

# Summary of focus groups with children and young people

Annex to Beyond the Labels: A SEND system  
which works for every child, every time

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November 2022

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## Introduction

The Children's Commissioner's Office (CCo) spoke with over 50 children in England in June and July 2022 to learn what they think about the government's proposed changes for the Special Educational Needs and/or Disability (SEND) review. The CCo prioritised speaking with children with additional needs and engaged with children across a range of settings. CCo also spoke with parents and carers as well as professionals. This Annex reports the voices of the children and parents who spoke with the CCo.

**Table 1: Children who spoke with the CCo to inform the SEND Green Paper consultation**

Group of children	Number of children
SEND children's group	4
Independent special school	4
SEND children's support group	2
SEND children's support group	1
Independent special school	3
SEND children's support group	1
SEND children's support group	1
Independent special school	8
Mainstream secondary school	7
Mainstream secondary academy	8
Independent special school	16
	TOTAL 55

The topic guide and questions posed to children were developed based on the questions posed to children in the Department for Education's (DfEs) child friendly version of the SEND Green Paper.<sup>1</sup>

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## Experiences of children with SEND and their views on the SEND Green Paper

### Question 1: Who gives you the most support & help?

Children frequently mentioned teachers, school support staff, social workers, friends and family as sources of support and help when they needed it.

*'My teacher because I like the teachers here [Independent school]. I didn't get much support from mainstream school. My family and friends because they listen to me. Basically, all the people that listen to me'* – Boy, independent school with an EHCP.

*'Teachers at this school, they care more than my last school or social worker. They've got more time for you, understand more about you and who you are as a person'* – Boy, 16, attending college with an EHCP.

*'Family, they were trying to support me when I was in mainstream but the school wouldn't do anything [...] I used to have a counsellor but they were no help, they made it worse all they did was give us medication and the medication made us worse. [...] When I was at mainstream I was predicted no GCSEs but then I came here and got C's and B's, two passes at maths and English. I never thought that would happen to me'* – Boy, 16, attending college with an EHCP.

*'My mum because she's by my side no matter what'* – Boy, 15, attending further education provision at a special school.

*'My heroes are my friends my family and my teacher'* – Boy, 19, attending further education provision at a special school.

*'My family, my teacher and my social worker [...] she's always been there when I was younger because I had something going on with my family'* – Girl, 19, attending further education provision at a special school.

*'My social worker, she's always sorted things out, she's contacted my mum, my dad, I think she's a really good person to speak to because I think she'll help me with any situation I have' – Boy, 17, attending further education provision at a special school.*

*'My family are the basis of everything that I do. They help me make decisions. They support me in what I want to do. [...] they help me be independent.[...] it's the whole of my family, not just my immediate family' - Girl, 13, with autism.*

*'My best friend helps me all of the time, and makes sure I enjoy things and have fun' - Girl, 13, with autism.*

*'My psychologist just gives me a different perspective on everything and makes sure that I am happy with the way my life is going [...] helps me see things from a different point of view [...] just a complete unbiased view of things' - Girl, 13, with autism.*

*'My climbing coach [...] [I go climbing] 3 to 5 times a week [...] climbing is a very important part of my life. I think it helps me deal with things in a different way. I think she helps me a lot do work through mental barriers I have' - Girl, 13, with autism.*

*'I have started to find that helpful [...] finding other people who are like me at school [...] it was really nice working in a small group and it was all girls [...] it's doing activities, we bake and stuff' - Girl, 13, with autism.*

### **Question 1b: Who is not supportive?**

However, just as social workers, family and teachers could be sources of support for children with SEND, for other children they were not. In regards to teachers, often the reason children gave as to why they were not supportive was that teachers lacked the training to properly help and support children with SEND.

*'Social workers are difficult, the just try and tear families apart. Their solution is to remove children instead of bringing family together' – Boy, 15, attending a special school.*

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*'My previous school was shite [...] the consequence room with booths where kids would sit from 9 to 2:30, not allowed to go to the toilet, get a drink, anything, no work to do. For kids like me with a disability it just doesn't help' – Boy, 15, attending a special school.*

*'I don't feel supported by my social worker. They are [shite], I've never seen them, they've never phoned. I don't think my parents have ever seen them either' – Boy, 16, Independent school with an EHCP.*

*'Teachers aren't trained to help us' - Girl, 13, attending mainstream school with an EHCP.*

*'My teachers who teach my main subjects. In the support plan I have, either they stick to it for a week or a short period or they don't pay attention at all' - Girl, 12, attending mainstream school with an EHCP.*

*'In government it should be someone with SEN themselves and knows how hard it is who makes decisions' - Girl, 12, attending mainstream school with an EHCP.*

*'I think at school it is very limited, having support [...] we have a worry box but it is still really hard to talk to people [...] it often limits me going into school because I can't work with teachers [...] it's a bit weird, the SEND team and the pastoral team aren't connected and we don't actually have a SENCO anymore, we have a head of SEND because we are part of a trust [...] the SEND part is quite good but the pastoral and the support we are supposed to get from them hasn't been very good [...] possibly not enough training around autistic girls [...] I think lots of people often don't believe me [...] because I don't show it, I mask a lot [...] there are not many people at school who I feel comfortable speaking to [...] they focus too much on attendance [...] we have an attendance tracker and it's the worst part of my week [...] I don't think they see that I'm struggling' - Girl, 13, with autism.*

## **Question 2: Who should be involved in decisions about your education?**

Many children felt that they should be involved in decisions about their education. Others wanted adults they trusted to be involved, which could be a family member, a teacher or someone else. It was important for children that whoever was involved knew them well and would be able to represent what

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they needed and what would help them. They didn't want people involved who didn't understand them and their needs.

*'I would want to be part of the meetings, physically there'* – Boy, 15, attending a special school.

*'It's my healthcare plan. I should be the one in charge of what's going to be put in it'* – Boy, 16, attending college with an EHCP.

*'Adults might think one thing is important as an outcome but you might not think it's important. I'd want to be involved in setting the outcomes'* – Boy, 15, attending a special school.

*'If you have a school who doesn't understand the kids then how can they support the young people? They can't'* – Boy, 16, attending college with an EHCP.

*'My friend, he knows me the best and would know what I would want. Also I want to be involved, it's my education'* – Boy, 16, independent school with an EHCP.

*'Me, because it's my education. I do have a say now, but not before. In mainstream nobody would listen to you unless you were on the brink of dying. Here I can fight more for what I want, I can talk to [name removed] or my Mum. I'm listened to better here, but I still had a lot of meetings. I'd prefer there to be better communication between schools and students'* – Boy, independent school with an EHCP.

*'Myself because I get that family speak for you, but sometimes your family's not always right'* – Girl, 15, attending further education provision at a special school.

*'I'd always want it to be my decision but I'd want to draw inspiration from my mum [...] so they give me the ideas but at the end of the day I'd get the decision'* – Boy, 15, attending further education provision at a special school.

*'I'd want it to be my decision too but I'd want to talk to someone like a professional who could give me ideas about the right choice'* – Boy, 17 attending further education provision at a special school.

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*'My friends because when I've been independent travelling, I've been helped by all my friends'* – Boy, 17, attending further education provision at a special school.

*'My decision but I would ask for help from my teacher and my TA because they help me quite a lot'* – Boy, 19, attending further education provision at a special school.

*'My decision because I think myself can think of decisions, I need to believe in myself and take care of myself, also I can always get advice off my friends'* – Boy, 17, attending further education provision at a special school.

*'Definitely my care worker and parents. They know me best and know what's best for me and what would support me'* - Girl, 12, attending mainstream school with an EHCP.

*'Teachers, family, you should have more of a say, if you're getting help it might not be the right help'* - Boy, 13, attending mainstream school with an EHCP.

*'We should make the decision, then family. They know you really well and what support you need'* - Girl, 13, attending mainstream school with an EHCP.

*'They [school] say they embrace diversity but as far as I've known autism and SEND hasn't been brought up and I would like it to be I would like everyone to be educated on it. It's better to know early so you know anyone can have them'* - Girl, 12, attending mainstream school with an EHCP.

*'My family, some teachers, my therapist and psychologist and me'* - Girl, 13, with autism.

*'Probably me, because I don't really like people making decisions about me'* - Girl, 8, diagnosed with autism and ADHD, attending a mainstream school.

*'I don't really like people making decisions about me unless I checked with them that they're ok [...] I would probably like me to make the decision and then if other people did to check whether I am ok with the decision. [...] They probably need to ask the child what help they would need, ask the parents, ask the teachers [...] if you only ask the child you might get a few extra extreme things [...] they [adults]*

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*might have noticed that the child works better when they're sitting in a certain place or when they're fidgeting with something' - Boy, 9, attending a special school.*

## **Question 2a: Are you involved in decisions about your education?**

*'No, not at all. I couldn't pick which school I went to, my grandad put me here. It's a good school but I wanted to go somewhere with my mates and I didn't get a decision I got told' - Girl, 15, attending further education provision at a special school.*

*'I got told as well, the decision I made before I even came to this school, the government decided it wasn't going to happen so it all just went over the top' - Boy, 17, attending further education provision at a special school.*

*'My mum speaks for me and she won't let me speak for myself so it's hard to talk to her [...] when I lived with my nan she understood me and she helped me make like my choice but now I'm back with my mum she won't help me she makes it for me' - Girl, 19, attending further education provision at a special school.*

*'My grandad doesn't even think about what I want to do he just bypasses me and makes decisions above me and that really annoys me [...] my grandad doesn't understand anything to do with my special needs so if I get frustrated he doesn't get why but he never actually asks me why [...] I think special needs altogether is something quite hard to understand as a parent you don't really get much help from the government' - Girl, 15, attending further education provision at a special school.*

*'Yes - before I started here I had a choice and my mum asked me that day which school would you like to go to and I chose because I'd had a tour before and it looked quite good and I thought that maybe I'd be OK here' - Boy, 19, attending further education provision at a special school.*

*'My mother does give me advice on what the decision is but at the end of the day she knows best but she knows the best is what I choose' - Boy, 15, attending further education provision at a special school.*

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*'My mum always says to me follow your dreams, whatever you want to be it's up to you, I know you're going to be a successful person'* – Boy, 17, attending further education provision at a special school.

### **Question 2b: What help from the government would you like / what help do you think parents need?**

*'More information from the government to create something like an information pack about different special needs'* – Girl, 15, attending further education provision at a special school.

*'Have you tried showing him on YouTube?' – Boy, 17, attending further education provision at a special school.*

*'He also says with special needs kids the government doesn't do much for us'* – Girl, 15, attending further education provision at a special school.

*'So you think if someone from the government told him about it then he would listen more?' – Boy, 19, attending further education provision at a special school.*

### **Question 2c: Difficulties with accessing an EHCP**

*'My EHCP, it took about 3 years to actually get one, it got pushed back. My parents and [special school] had to fight for us to get one. When I got one me and my mam went through it but that was aged ago. It was a pain to get one. I was not getting no help for my education but they want us to do well'* – Boy, 16, attending college with an EHCP.

### **Question 3: Sections of the EHCP**

Children were given a sheet with each section of an EHCP form summarised and were then asked to discuss which sections they thought were the most important. Most children who were asked about this had not been shown the sections of an EHCP before and were unfamiliar with what was included under each section. Section C, health and care needs, section G, what the school will do to support a child's health and section E, outcomes were given by some children as the most important.

*'Section C, healthcare needs are most important. Your health matters more than how you are doing in school. If you have good mental and physical health, that's going to mean you have better goals, and then a better education. But all of the sections are important, depending on the person'* – Boy, independent school with an EHCP.

*'Section G – this school has helped me a lot with my mental health over the years, I can always go to the school and tell them, I can always trust my school with it and they'll help out [...] this school, it makes us closer because we all get what we're going through, this school really helps us communicate with each other and helps us in our own ways'* – Girl, 15, attending further education provision at a special school.

*'Section G for me is more important because last year it was really hard for me because I lost my auntie my teacher and TA helped me get through it, I didn't struggle or lash out at anyone. If it wasn't for everyone here I wouldn't be the person I am today. It means a lot having friends, teachers... They helped me even during like lockdown, everyone struggled with mental health and other things, they managed to get us through it even working from home, they got us through it like it will be ok [...] this whole building is like one family it's amazing the bonds we have with each other, the bonds I have with staff, it's like family honestly. Even if one day I walked in and looked happy but inside I was a bit down they would know, it's like they know me too well'* – Boy, 19, attending further education provision at a special school.

*'Section E – I get that adults want us to achieve but us as young people we also have our own goals [...] I get that parents want to be involved but I also think us reaching our goals and reaching theirs is too much [...] my grandad wants me to be an independent traveller but he wants that in 5 years and I want to do that now, I want to do this for me'* – Girl, 15, attending further education provision at a special school.

*'I think that the goals that adults set for you [Section E] isn't as important as the others, because I feel like they're not really goals if they are set by someone else. I would want my voice to be heard on that'* – Boy, independent school with an EHCP.

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### **Question 3a: Developing independence**

*'I feel like if some people start independent travelling then their parents might get overprotective because they worry something might happen' – Boy, 19, attending further education provision at a special school.*

Young people wanted to set their own goals and plan their own timeline for their goals rather than their parents deciding for them. They wanted opportunities like independent travelling to develop independence.

*'I wanted to be an independent traveller, when I grow up I can't just go on buses all the time you need some walking too, when you get a job [...] I want to drive a car as well and also get a better lifestyle. Also [...] work experience for the day that would be a good one and trips places [...] like if you wanted to work as a shopper for a day, like a taster as a till worker' – Boy, 17, attending further education provision at a special school.*

### **Question 3b: Other views on the EHCP**

*'Having a back-up plan would be really important [...] not having to communicate, going into a class room and the teacher would know what to do [...] having a safety plan without having to come home and leave home because that in itself is stressful and then you feel stuck. Because you feel like you can't deal with the stressfulness of coming home but then you also can't deal with the stressfulness of school [...] like being able and sit in a quiet room [...] and no one ask any questions' - Girl, 13, with autism.*

*'I think often plans get made and then it's not actually possible for a child to do the plan [...] because plans get made and in theory you need this, but when it gets to the point where you need the plan [...] the plan fails [...] it has to be easy enough for you to be able to do it [...]' - Girl, 13, with autism.*

### **Question 3c: Do you feel involved in your EHCP?**

*'I had an Annual Review meeting yesterday. I just chatted about how everything was going and whether we should change anything, and whether anything should stay as it is. I think I was listened to but I wasn't there for the bit where they discussed things that weren't working for me, I came in and talked*

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*about what's gone well and what I should work on next year' – Boy, age not recorded, independent school with an EHCP.*

*'My Mum normally chats with [the headteacher] about my EHCP, rather than me. Mum and I talk about it beforehand. I'm better at talking to my Mum than someone else' – Boy, age not recorded, independent school with an EHCP.*

#### **Question 4: What are the most important aspects of school to you?**

Having the right staff, the right curriculum, being at the right school and trusted relationships with teachers and school staff were given as some of the most important aspects of school to children and young people. Children valued education settings which were able to meet their needs through staff, curriculum offer and support in place.

##### **Staff**

*'Staff, I could go to a school that's a massive palace and have teachers who are rude. It's all about the people inside rather than what it looks like' – Boy, 16, attending college with an EHCP.*

*'I think they're all important because they all have a huge impact on how much stress you have during the day and how much energy is being taken out. One thing [...] was lessons, like what you're actually learning and what you're expected to learn in a lesson and how it's approached [...] like do you have to have your hand up? Something that I always find really stressful is between lessons I always forget which lesson you're supposed to have your hand up, which lesson you're not, which lesson you have a card. So all of it, and have a plan for every single thing on there, every single aspect that could go wrong. Like what if your transport breaks down, are you going to get a detention [...] making sure that in the building you feel safe and the teachers you feel happy with [...] making sure you have all the information about things and have a plan about things so you feel able to continue [...] teachers knowing the things that are most important to you [...] it's different for every child [...] but teachers needing to know what that one point is' - Girl, 13, with autism.*

*'Asking a child [...] because without asking you won't know the pivotal thing [...] and it needs to be reviewed regularly' - Girl, 13, with autism.*

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## **Trust**

*'I think trust between me and the staff [...] there was this one occasion where I found it really difficult to go in and then I went in to speak to the teacher and then my dad left me to get my school bag even though he knew I was going to come home and then they forced me into a lesson, like I couldn't wait for me dad to come and get me and I had to stay for the rest of the day and I really didn't want to and I had an awful day. And then I never trusted them again, I just don't come in. I don't even try [...] they ruined the small amount of trust I had' - Girl, 13, with autism.*

## **Attending the right school**

*'Going to secondary school has been a really positive change. We were worried because the difference in size between schools could have been really overwhelming but the [secondary] school is calm. We have a good dialogue with the SENCO. I think there are quite a few girls there with SEND, whether they are diagnosed or not. Girls tend to escape in books' - Mum of girl, age 12, attending a mainstream school.*

*'I used to hate school. I actually want to come in now' - Boy, 15, attending a special school.*

*'Here, I know everyone I get on with everyone, if I had a problem I would say to my teacher miss could I talk to you for a minute and they'd say yeah that's fine, you know, it's better' - Boy, 19, attending further education provision at a special school.*

*'In my old school they never knew what problems you had, they never give you help whereas in this school they'll always give you help and they'll always be by your side when you need that help' - Girl, 19, attending further education provision at a special school.*

## **Question 4b: How could schools be better for young people like you?**

Children had lots of ideas for how school could be improved for children with SEND, drawing from their own experience of what had worked for them. For some children they wanted schools to prioritise mental health, for others it was about having teachers able to support them with their work and make classes engaging. Children also talked about the need to address bullying in schools and communities.

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## **Mental health**

*'Do a better job caring about kids mental health [...] obviously this school does care but last school I was in hospital and the school was asking am I going to be in the next day. I was on the verge of not being here [...] Inclusion of mental health, take an interest in a kid when they are struggling. Isolation needs to be banned'* – Boy, 15, attending a special school.

*'In my old [mainstream] school, I struggled a lot with eating in the canteen with people around, and the smells. Also, mental health support. It's not just autistic people or children with special needs that need additional support, school is just really stressful, and we maybe need a designated mental health service in school. I waited for 8 hours in hospital once to see someone. More diverse people [MH support in school] would be better, in my old school most were boring, White, Cis people'* – Boy, age not recorded, independent school with an EHCP.

## **Teachers, classrooms and school facilities**

*'No teacher will be able to go round every kid, get more staff [...] better staff to pupil ratios. Make lessons practical, get up get moving. There are different styles of learning. I learn more when it's dynamic and varied, being in the same room day in day out it's mentally draining [...] you need to make them love it'* – Boy, 16, attending college with an EHCP.

*'Teachers, we can go up to any teacher and tell them our issues and in some schools you can't do that, in some schools you can't trust all the teachers here but here you can [...] you can go up to any teacher and they just get it'* – Girl, 15, attending further education provision at a special school.

*'Experienced teachers experienced in teaching pupils with SEN. Not being ashamed to have a pupil with it, saying it's not something to be embarrassed about. A teacher who helps and understands'* – Girl, 12, attending mainstream school with an EHCP.

*'For me it's quite important that they're smaller classes and that they're trustworthy teachers and that you can be friends with anyone in school [...] at lunch, there's a room called the snug [...] and you can be with the older or the younger kids if you want, you don't have to be with your year group [...] if it feels*

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*too much [...] you are allowed to walk out of the room without people asking where are you going, get back in here [...] teachers don't shout' - Boy, 9, attending a special school.*

*'And another thing that is quite helpful, is that there is no time pressures, you don't have to do it all in a limited amount of time' - Boy, 9, attending a special school.*

*'Skills based education, so work that's not too difficult or way too easy for the student. I've had a few years of learning the same stuff I already know, some subjects are managed well but others are not managed too well [...] education is not always based on the needs of the students' - Boy, 15, attending further education provision at a special school.*

*'The day should be longer because we don't get enough time for lessons, so if we had a longer day [...] we don't have enough time in lessons or enough time together' - Girl, 15, attending further education provision at a special school.*

### **Addressing bullying**

*'Society should accept us. As someone who's seen what it's like, I used to be bullied all the time for my special needs, society is so against us, for people who don't understand us they don't accept us like oh I can't even speak to you you've got special needs' - Girl, 15, attending further education provision at a special school.*

*'I don't share this with lots of people. When I was in a club I used to get bullied because of my special needs [...] different clubs need to learn about special needs, I think special needs is a very big word, people don't realise that, they need to know what special needs are' - Boy, 17, attending further education provision at a special school.*

*'I used to get bullied because of my hair cut because I used to be bald, people bullied me because of my skin colour just because I'm brown you don't need to think there's something wrong with me, people need to understand what racism is about' - Boy, 17, attending further education provision at a special school.*



*'For 14 years I didn't have any friends, until I came here, I was also bullied racially, because of my skin colour. Once I got pushed into like a little ravine it was that bad [...] A kid knew I'm Muslim and he took some bacon and like slapped me with it' – Boy, 19, attending further education provision at a special school.*

### **Other things children would change**

One boy mentioned the school's approach to restraint and managing children with challenging behaviour. For him, the solution was removing the child from the situation which had caused the behaviour and to give them a chance to calm down:

*'Staff would pounce on top of us, bend my arm back. Here they would take us out for a walk, go down to the beach. Getting them out of that environment, instead of keeping them in, get them out and away from the situation' – Boy, 16, attending college with an EHCP.*

Having reliable transport to and from school, which children felt confident to use was another issue that children raised:

*'Transport is important as she can get the bus from the end of the road, which is a big step forward...I was worried about her walking by herself or people walking with her that she wouldn't want to talk to, but on the bus, she can read her book and it's door to door' – Mum of girl, age 12 attending a Mainstream school.*

*'Transport to and from school. Most people here have anxiety and I find the bus really stressful with loads of people. A bad experience coming in can ruin the school day and make you less excited to go to school' – Boy, age not recorded, independent school with an EHCP.*

## **Question 5: What kinds of support do you think are the most important to help you prepare for growing up?**

Children talked about including 'life skills' in the school curriculum and have opportunities to explore potential careers and opportunities after school as things that would help them prepare for adulthood.

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However, when discussing careers, some children with SEND felt that there weren't enough opportunities for children with SEND to enter employment and they were worried about discrimination from employers.

### **Including 'life skills' in the curriculum**

*'When it comes to school, there should be more lessons that teach you about life, like interview prep, life lessons, what should you do in different situations, how to ring the doctors. They should focus on building your life up rather than just education [...] If you're inside in a school, not every kid wants to be the same thing. They should get people in who can talk about different careers [...] at college they get people from different uniform services to come in and talk about their job and how they got into it, give you advice for interviews'* – Boy, 16, attending college with an EHCP.

*'Kids are told they need to have their whole lives planned out from school...they feel like they are just a number. Here we focus on their confidence and aspirations. With support we often find that they naturally know what they want to do, and they stick at it...So many children are slipping through the net and it's really sad'* – Careers advisor, independent school.

*'What type of math you're doing, it should be more practical, like life skills, how to use a credit card'* – Boy, 13, attending mainstream school with an EHCP.

### **Career development and opportunities**

*'I don't think they necessarily support pupils to go to a careers fairs [...] they're very good for everyone [...] but not for a child with SEND to access that [...] possibly letting the people know [...] again, making a plan first of this is how I want to do it [...] you are really passionate about doing something but you find it really hard to actually do it. I hate careers fairs. [...] Again, making a plan'* – Girl, 13, with autism.

*'Teachers and family giving you support to find a job'* – Girl, 19, attending further education provision at a special school.

*'I don't think work experience is even allowed [...] we need that though since when we leave here it's only, is it [special higher education provision]? We need work experience before then'* – Girl, 15, attending further education provision at a special school.

*'We use UniFrog, which is a platform to learn about careers stuff in form period, but I've only used it a couple of times'* – Girl, age 12, in mainstream school.

### **Discrimination in work places**

*'Some jobs are very fussy, some jobs would not hire people with special needs, I think people discriminate against people with special needs, people with special needs can do stuff but people think we're weird'* – Girl, 15, attending further education provision at a special school.

*'We're all equal'* – Girl, 19, attending further education provision at a special school.

*'I agree it's not fair on us. People these days need to learn we're equal and we can do what's best and we are very capable of ourselves. I behave good myself and I'm a very sociable person'* – Boy, 17, attending further education provision at a special school.

*'People think of you like you're nothing [...] they just don't understand'* – Girl, 15, attending further education provision at a special school.

*'We all get judged'* – Boy, 19, attending further education provision at a special school.

*'You deserve a chance to work'* – Girl, 19, attending further education provision at a special school.

*'Depending on the job though it might depend on the quality of how well you can do it to be fair, some might be a bit different'* – Boy, 15, attending further education provision at a special school.

<sup>1</sup> DfE, SEND Review: right support right place right time. A guide for children and young people to the special educational needs and disabilities (SEND) and alternative provision green paper, 2022. [Link](#)



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