority ethnic (BME) backgrounds are underrepresented in this report. This suggests that more still needs to be done to engage young people from BME backgrounds, including producing information that is specifically relevant to this group.

More specific information about the diversity of young people who took part in the focus groups can be found in appendix 3.

2. Young people's views on the reforms.

The following sections provide detailed feedback on young people's response to the reforms.

2.1. Decision making

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

Being involved in making decisions about their SEN support was a welcome discussion topic for all young people taking part in the focus groups. They felt strongly that being involved in making decisions was important, both for themselves and their families. Overwhelmingly, the majority of young people we spoke with wanted to be more involved in making decisions about their SEN support, with several key issues arising:

- More accessible and impartial information is needed to help young people understand their options and make choices
- Whilst young people appreciate that professionals have knowledge and experience they feel that only they know what it is like to have their impairment and it is their input that is the most important and needs to be the priority
- Young people's views at assessment and review stages for their SEN support should be given more weight
- Some young people who would like to be more involved in making decisions feel they need more confidence to share their views with professionals and would like support to do so
- All young people would like further participation and confidence building opportunities to increase confidence to effectively have their say, they would also like to have skills workshops to continue developing decision making skills
- The needs of the young person should be the most important factor when establishing SEN support, not the structures and processes that the school or local authority need to go through to provide that support.

“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 a gradual process and that young people should not be expected to suddenly take on this role, within the context of their SEN support, especially if they do not feel equipped to do so. The young people taking part in the focus groups felt they needed to be given some independence and the experience of making everyday decisions in order to help them learn how to make bigger life choices.

An issue that was raised, particularly by young people with learning disabilities and complex needs, was concern over how they would be supported to be involved in decision making, and whether their mental capacity would be challenged when they did contribute to decision making. The young people we spoke with asked for more information on how the reforms would work alongside the Mental Capacity Act and felt that they also needed more information on what the Mental Capacity Act meant for them in making decisions.

“My mum and dad talk to my school and tell them what help I need. I like it when teachers ask me if I need help. I find maths hard.”

Younger children who did not yet feel able to make decisions about their SEN support said more support is needed for parents to be able make informed decisions about their child’s SEN support, particularly decisions that may have long-term implications, like what school their child should attend. They also said they would like to have more help, perhaps in the form of a class, where parents can help young children understand more about their SEN and how to be involved in making decisions.

2.1.1. Assessment and reviews

As with overall decision making, young people wanted to have more say in their assessment and review process. Currently young people feel they do not have the necessary involvement in their assessment and annual review meetings that they need to have and this leads to young people feeling marginalised, impacting on their confidence and sense of self worth. Some of the comments we received from young people included:

- **“I went to my reviews in school but I didn’t say anything”**
- **“It could make you feel not confident if you were worried about what they were gonna say”**

- **“ I didn’t get a real say in my support until I went to uni”**

Young people felt that if they had greater involvement in their assessment and review meetings they would have more confidence to make decisions, be able to communicate their support needs and form better working relationships with support staff, agencies and service providers.

Whilst experiences of assessment and review meetings had been largely negative the young people we spoke with did identify several areas where small changes would make a big difference to their ability to participate in these meetings:

“[We need] to be made more aware of what will happen step by step, who will be involved and why they are involved.”

- Young people need to know who will be attending the meetings and why they are there
- An agenda needs to be agreed prior to the meeting to enable a young person to prepare what and how they contribute to the meeting
- Jargon and technical language is unnecessary in assessment and review meetings. Professionals need to use appropriate language that young people can understand
- Each meeting needs to have a dedicated period of time set aside for the young person to talk about what has worked well in their support to date and what needs to be changed
- Young people should be allowed to bring an advocate or key worker with them to each meeting, if they feel the need
- Meetings need to allow for breaks to give young people time to process what has already happened and allow them to prepare for the next agenda item
- Professionals need to be aware they are meeting with a young person who is learning how to take control of their support needs and who is developing decision making skills
- Professionals also need to be aware that some aspects of a young person’s support needs can be potentially embarrassing for them and such needs should be handled sensitively, with unnecessary individuals leaving the room to respect the young person’s privacy

Young people also raised concerns about not being able to meet with professionals to discuss

their SEN support outside of their annual review meetings. Many felt that this meant that they were receiving insufficient, or conversely, excessive support for months at a time before being able to discuss the problem with anyone able to effect real change. They felt that this could have a very real impact on their mental health and emotional wellbeing and that therefore processes needed to be in place to enable young people to address concerns in their SEN support as the need arose.

2.1.2. Advocates and key workers

“I am able to make my own decisions and I am entitled to make a bad decision as much as an able bodied person”

It was unsurprising that the younger children we spoke with said their parents made decisions about their SEN support for them. It was clear that younger children trusted their parents to make the right choices for them and wanted this to continue. However, as the young people we spoke with grew older the more they said that making their own decisions was important to them and that, at times, these decisions were in direct conflict with what parents and professionals might want for them. The quote above illustrates that disabled young people feel they should be able to make their own choices in the same way that non-disabled young people do and that making bad decisions is not necessarily a reflection of their decision making skills.

“Parents can do a lot of ‘guilting’; you end up agreeing and accepting things.”

Many young people we spoke with felt that having access to advocacy and key worker support of their choosing would allow them to feel more confident in understanding their rights and making decisions. Young people said worrying that they may have made the wrong decision prevents them from making any decision at all. They felt that if they were to have impartial advice and support available to them they would feel more confident making decisions and responding to those that criticise those decisions. One young person felt that their support worker was chosen by his parents because “they agreed with them (the parents) and got on with them”. As a consequence the young person was not able to develop decision making skills.

“I need to know all my options, and be aware of the consequences of my choices”

There were many suggestions on how young people could access impartial advice. These ranged from having an advocate and key worker assigned pre-assessment to knowing where they could

go for one-off advice and support, whether that be a face-to-face meeting or via a dedicated advocacy website, more examples of accessing information and advice is detailed in appendix 2.

2.2. Education, Health and Care Plans

The replacement of Statements of SEN Support with Education, Health and Care (EHC) plans was a confusing and worrying concept for some young people. A small number of the young people we spoke with were currently completing their assessment for an EHC plan. However, worryingly, they too needed clarity on the purpose of the single plan and how joint commissioning and implementation would work in practice.

The question of eligibility for an EHC plan remains unclear for many young people. As a result of focus group discussions the young people we spoke to were aware that, in principle, every young person with a Statement will be eligible for an EHC plan. However, they were worried that this would in fact not be the case and some people would be moved to a lower level of SEN support. Young people also remain unclear about:

- When they will transition to the new system
- What criteria they need to meet to have or retain their EHC plan post-16
- What happens for the young people who are already past further education but still need transitional support

Young people were also worried about those who need SEN support but don't meet the criteria for an EHC plan. They also wanted more information to explain the support they are entitled to as they transition into adulthood.

2.2.1. Transitioning to an EHC Plan

A common concern of the young people we spoke with was at what stage they would move from their current Statement to an EHC plan.

- Very few of the young people we spoke with had received information about EHC plans;
- They did not know whether the changes would apply to them; and
- If they were eligible, did not know how they would be assessed for an EHC plan.

“I don’t really know what exactly they’re going to be changing. I know they’re changing a lot of stuff in education and stuff, but I don’t know a lot of detail about it.”

It seems clear from this feedback that more needs to be done to communicate to young people what is happening and what the timetable for change will be. Young people did not seem to understand what rights they had under the current SEN system, nor what procedures are necessary for them to maintain their SEN support. This meant that they struggled to envisage what the reforms mean for them which in turn caused them confusion and anxiety.

2.2.2. Control of content

Whilst awareness and understanding of an EHC plan was limited for many of the young people they were still able to contribute very effectively to discussions on what information they felt should be included in an EHC plan to enable professionals to provide the support they need.

“I think a plan should change in questions asked as you get older, what you might need asked at 5 might not apply at 14”

All young people taking part in the focus groups completed an activity to identify what content they would like to have included in an EHC plan. This was based on the content of existing EHC plans in pathfinder local areas². The single identifiable outcome from the activity was that every young person had their own ideas on what categories and content was relevant to them. All groups unanimously agreed that an EHC plan should only include information that is relevant to them and that this information will frequently change as they grow older.

It became very clear that young people need the content of their plan to reflect not only their support needs but also who they are as individuals. Therefore, that it is imperative that young people are included in the design and creation of their EHC plan, and at every stage of assessment and review.

Young people agreed that although local authorities may work from a list of criteria or identified areas of support no EHC plan should be drafted using a proforma template, but needs to more fully reflect the individual needs of the young person and be drafted with their understanding and involvement.

² The SEN and Disability pathfinder programme was launched in September 2011 and will run to September 2014. The 20 SEND pathfinders formed of 31 Local Authorities in England, and their health partners have been testing many of the proposals identified in the Children and Families Bill. More information about the pathfinder programme can be found on the pathfinder support team website, <http://www.sendpathfinder.co.uk/thepathfinderprogramme/>.

Many young people also expressed concern at who would have access to their EHC plan. Young people wanted to be made aware of how their plan would be stored, who would be able to access it and who would be able to share it with others. All young people agreed that they would want to approve who had access to their plan prior to it being shared.

In addition, there was considerable worry over who would be able to see personal and private details about a young person's support needs. These worries included:

- Access to mental health information
- Details about potentially embarrassing personal care needs
- Information about a young person's home life i.e. if they were under social services care
- Incidents of bullying, particularly if the bullying is carried out by an adult
- Emotional wellbeing concerns i.e. at risk of self harm, eating disorders etc.

Young people strongly suggested that some parts of their EHC plan be restricted to and made available only to those people who absolutely needed to see that information. Some young people felt that if their all of their EHC plan was available to a range of professionals they would be less likely to ask for help with serious issues when the needed it.

2.2.3. Taking control at 16

“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”

Taking control of their EHC plan was welcomed by many of the older young people we spoke with. Again, key issues were raised during these discussions that young people felt needed to be addressed in order for them to feel confident taking control of their EHC plan:

- Taking control needs to be a gradual process that begins well before a young person approaches transition and, if necessary, can be extended past 16
- Long term involvement in decision making is crucial for a young person to feel confident in taking control of their plan

- Young people need to understand what taking control of their EHC plan means for them in practical terms, there are concerns about pressures on their time and fully understanding their rights
- Support of an advocate or key worker should continue/be made available, particularly in instances of disputes with their school/college or local authority, and for people who face communication barriers
- Professional advice and support also needs to be available to help young people understand the appeals system
- Not all young people want, or are able to, take full control of their EHC plan as they transition into adulthood

2.2.4. Joint working

All young people we spoke with welcomed, in principle, the idea of education, health and social care working together to deliver a joined up approach to SEN support. However, young people were unclear on how this would work in practice. More information needs to be made available to young people that transparently lays out who is responsible for delivering what aspect of their SEN support and how it will be done. This includes:

- How will education, health and social care work together
- Who is responsible for ensuring support is in place
- How will education, health and social care resolve disputes amongst themselves in a way that does not disrupt the support that is in place
- How do young people and their families appeal against elements of support without jeopardising other areas that work

Again, there were concerns over who would have access to sensitive information in an EHC plan. Young people wanted there to be clear agreement over what information would be contained in an individual's plan and who would be able to access it. Above all, they felt that a young person should retain control over who accessed their plan and why.

2.3. An accessible Local Offer

Young people reported that access to information on SEN reform continued to be a significant barrier for disabled young people's engagement; suggesting an urgent need to produce materials in a range of formats for young people to develop their understanding of the reforms and what their local authority provides. These materials will be an invaluable source for young people wanting to understand more about how the reforms will affect both their short and long-term support.

“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 a duty to provide an accessible local offer that clearly outlines the services available to young people with SEN. Finding out that local authorities must tell young people of services and opportunities in their area was very positively received, however, young people wanted this system to be more transparent with an identified procedure for redress.

2.3.1. Where to find information

Disabled young people were aware of the reforms only through information they had been given by parents and professionals. Universally those disabled young people involved in the focus groups had not be able to find out further information independently, and that had had a serious impact on the extent to which they had been able to engage in the SEN reform process; form their own opinions, and make their own decisions.

Young people suggested that information, in a range of accessible formats, needed to be made available through a range of sources, for example: schools, public libraries, youth groups, GP surgeries, community programmes, support agencies and local authorities and face to face meetings. Appendix 2 provides more information on the range of formats and ways young people have suggested information can be accessed.

In particular, young people wanted access to the following information:

- What does it mean to have control and make decisions

- What support a young person is actually entitled to
- How can a young person make sure their rights are protected
- How to gain skills and transition into employment
- What support is going to change and when
- Timetable of a young person's journey through SEN support – from initial assessment to transition into adulthood

Young adults raised concerns about access to age-appropriate materials and transition services.

“I need to know all my options, and be aware of the consequences of my choices”

They felt very strongly that it was essential that young adults received support that was appropriate for their needs, including skills workshops, social events and support to find employment.

2.3.2. Eligibility for funding and benefits

Many of the young adults we spoke with identified a lack of information and support on disability related discounts, funding and benefits available to them. Those young people who were more knowledgeable about the reforms felt that information about benefits and their eligibility criteria should be a statutory element of the Local Offer.

2.4. Transition to adulthood

Preparing young people to move into adulthood was raised by many of the young adults we spoke to. Those that had already experienced transition gave mixed feedback regarding the support they had - and for some continue to have - whilst the young adults about to enter post-16 support were apprehensive about choosing the next step in their academic career, notably how their choices would impact the support they continue to receive as they moved into adulthood. There was a concern that young people would be biased towards choosing the academic or career path that would enable them to keep a consistent level of support for the longest time possible.

“I’m worried about what will happen when I leave school. I don’t know what options there are or who I can talk to. I don’t want to lose my support, things are hard enough already.”

The move between children and adult services has long been acknowledged to create many practical everyday problems for young adults, for example, changes in support staff that the young person already knows well, financial hardship caused by a change in benefit or allowance criteria and disparities in services provided by children and adult services. Moving between child and adult health services has also been cited as a major concern for young people entering adulthood. Where the system has worked well, a young person may have had the same clinicians overseeing management of their health conditions since infancy. Moving into adulthood and coming under the care of new health professionals is often a difficult and frustrating time for young adults, as they need to explain to new doctors the nuances of their condition and how it affects their life. The young adults we spoke with strongly felt there needed to be better links between child and adult health services to ensure transition is as smooth as possible. They felt that having an EHC plan should help to bridge the transition gap across all three areas but were worried about the lack of information available to explain how this would be done.

The most notable issue of moving into adulthood for many young people was the inability to carry an EHC plan into university. This provoked very strong reactions from almost all the young adults who had plans to apply to university. They felt not being able to take an EHC plan to university would penalise them and would potentially deter other young adults from applying to university, thus impacting on their aspirations. Those young adults who were already at university, or had graduated, agreed that having an EHC plan at university would have helped them to secure the support they needed prior to enrolment, and would have made them feel more equal to their non-disabled peers, instead of the ongoing struggles to put their support plan in place as they went along.

2.4.1. Information and access to information

Young adults we spoke with were keen to highlight their need for information specific to the particular period they were at in their lives. All of the young adults we spoke with indicated that they needed clear information to help support them through the transition period. They wanted this information to include:

- Education and career options, with clear explanations of what support they would be

entitled to

- Information about benefits and funding, and where to access help to explain and complete forms
- Moving to adult health services: what will change and how can disruption to their treatments be minimalised
- Transport entitlements
- How will their social care needs be met under adult services
- How to develop independent living skills
- Information of their rights and access to advocates

“I want more support and information on how to get a job”

Some older members of the young people’s groups had completed further and higher education and were actively seeking employment. They were concerned about the lack of support and information available to young people who were not in education, employment or training. They were concerned about how those young people would be able to access services to gain the necessary skills they would need for employment, or in cases where they had skills in their desired field, how they would be able to secure support to remove social barriers to employment.

2.4.2. Skills and qualifications

Many of the young people expressed concern over the impact that qualifications had over preparing for adulthood. They felt that an EHC plan should include enough forward planning to assess a young person’s aspirations and career goals to identify what skills and qualifications they would need to achieve their aims.

“I want to do an apprenticeship in a certain area of transport or travel and they ask you to have five or so GCSEs, but I don’t have them. How do you go about getting them?”

Where young people had left school without standard qualifications, like GCSEs, there was much concern that they would be ineligible for apprenticeships, supported internships and skill development workshops. Young people would like their EHC plan to clearly identify how they are

able to gain the necessary skills and qualifications to give them an equal opportunity to secure competitive and valuable employment.

2.4.3. Ongoing assessment and review

Understandably, concerns were raised over how young people would continue to receive support and guidance as they move into the post-16 stage. Young people wanted clarity on what support would continue to be available to them, and a mutually agreed timetable for transition into adult services.

“I do need a very good strong advocate because my parents are exhausted.”

Young adults felt advocacy at this stage was more important than ever because moving to adult services could feel like starting all over again from the beginning.

2.4.4. Transitioning out of an EHC plan

Securing employment and living independently was a key issue discussed by all the young people’s groups we met with. Young people wanted to know what support would be available for them post-25 years to enable them to continue in employment, contribute to their communities and live equally with their non-disabled peers.

“That [Access to Work] sounds pretty good... if I was 25 I’d definitely want to be completely clued up on how that all works, because I’d like to fully understand. One of my principle concerns now - and I’m way off that stage, is what am I going to do when I’m in an adult working environment and stuff needs to be sorted out?”

Young people are confused about what support they will be able to access to prepare them for adulthood, with and without an EHC plan, and feel they need to have a greater understanding of the whole SEN support system to enable them to make informed decisions.

One young people’s group talked about wanting to meet with disabled role models. They felt meeting with someone who would be able to share experiences and give advice to young adults who are looking for employment and skills development in similar fields, or who have personal aspirations in common with a particular group of young people would be very beneficial. They felt this would be an important step to gaining confidence, recognising all that a disabled person can achieve and help them to focus their own career goals.

2.4.5. Transport = Independence

Lack of access to transport was another concern for the young people we spoke with. They expressed concern that an inaccessible and expensive transport system would be a major barrier to both independence and employment.

“I’d like advice on transport... I’ve heard different things about what transport allowance I can be given. And I’ve looked it up on various transport providers’ websites and they purposely make it very, very difficult for people to understand.

Young people felt that the information available on for accessible transport is insufficient and that it would be useful to have transport information in the local offer.

2.5. SEND Tribunal

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

In many of the focus groups concerns were raised by the young people about the tribunal and appeals process for EHC plans. Many of the young people we spoke to were unaware of the current processes. However when the discussion looked at taking control of their plans at 16 years old questions were immediately raised around how they would appeal decisions. The majority of the young people we spoke with did not feel they would have the skills or confidence to go through the tribunal process at 16 without the support of an advocate or parent.

2.5.1. Information and Advice

All the young people expressed the need for more information on tribunals for young people with SEN, whether they currently had reason to go to tribunal or not. They wanted the Local Offer to give clear information about how to access advice and support. Knowing who had responsibility for the different aspects of support in an EHC plan was a concern that was frequently raised by young people when they discussed challenging decisions and ensuring that the support recorded in their EHC plans was met.

The tribunal process was an intimidating idea for a lot of the young people we spoke with, many raised points around what they felt would help to make the process more young person friendly. Ideas included:

- Being able to meet people involved in making a decision before the tribunal
- Visiting the venue before the tribunal
- Being able to submit their views in different ways/formats
- Being able to have support from an advocate or parent
- Having more time so that young people can get their point across

“I think that all court-like assessments should be done properly and thoroughly, instead of, just like rushed and not really listening to the young person or the family.”

2.5.2. Impartial support

The young people felt that there needed to be impartial support and advice for both young people and their families so that they could make informed decisions and strong cases for the inclusion or exclusion of information or support. Many young people felt that if they had access to impartial advice and support throughout the process of getting an EHC plan they would be less likely to go to a tribunal.

Young people felt very strongly that they should have access to separate advice and support from their parents.

2.5.3. Access to funding

Young people also felt that clear information was needed to identify the cost of tribunals, explain who was responsible for what costs and advise where to secure funding, if necessary. Young people were worried that some individuals and families would be put off from appealing a decision because they would be unable to pay for expert advice.

2.6. Wider issues

While all of the focus groups looked at the same key topics of decision making and the Education, Health and Care plans, the groups were encouraged to look at specific areas of the reforms that concerned them; these are detailed in the following sections.

2.6.1. Inclusive schooling guidance

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

One of the focus groups chose to look at how the Code of Practice reforms would affect access to mainstream education for disabled students. In this group there was concern that in the new system it would be too complicated to get support and they would be forced into special schools. There was also concern at the amount of time they would need to take off from lessons to meet with providers for assessment and transition to the new system.

The young people felt very strongly that there needed to be clear and specific advice in the code of practice about how schools can be inclusive.

The group then came up with a list of things that needed to be clearly stated in the code including:

- Having people support you who you’ve chosen
- Making sure that there is access to a differential curriculum and that there is flexibility in how you are assessed
- Access to school trips and extracurricular activities which does not rely on a disabled student bringing a parent
- buildings which are fully accessible
- peers, providers, teachers and support staff should have training and support to assist disabled students

2.6.2. Transport services

Transport was raised by lots of young people as a key issue in whether the new system and EHC plan would work for them. Several young people reported that lack of accessible transport meant they wouldn’t be able to make use of services described in their local offer.

In addition, a number of young people raised concerns about the way in which the inflexibility of transport meant that they could not access extracurricular activities.

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

Many of the young people we spoke to felt that if transport was not flexible then the holistic approach of the EHC plan would be difficult to achieve.

2.6.3. Friendship

“Plans need to cover support for peers and friends so that they can communicate with me - like support to learn sign.”

Across many of the focus groups the need to support and facilitate friendships in education settings was raised. Friendship was identified as a key factor that the young people hoped EHC plans would support and promote. Some of the young people we spoke with said they felt socially isolated and that for them to achieve wider goals identified in their EHC plan, like to get a job or live independently, for example, they would need assistance with developing and maintaining friendships while in education.

3. Conclusion

“The Code of Practice uses the word ‘should’ when I think it should say ‘must’. I think the Code tells you what they want to happen but that doesn’t mean it will happen”

Disabled young people we spoke with were clear that the final version of the Code of Practice needs to explicitly identify to professionals what is necessary to properly support disabled young people to develop life skills and achieve their aspirations. They were concerned that any softening of the language in the Code could be interpreted as a suggestion of best practice rather than a statement of what a young person is entitled to. They wanted to see the language in the final Code reflect the commitment of the new SEN system to provide real, meaningful and effective support to disabled young people.

It has been a considerable challenge to encapsulate all of the information we collected from the focus groups into this report. The vast amount of data we received is proof that disabled young people have relished the opportunity to access forums where they feel comfortable to share their views in a way that works for them.

Throughout this report the lack of accessible information has been raised consistently. This

highlights the very real gap between what information already exists and what is actually needed. Lack of relevant information is an issue that can be addressed reasonably quickly and easily, and would lead to positive, measurable and cost effective outcomes.

As we have seen, a lot of the young people's responses focus on anxiety around transition to new system. This is, in part, a symptom of the lack of information. Clear transition between the current and new system needs to be handled carefully and with the needs of disabled young people at the forefront. It is not so much the transition process itself that causes anxiety amongst disabled young people; it is the concern that their needs will not be met. If Government can evidence how disabled young people will move through the transition process, and make necessary information available, disabled young people will feel much more confident that the process will work for them.

Of equal concern to young people is how their privacy will be maintained under the new SEN reforms. Disabled young people are concerned that not enough privacy measures have been put in place to ensure the information contained in EHC plans will remain confidential, with access of sensitive information restricted only to those who absolutely need to know it. Disabled young people are clear that they need to approve who has access to their EHC plan and need to know what it contains at all times.

As this report has illustrated, whatever their support needs disabled young people want to be identified foremost as individuals who need to have their rights respected. Disabled young people feel that the support they need should not be given at the expense of self or identity. SEN support providers need to be aware that assessment and provision of support can sometimes be embarrassing and challenging for young people, and can single them out to their peers as different. Enabling disabled young people to have the confidence to take control in these situations acknowledges their right to make decisions and protects their individual identity.

Disabled young people are very pleased that they will have more opportunity to make decisions in the new system. They agree that young people should be the driving force behind their SEN support, and that their opinions should be given priority. Crucially, they are clear that taking control of decision making needs to be a gradual process where they are given appropriate support and access to necessary information to enable them to make informed decisions.

Unanimously the young people who have given their views to this report have welcomed and appreciated the opportunity to be involved. They have all expressed how much they have enjoyed being consulted and feel that their views and opinions have made a valuable contribution. CDC hopes there will be increased opportunity for disabled young people to participate in consultations and feed their views back to Government.

4. Next steps

CDC will submit this report to the Department for Education on Friday, 10th January 2014.

The Department will provide a response to draft Code of Practice consultation, of which this report is a part, and have agreed to answer as many of the questions posed in appendix 1 as they can. We will share this report and any responses to it with the young people we spoke with.

The information in this report will be considered by the Department as they begin the process of revising the Code in response to the consultation.

Appendices

Appendix 1: Questions to the Department

EHC Plans

1. What safeguarding measures will the Government put in place to ensure my EHC plan is kept secure and my safety and rights respected?
2. How will the Government make sure that certain information in an EHC plan is kept private? I don't want providers to look at bits of my plan that are not relevant to the support they give me. Lots of people don't need to know personal things about me.
3. How will I be able to access my EHC plan?
4. Why are EHC Plans so complicated and long winded?
5. If you have an EHC plan what happens if you need to stay in hospital for a long period of time, how does this relate to Guidance on children and young people unable to attend school due to health needs?
6. What independent support do you get when you don't have an EHC plan?
7. How are the responsibilities of providers e.g. health, education and social care going to be set out in the plan and how are we (young people) going to know who does what?
8. Why doesn't an EHC plan cover university?
9. Can a young person add sections to their EHC plan, like, for example, supporting peers to be friends with you and support to develop friendships outside of school?
10. What happens if the LA refuses to fund you in achieving the aspirations identified in your EHC plan?
11. How can you reduce the paperwork and risk assessments so that disabled young people can join in with things and achieve some independence?
12. The Code of Practice uses the word 'should' when I think it should say 'must'. I think the Code tells you what they want to happen but that doesn't mean it will happen

13. How will the Government make sure essential information is passed to the correct professional, making sure there is not a break in service support?

Post-16

1. I have support at college but I'm not sure what is going to happen after, how do I find out what I need to know?
2. There should be work experience at college to help young people learn skills and get experience. How do I find out what work experience is available for me?
3. I get good support at college – better than 6th form and school; we have trained 1-2-1 staff who can give me medication. How does the Government plan to make this support available to all young people who need it?
4. I don't know what support there is for achieving goals and aspirations, how do I find out what is available to me?
5. What transition to adulthood support is available for people without an EHC plan?
6. Young people in mainstream schools can miss out on independence skills training (this is also the same for non-disabled young people). What will be done to make sure young people gain essential life skills, including making sure there is enough support available for the people who need it?
7. Will young people in mainstream schools get the same level of support when they transfer into adult services?
8. How will the Government make sure that people at residential colleges continue to gain valuable life skills?

Joint working

1. How will education, health and social care work together?
2. Who is responsible for ensuring support is in place?
3. How will education, health and social care resolve disputes amongst themselves in a way that does not disrupt the support that is in place?

4. How will young people and their families appeal against elements of support without jeopardising other areas of support that work

Decision making

1. What will happen to young people who don't want, or are not able, to take full control of their EHC plan as they transition into adulthood?
2. Building young disabled young people's confidence to enable them to give their views and opinions about what they want from their lives is a big issue. What is the Government doing to help with this?

Information

1. What is the Government doing to make sure disabled young people have appropriate, accessible information about all aspects of support?
2. What is the Government doing to make reforms and consultation questions more accessible?

Support

1. Deaf students are not being given the support they need to communicate with their peers. How will Government make sure there are enough high quality BSL interpreters in mainstream schools?
2. Teachers need to listen more. Bullying is a problem and so being excluded from classes I want to do what is the Government doing to stop bullying in school and what are you doing to stop exclusions?
3. How are Government going to get teachers to work better together to support and include disabled children and young people?
4. How will these reforms make education more inclusive so more disabled children can access mainstream education?
5. Who do you go to as a young person, who can help instead of just my parents all the time?

Employment

1. Why is it so hard for disabled people to find a job? I am deaf and workplaces don't understand what my support needs are, they put unnecessary barriers in place. If I need the necessary support or a social worker I have to fight for one.
2. I don't know what I want to do after college. I've completed a 3 year course but now they won't let me show what I can do
3. What are the Government doing to help disabled people get work?
4. Does having a disability affect the age I am eligible for work?
5. How do I access work experience, apprenticeships and internships?
6. How do young people feedback views and comments on accessing work opportunities?
7. What employment opportunities / apprenticeships do you have if you don't have GCSEs?

Transitioning out of an EHC plan

1. What happens after 25 years old if you move LA (social care support)?

Appendix 2: Accessing information

Access to information across the entire SEN system was reiterated again and again by all the young people's groups we spoke with. From understanding their rights to gaining skills and confidence, young people identified access to information as their main source of empowerment. All young people's groups said that there was not enough accessible information for young people available.

There were numerous suggestions for how accessible information should be made available to young people. The most common suggestions are included here:

- Written information
 - ◇ Leaflets
 - ◇ Posters
- Online
 - ◇ Websites
 - ◇ Apps
 - ◇ Videos
 - ◇ Forums to share experiences
- Face to Face
 - ◇ Via Skype
 - ◇ In dedicated offices/centres for young people
 - ◇ SENCOs
 - ◇ Advocates
 - ◇ Key workers
- Social media
 - ◇ Facebook
 - ◇ Twitter
- Other
 - ◇ Helplines

All young people agreed that information needs to be presented in a way that includes as many impairments as possible. For example, all videos should include subtitles and BSL sign language. Written information should be available in different font sizes, in Braille and with Easy Read.

Documents online should be compatible with screen readers.

Young people agreed that information needs to be made available through a range of outlets to ensure young people can access what they need to know in a comfortable and safe environment.

Examples of such outlets include:

- Schools
- Public libraries
- Youth groups
- From support workers and support providers
- Community programmes
- Local authority SEND and Children Services departments
- NHS services e.g. GP surgeries and specialist departments

Appendix 3: Equality and Diversity

During the focus group stage of this report CDC spoke with 168 young people from 19 young people's groups. We asked all the young people we spoke with whether they wanted to complete an equalities monitoring form; 101 young people completed the form in full with a further 18 young people giving their age and gender. This information has been summarised below.

1. Geographic location

The young people's groups met in the following areas:

- Cheltenham
- Darlington
- Essex
- Harrogate
- London
- Lowestoft
- Mitcham
- Nottingham
- Preston
- Sandwell & Wolverhampton
- Sunderland
- Torbay

Although some groups chose to meet in one geographic location they have recruited young people to their group nationally, which enabled them to discuss young people's experiences at a national level. One national young people's group also regularly meets via Skype, although for the purpose of the focus group they met in person.

2. Age

We were pleased with the diversity in age of the young people who took part in the focus groups:

- 5-9: 16
- 10-12: 6
- 13-18: 52

- 19-25: 43
- Age not given: 2

3. Gender

As you can see, we had nearly twice as many male young people taking part in the focus groups as female.

- Male: 77
- Female: 41
- Not given: 1

4. Urban vs Rural locations

The young people who participated came from a diversity of locations in terms of levels of urbanisation, useful information to have when discussing access to suitable support and awareness of their local offer.

- A city: 28
- A town: 52
- A village: 10
- Rural area: 8

5. Ethnicity

As previously highlighted, the lack of young people from BME backgrounds taking part in the focus groups highlights the urgent need for more information for, and engagement of, young people from minority backgrounds.

- White UK: 88
- White Irish: 1
- White Other: 1
- Black UK: 1
- African: 1
- Asian UK: 4
- Indian: 1
- Mixed race: 3
- I don't know: 1

Other ethnicities not represented:

- White EU
- Caribbean
- Black other
- Pakistani
- Bangladeshi
- Asian other
- Other

6. How do you spend your time?

We wanted to identify with young people the stage they are at in their support. This information is useful when talking with young people about where they have reached in achieving their aspirations.

- I go to school: 4
- I go to college or university: 29
- I have a job: 6
- I am in training: 1
- I volunteer: 11
- I go to school and I volunteer: 2
- I have a job and I volunteer: 2
- I go to college or university and I volunteer: 5
- I go to college or university and I am in training: 1
- I volunteer and I am in training: 1
- I prefer not to say: 2

7. Impairment range

Some of the health conditions detailed by the young people are life limiting, whilst other young people identified their impairment as fluctuating. A small but significant number of young people did not want to disclose their disability.

- Sensory disability: 3
- Physical disability: 12
- Communication disability: 13

- Learning disability: 26
- Long term health: 7
- Multiple impairment: 28
- Prefer not to say: 12

8. Young People living in care

Perhaps not as significant a criteria as the others in this appendix, however it is useful to note that disabled young people living in care often struggle more to secure the support they need.

- Yes: 2
- No: 99

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. CDC is a semi-independent council of NCB, and has a staff team reporting to its director. The CDC Council is made up of a wide range of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations. CDC hosts the following networks;

- The National Parent Partnership Network
- The Special Educational Consortium
- The Transition Information Network
- **The Early Support Programme**
- The Every Disabled Child Matters Campaign
- Making Ourselves Heard

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