

# Autistic young people's experiences of transitioning to adulthood following the Children and Families Act 2014

Laura Crane<sup>a\*</sup> , Jade Davies<sup>a</sup>, Anne Fritz<sup>a</sup>, Sarah O'Brien<sup>b</sup>, Alison Worsley<sup>b</sup> and Anna Remington<sup>a</sup>

<sup>a</sup>University College London, UK; <sup>b</sup>Ambitious about Autism, London, UK

Changes to special educational needs and disability (SEND) legislation in England were implemented in 2014. Here, we evaluate the impact of these changes from the perspective of 80 autistic young people aged 16–25 years. Using an online survey and/or interviews, we examined young people's views on three key principles of the SEND reforms: the help and support provided to them; whether they were given a say in the choices and support that they were offered; and their satisfaction with their educational journeys and outcomes. The results paint a mixed picture. Our sample of young people reported varied experiences regarding the help and support they received, and how much of a say they had regarding the choices and support available to them. The types of schooling they accessed played a role here: young people in mainstream schools highlighted particular challenges in accessing appropriate support, while many young people in special schools said they felt well supported. Parental advocacy was crucial for all young people, as was having key 'champions' in the form of teachers who really knew them well. The need for the development of general life and self-advocacy skills was apparent, however, especially in preparing the young people for life after school. Encouragingly, most of our participants were generally happy with their current situation, despite identifying several areas for further improvement. Overall, the results highlight the importance of listening to—and learning from—autistic young people, throughout their educational journeys and especially as they transition to adulthood.

**Keywords:** advocacy; autism; special education; transition

## Introduction

The move into adulthood can be challenging for any young person. For those with special educational needs and disabilities (SEND), including those who are autistic,<sup>1</sup> this transition can be particularly difficult. Autism is diagnosed on the basis of social communication difficulties, as well as the presence of restricted and repetitive interests, activities and behaviours (American Psychiatric Association, 2013). These characteristics can make transitions particularly challenging. For example, autistic young people may show a preference for sameness; finding it uncomfortable, or even distressing, to deviate from one's usual routine. As such, the move to new post-16 educational or

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\*Corresponding author. Centre for Research in Autism and Education (CRAE), UCL Institute of Education, 55–59 Gordon Square, London WC1H 0NU, UK. Email: l.crane@ucl.ac.uk

vocational settings may be extremely demanding (Reid, 2007; Rydzewska, 2012). In addition to the challenges inherent in any transition, a lack of accessible and supportive options has resulted in the move from child into adult services being described as a ‘cliff edge’ (Prime Minister’s Strategy Unit, 2005; Beresford *et al.*, 2013). The need to address post-16 transitions for autistic young people is underlined by poor adult outcomes for this group. Lower levels of independence, social relationships, post-secondary education and employment have all been reported for autistic young people (Roux *et al.*, 2015), as well as a lack of personal autonomy (Wehman *et al.*, 2014). Further, data from the Office for National Statistics (2021) suggests that fewer autistic individuals are employed (21.7%) than many other disability groups. For example, data from this survey suggested that the rate of employment for those with ‘mental illness or other nervous disorders’ was 33.3%, and the rate for all disabled people was 53.6%. Many of these outcomes for autistic young people have been attributed to negative transition experiences (Wittemeyer *et al.*, 2011).

On 1 September 2014, the Children and Families Act was introduced, heralding significant changes to SEND policy and provision for young people in England (Department for Education, 2014a). The Act, which included the introduction of a SEND Code of Practice (Department for Education and Department of Health, 2015), encompassed five main principles: (1) to involve children, young people and parents in decision-making; (2) to promote early identification of need and provision; (3) to give young people and parents additional choice and control over support; (4) to ensure collaboration between education, health and social care providers; and (5) to strive for excellent provision of support (Norwich & Eaton, 2015). With respect to the latter, the SEND Code of Practice makes specific suggestions for formal supports that young people may be given access to; for example, access to specific therapies, accessible information and independent living training. These formal supports should be differentiated and personalised; tailored based on each individual’s needs as opposed to their diagnosis (Department for Education and Department of Health, 2015). Alongside formal supports, young people with SEND often require, and benefit from, high levels of informal support (Palikara *et al.*, 2009; Mitchell & Beresford, 2014), some of which may be provided through initiatives advertised in Local Offers.<sup>2</sup> Additional changes as part of these reforms included the extension of SEND provision from 19 years to (potentially) 25 years, and the replacement of Statements of SEND with Education Health and Care (EHC) plans.<sup>3</sup>

There have been mixed views on the utility and impact of these reforms. Celebrated as the most substantial reforms in decades, they modernised outdated legislation that had been criticised for bias towards the inclusion of children and young people with SEND in inappropriate mainstream provisions (Robertson, 2012; Stobbs, 2014). Further, EHC plans were reported to offer a better process for assessment, planning and outcomes than Statements of SEND, and attained better parental involvement while taking a more person/child-centred approach (Hellowell, 2017; Sales & Vincent, 2018). Despite these positives, a gap between theory and practical implementation has been noted. Without an evidence-based framework or guidance about how to apply the holistic principles put forward (Castro & Palikara, 2016), many education professionals have reported anxieties and insecurities about embedding the new processes in their practice (Hellowell, 2017), fearing that they were not adequately

including the child's voice (Palikara *et al.*, 2018). Both parents and professionals have reported issues such as unfeasible timelines, budget cuts and challenges in collaborations across education, health and care (Adams *et al.*, 2018; Boesley & Crane, 2018; Palikara *et al.*, 2018). These challenges often resulted in poor outcomes for the young people involved and a variable standard of EHC plans (Castro *et al.*, 2019). Existing research provides insight into the factors that parents perceive to impact the standard of EHC plans, and their consequent satisfaction with them. Key facilitators include meaningful involvement of all parties, and key champions (e.g. from education provisions) who provide exceptional support (Adams *et al.*, 2018). Barriers include the lack of accessible information and poor communication (Adams *et al.*, 2018). Overall, despite the promise of a radically different system, many have argued that changes were actually marginal (Norwich, 2014).

While much research has examined the impact of the reforms, there has been limited work specific to autistic young people, and especially from their own perspectives. In one of the few studies on this topic, Gaona *et al.* (2019a) interviewed 12 autistic young people (16–25 years) who were either about to transition ( $n = 10$ ) or had just transitioned ( $n = 2$ ) to post-16 education. Eleven of these young people attended specialist schools, and all were able to participate in verbal interviews (although patterns of communication were described as 'heterogenous'). The young people reported mixed feelings about the transition to post-16 education, noting that they were excited at the prospect but had feelings of uncertainty and sadness. They spoke of social connections; the benefits of friendships but also the struggles that they had due to bullying. They also emphasised the critical and significant role that their families and schools played in supporting them. A related study examining these young people's EHC plans (Gaona *et al.*, 2019b) emphasised that while they were able to share their views on their education (in Gaona *et al.*, 2019a), the extent to which they were actively involved in planning and decision-making regarding their education and outcomes was questionable. Taken together, this work provided valuable insights into the challenges that a small sample of autistic young people faced as they entered a crucial phase of education. It is now important to extend this work to a broader sample of young people (across mainstream and special schools), with a focus on the whole post-16 transitional phase (up to the age of 25 years, as opposed to just focusing on those who had just made—or were about to make—the post-16 transition). These were the goals of the current study.

### **The current research**

As part of a broader project evaluating the impact of the SEND reforms on autistic young people (commissioned by the Department for Education), we sought to examine the impact of the Children and Families Act and associated SEND Code of Practice on autistic young people from the perspectives of education professionals (Crane *et al.*, 2021a), parents (Crane *et al.*, 2021b) and young people themselves (reported here). To address this aim, we reviewed the Young Person's Guide to the Children and Families Act (Department for Education, 2014b), organising the principles under three key headings: (1) help and support; (2) having a say; and (3) getting better outcomes. We worked with a team of autistic young people from the charity

Ambitious about Autism to identify research questions and design methods for data collection. Collectively, we decided to use surveys, to gather information from a broad range of young people, as well as in-depth interviews, to examine specific experiences in more depth. Our specific research questions were:

#### *Help and support*

1. Do autistic young people feel they get the support they need up until the age of 25?
2. Do autistic young people know what support is available to them, and where to access this?
3. What are autistic young people's experiences regarding the barriers and facilitators to useful support?

#### *Having a say*

1. Do autistic young people feel they get a say in the choices and support they are offered up until the age of 25?
2. What are autistic young people's experiences regarding EHC plans?
3. Do autistic young people feel their problems are taken seriously and that any problems get resolved?

#### *Getting better outcomes*

1. Are autistic young people satisfied with their educational journeys and final destinations?
2. Do autistic young people feel that schools and school staff (including specialist autism staff) have the skills to support them in achieving their ambitions?

When designing our study, we carefully considered our target sample. Building on work by Gaona *et al.* (2019a), we sought to collect data from a broad sample of autistic young people who had attended both mainstream and specialist educational provisions. While specialist provisions cater for pupils with a wide range of needs and abilities, all of the young people attending specialist provisions would need to independently complete an in-depth survey, interview or focus group. As such, we acknowledge that our research would likely preclude the inclusion of some autistic young people with intellectual disability/ies.<sup>4</sup> We also aimed to recruit participants between 16 and 25 years of age, covering the entire post-16 transitional phase. We acknowledge that participants at the latter end of this age bracket may not have experienced *all* of the changes that came as a result of the reforms, yet it was difficult to pinpoint an exact stage at which all autistic young people would fully benefit from the reforms as implementation was a gradual process. Following deliberations, it was mutually agreed that it was important to gather the views and experiences of all autistic young people aged 16–25 years, to gain a holistic insight into their experiences since the implementation of the reforms.

## **Method**

### *Participants*

Criteria for inclusion in the study were that participants needed to: (1) be 16–25 years of age; (2) self-identify or be formally diagnosed as autistic;<sup>5</sup> and (3) have experienced post-16 education in England. There were no exclusion criteria for the study although (as acknowledged earlier) the nature of the data collection techniques employed (an online survey and in-depth interviews) meant that some young people with intellectual disability/ies were likely excluded (as is common in research on this group; e.g. Chiang *et al.*, 2012, 2013; Mitchell & Beresford, 2014; Roux *et al.*, 2015; Russell *et al.*, 2019). Opportunity sampling was used to recruit participants, and the research was advertised via charities, schools/colleges, social media, support groups and professional contacts of the research team. Recruitment and data collection took place between January and March 2020.

### *Online survey*

Seventy-three autistic young people engaged with the survey, yet five cases were removed: four (5.5%) had not yet completed their secondary education and one (1.4%) had not experienced post-16/post-19 education in England. A final sample of 68 young people were included in the analyses. Most participants identified as women ( $n = 38$ , 55.9%), had a formal autism diagnosis ( $n = 65$ , 95.6%) and attended mainstream state secondary education ( $n = 40$ , 58.8%). Three-quarters ( $n = 51$ , 75.0%) of participants were aged 19 years or above and, of these, around half ( $n = 28$ , 54.9%) attended a form of higher education (e.g. university).

### *Interviews*

Twenty-one autistic young people participated in semi-structured interviews, either individually ( $n = 13$ , 62%) or as part of a focus group ( $n = 8$ , 38%). Of these, nine also took part in the online survey. Our interview participants largely identified as male ( $n = 14$ , 66.7%) and had a formal autism diagnosis ( $n = 18$ , 85.7%). Eight (38.1%) were aged 19 or above and, of these, most ( $n = 7$ , 87.5%) attended a form of higher education (e.g. university).

Participant information can be found in Table 1.

## **Materials**

### *Survey and interview schedule*

Surveys and interviews were developed with support of autistic young people from the charity Ambitious about Autism. First, the autistic collaborators worked with the academic researchers to generate ideas for questions and topic areas to include in the survey and interviews. The academic researchers organised these under broad research questions adapted from the Young Person's Guide to the Children and

Table 1. Participant demographics (survey and interviews)

Background variables	Survey ( <i>n</i> = 68)	Interviews ( <i>n</i> = 21)
Age (years), <i>n</i> (%)		
16	4 (5.9)	4 (19)
17	6 (8.8)	3 (14.3)
18	7 (10.3)	5 (23.8)
19	9 (13.2)	2 (9.5)
20	8 (11.8)	1 (4.8)
21	7 (10.3)	1 (4.8)
22	9 (13.2)	1 (4.8)
23	6 (8.8)	2 (9.5)
24	5 (7.4)	1 (4.8)
25	7 (10.3)	1 (4.8)
Mean (SD)	20.6 (2.68)	19.1 (2.83)
Diagnosis, <i>n</i> (%)		
Yes	65 (95.6)	18 (85.7)
No, I am awaiting diagnosis	3 (4.4)	0 (0)
Unsure	0 (0)	3 (14.3)
Age at diagnosis (years)		
Mean (SD)	12.2 (6.54)	8.4 (6.34)
Range	1–24	1–21
Identified as, <i>n</i> (%)		
Man	26 (38.2)	14 (66.7)
Woman	38 (55.9)	7 (33.4)
Non-binary	1 (1.4)	0 (0)
Transgender man	1 (1.4)	0 (0)
Outwardly identify as male, inside feel more female	1 (1.4)	0 (0)
Mostly identify as male	1 (1.4)	0 (0)
Geographic location, <i>n</i> (%)		
North of England	5 (7.4)	7 (33.4)
East of England	6 (8.8)	1 (4.8)
South of England	41 (60.3)	11 (52.4)
The Midlands	12 (17.6)	1 (4.8)
Yorkshire and the Humber	4 (5.9)	1 (4.8)
EHC plan, <i>n</i> (%)		
Yes	24 (35.3)	9 (42.9)
No	32 (47.1)	6 (28.6)
Unsure/undisclosed	12 (17.6)	6 (28.6)
Secondary education, <i>n</i> (%) <sup>a</sup>		
Mainstream	40 (58.8)	11 (52.4)
Specialist school/unit	8 (11.8)	11 (52.4)
Independent/private school	11 (16.2)	1 (4.8)
Academy	6 (8.8)	0 (0)
Home school	7 (10.3)	0 (0)
Other (e.g. care home, online school, hospital school)	6 (8.8)	3 (14.3)
NEET	1 (1.5)	0 (0)
Post-16 education, <i>n</i> (%) <sup>a</sup>		
Sixth form	42 (61.8)	11 (52.4)
College	20 (29.4)	5 (23.8)
Apprenticeship/traineeship	2 (2.9)	0 (0)

Table 1. (Continued)

Background variables	Survey ( <i>n</i> = 68)	Interviews ( <i>n</i> = 21)
Vocational course	3 (4.4)	0 (0)
Home-schooling	2 (2.9)	0 (0)
Specialist placement	1 (1.5)	5 (23.8)
Other (e.g. employment, online courses, care home)	6 (8.8)	1 (4.8)
NEET	4 (5.9)	1 (4.8)
Post-19 outcomes, <i>n</i> (%) <sup>a</sup>		
Higher education (e.g. university)	28 (54.9)	7 (87.5)
Sixth form attached to school	4 (7.8)	0 (0)
College	9 (17.7)	0 (0)
Apprenticeship/traineeship	3 (5.9)	0 (0)
Vocational course	2 (3.9)	0 (0)
Supported internship	2 (3.9)	0 (0)
Other (including employment, home education programmes)	5 (9.8)	4 (50.0)
NEET	2 (3.9)	2 (25.0)

<sup>a</sup>Overall percentages may exceed 100% as participants were able to list as many different settings as they attended during each time period.

Families Act (Department for Education, 2014b) and developed a draft of the survey and interviews. The drafts were sent to the autistic collaborators to review, with a focus on ensuring the surveys and interviews were understandable and accessible. Minor suggestions for revision (around wording and structure) were then incorporated into final versions of the survey and interviews, before data collection began.

The online survey (see Appendix S1) comprised four sections, featuring both open and closed questions. In Section One, we gathered key demographic information about participants (e.g. age, gender identity, location, whether they had a formal autism diagnosis and, if so, when they received this). In Section Two, we asked participants to reflect on the help and support they received in the transition into, and during, post-16; and where applicable, post-19. We also probed for: the kind of help they received and their satisfaction with it; if they experienced any barriers to accessing support or had received any useful support; and experiences with the Local Offer (specifically, how satisfied they were with it and if they had received any of the additional support available via their Local Offer). In Section Three, we questioned participants about their understanding of the rights and entitlements that young people with SEND and their families have access to as a result of the SEND reforms. Specifically, we asked about their experiences of communicating with their providers and/or their Local Authority (e.g. if they were told about support on offer in their locality; if they felt listened to about the help they received and the content of their EHC plan, where applicable; and if their Local Authority and education provider(s) ensured they got the support they needed). In Section Four, we asked about how satisfied the young people were with their post-16 experiences and outcomes thus far. We also asked the young people if the staff in their setting(s) gave them enough

support; and what one thing did/would have made a difference to their post-16 experiences. The survey finished by thanking the young people for taking part and inviting them to take part in a semi-structured interview, if they wished.

The interview schedule (see Appendix S2) started by explaining what the research was, why we felt it was important and what the structure was, before obtaining informed consent to continue. The rest of the interview was split into four sections, largely based on the questions asked in the survey.

### *Procedure*

Ethical approval was obtained via the Research Ethics Committee at UCL Institute of Education. Informed consent was obtained from all participants. The online survey took approximately 30 minutes to complete and was administered via the online survey platform Qualtrics. To maximise the inclusivity of the project, individual interviews were conducted either face-to-face ( $n = 5$ , 38.5%), on the phone ( $n = 2$ , 15.4%), by video call ( $n = 1$ , 7.7%), by instant-messenger ( $n = 4$ , 30.8%) or by email ( $n = 1$ , 7.7%), depending on participants' preferences. The mean length of individual verbal interviews ( $n = 7$ ) was 40 minutes (SD = 12.51, range = 23–63 minutes), whilst the two focus groups conducted face-to-face ( $n = 8$ , 100%) took 32 minutes, on average (SD = 2.84, range = 30–34 minutes).<sup>6</sup> Verbal interviews were digitally recorded with participants' consent, and transcribed verbatim.

### *Data analysis*

Quantitative data was analysed descriptively ( $n$ , %). Qualitative data from the online survey, individual semi-structured interviews and focus groups was considered together due to considerable overlap. Where possible, data from the focus groups was analysed on an individual basis as opposed to by group. Therefore, quotes provided from focus group members should be attributed to individuals.

Qualitative survey and interview data was analysed using reflective thematic analysis, as described by Braun and Clarke (2006, 2013, 2019). Adopting a critical realist framework, analyses involved identifying both semantic and latent meanings in the dataset, following an inductive approach (Braun & Clarke, 2013). Data analysis was led by two authors who conducted the majority of the semi-structured interviews and focus groups (JD and AF, both junior researchers with expertise in autism). JD and AF independently familiarised themselves with the qualitative data, identifying (and repeatedly returning to and revising) preliminary codes and themes that were organised under each of our key areas of focus: (1) help and support; (2) having a say; and (3) achieving better outcomes. With input from LC and AR (both senior researchers with expertise in autism), JD and AF discussed the findings on multiple occasions, recursively proceeding through the stages of data familiarisation, coding, theme development and review. JD and AF worked together to resolve any discrepancies, merge overlapping themes and agree on a final set of discrete themes and sub-themes.



## Results

### *Quantitative (online survey) results*

*Experiences of help and support post-16.* Just over half ( $n = 37$  of 68, 54.4%<sup>7</sup>) of the participants had little or no support in deciding what to do following their secondary education. When asked whether they were happy with this amount of support, responses were split more evenly: around a third of participants ( $n = 27$  of 68, 39.7%) answered that they were happy, around a third ( $n = 26$  of 68, 38.2%) stated that they were unhappy and the remainder were neither happy nor unhappy ( $n = 15$  of 68, 22.7%). Once in their post-16 provision, most young people ( $n = 39$  of 62, 62.9%) reported that they received useful support, although many ( $n = 39$  of 66, 59.1%) also experienced barriers to accessing this support. Overall, around half of our participants felt that they got the support they needed ( $n = 33$  of 62, 53.2%) and were satisfied with their post-16 experience ( $n = 25$  of 51, 49.0%).

In contrast, less than half of the young people ( $n = 31$  of 66, 47%) knew what post-16 support was available, and most of our participants did not feel informed about their special educational needs ( $n = 34$  of 54, 63%). Likewise, most participants reported that they had not been told about their Local Offer ( $n = 41$  of 55, 74.5%), did not know what was in it ( $n = 42$  of 61, 68.9%) and did not receive any additional support through it ( $n = 36$  of 61, 59%). Indeed, the majority ( $n = 49$  of 61, 80.3%) were unable to ascertain whether they were happy with their Local Offer (see Table 2).

Responses regarding post-19 support were more positive. Of those that reported on their experiences of post-19 education ( $n = 41$ ), over two-thirds ( $n = 29$  of 41, 70.7%) reported knowing about the help and support available to them. However, more than half ( $n = 24$  of 41, 58.5%) did not get the support they needed in the transition from post-16 to post-19.

When asked specifically about their EHC plan ( $n = 24$ ), almost all knew what an EHC plan was ( $n = 23$  of 24, 95.8%), but only half were sure about what was in their plan ( $n = 11$  of 24, 45.8%). More than half of those with an EHC plan ( $n = 13$  of 24, 54.2%) reported that their local council or school *did not* make sure they received the help that was specified in their plan: less than a quarter answered yes ( $n = 5$ , 20.8%), with the remainder ( $n = 6$ , 25%) indicating that their local council/school *sometimes* made sure that they received the help outlined in the EHC plan. Further, under half of the participants ( $n = 11$  of 24, 45.8%) indicated that their EHC plan had been updated since it was first made.

*Young people's experiences of having a say in their post-16 help and support.* Of our participants with an EHC plan ( $n = 24$ ), just over half ( $n = 13$  of 24, 54.2%) had a say regarding what went into it. However, of our sample overall, many of the young people felt that their views were not listened to ( $n = 25$  of 55, 45.5%) and that their problems were not taken seriously and/or fixed ( $n = 28$  of 52, 53.9%) (see Table 3).

Table 2. Young people's experiences of help and support post-16

	Lots of help	Quite a lot of help	Not a lot of help	No help	Variable help
Did you have any help/support in deciding what to do after secondary school? ( <i>n</i> = 68)	10 (15.2%)	16 (24.2%)	21 (31.8%)	16 (24.2%)	5 (7.6%)
Are you happy with the amount of help/support you got when deciding what to do after secondary school? ( <i>n</i> = 68)	Extremely happy 8 (12.1%)	Somewhat happy 19 (28.8%)	Neither happy nor unhappy 15 (22.7%)	Somewhat unhappy 11 (16.7%)	Extremely unhappy 15 (22.7%)
Do/did you know what support is/was available to you, during your post-16 education, and where to access it? ( <i>n</i> = 66)	Yes 31 (47.0%)	No 35 (53.0%)			
Do/did you know what support was available to you and where to access it during your post-19 education? ( <i>n</i> = 41)	Yes 29 (70.7%)	Sometimes 12 (29.3%)			
Do you and your parents get told what you need to know about your special educational needs (either by your school/education provider or by the local council)? ( <i>n</i> = 54)	Yes 10 (18.5%)	Sometimes 10 (18.5%)	No 34 (63.0%)	Unsure	

Table 2. (Continued)

	Lots of help	Quite a lot of help	Not a lot of help	No help	Variable help
	Yes	No			
Have you received any useful support during your post-16 education? ( <i>n</i> = 62)	39 (62.9%)	23 (37.1%)			
Have you experienced any barriers to accessing support, during your post-16 education? ( <i>n</i> = 66)	39 (59.1%)	27 (40.9%)			
	Definitely yes	Somewhat yes	Somewhat no	Definitely no	
Do you feel you get/got the support you need, during your post-16 education? ( <i>n</i> = 62)	21 (33.9%)	12 (19.4%)	17 (27.4%)	12 (19.4%)	
	Yes	Some of it	No		
Do you know what is in your EHC plan? ( <i>n</i> = 24)	11 (45.8%)	9 (37.5%)	4 (16.7%)		
	Yes	Sometimes	No	It varied	
Do you think the people that work in your school/college/apprenticeship give/gave you enough support? ( <i>n</i> = 51)	12 (23.5%)	18 (35.3%)	17 (33.3%)	4 (7.8%)	

Table 2. (Continued)

	Lots of help	Quite a lot of help	Not a lot of help	No help	Variable help
	Extremely Satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Extremely dissatisfied
Overall, are you satisfied with your education since you were 16? (n = 51)	7 (13.7%)	18 (35.3%)	7 (13.7%)	7 (13.7%)	12 (23.5%)
	Yes	Some of it	No	Unsure	
Do you know what is in your Local Offer? (n = 61)	4 (6.6%)	10 (16.4%)	42 (68.9%)	5 (8.2%)	
	Yes and I have/had one	Yes but I've never had one	No but I have/had one	No and I've never had one	
Do you know what an EHC plan is? (n = 56)	23 (41.1%)	16 (28.6%)	1 (1.8%)	16 (28.6%)	
	Yes	No	Unsure		
Has your EHC plan been updated since it was first made? (n = 24)	11 (45.8%)	10 (41.7%)	3 (12.5%)		
	Yes	Sometimes	No		
Does your local council, or school, make sure you get the help that your ECH plan says you should? (n = 24)	5 (20.8%)	6 (25%)	13 (54.2%)		
Does your school/education provider make sure you get the help you need? (n = 54)	15 (27.8%)	20 (37.0%)	19 (35.2%)		

Table 2. (Continued)

	Lots of help		Quite a lot of help		Not a lot of help		No help		Variable help	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Do you get told about all of the support on offer in your local area (either by your school/education provider or by the local council)? This is known as the Local Offer ( <i>n</i> = 55)	7 (12.7%)	7 (12.7%)	41 (74.5%)							
Are you happy with what is in your Local Offer? ( <i>n</i> = 61)	3 (4.9%)	4 (6.6%)	5 (8.2%)	49 (80.3%)						
Have you received any of the additional support that is offered to you, through your Local Offer? ( <i>n</i> = 61)	2 (3.3%)	3 (4.0%)	36 (59.0%)	20 (32.8%)						
Do you feel that you got the support you needed during the transition from post-16 to post-19 education (where applicable)? ( <i>n</i> = 41)	10 (24.4%)	7 (17.1%)	8 (19.5%)	16 (39.0%)						

Note: Given that all questions were optional, the percentages presented are calculated as the number of participants out of the total number of those who answered the question. For each question, the total number of respondents is indicated in brackets in the far left column.

Table 3. Young people's experiences of having a say in their help and support

	Yes	A little	No	Unsure
Did you have a say in what went into your EHC plan? <sup>a</sup> ( <i>n</i> = 24)	13 (54.2%)	6 (25.0%)	4 (16.7%)	1 (4.2%)
	Yes	Sometimes	No	N/A
Do your local council listen to what you and your parents say should go in your EHC plan? For example, by checking you are happy with the plan before it is finished off ( <i>n</i> = 55)	7 (12.7%)	6 (10.9%)	13 (23.6%)	29 (52.7%)
Do you feel that your views about the help you receive are listened to (either by your school/education provider or by the local council)? ( <i>n</i> = 55)	12 (21.8%)	18 (32.7%)	25 (45.5%)	
The Children and Families Act (2014) says that all young people should get a say in their choices and the support they are offered—is this your experience too? ( <i>n</i> = 52)	9 (17.3%)	23 (44.2%)	20 (38.5%)	
The Children and Families Act (2014) says that all young people should have their problems taken seriously and get their problems fixed—is this your experience too? ( <i>n</i> = 52)	6 (11.5%)	18 (34.6%)	28 (53.9%)	

<sup>a</sup>Only presented to those who selected 'yes and I have/had one' or 'no but I have/had one' to 'Do you know what an Education, Health and Care Plan is?'

*Post-16 outcomes.* Of those who answered the question regarding their current situation (*n* = 51), more than half were either somewhat happy (*n* = 18, 35.3%) or extremely happy (*n* = 15, 29.4%) with what they were currently doing. A further six participants were neither happy nor unhappy (13.7%) and almost a quarter of the respondents were somewhat unhappy (*n* = 7, 13.7%) or extremely unhappy (*n* = 5, 9.8%) with their current situation.

### Qualitative results

Four themes were identified from the qualitative data: (1) variable experiences of support; (2) parent support and advocacy is vital; (3) the impact of key stakeholders; and (4) young people are not well-informed about their rights.

*Theme 1: Variable experiences of support*

Within this theme, four sub-themes were identified: (1) insufficient support, particularly within mainstream settings; (2) more positive experiences in specialist settings, but not without challenges; (3) the need for continuity of support; and (4) limited support outside of education.

*Sub-theme 1: Insufficient support, particularly within mainstream settings.* Young people from mainstream schools explained how they experienced barriers to accessing post-16 support: ‘I can’t really comment on support as it was not really existent’ (Interviewee 15; henceforth I-15). Often, this was linked to the unsuitability of the mainstream environment. For example, participants noted challenges associated with: (a) staff changes (‘the teachers changed so often I couldn’t keep track’; I-2); (b) short-notice timetable changes (‘They would change every week what time and what day [my support sessions] were’; I-4); and (c) a lack of reasonable adjustments (‘I just got the same as everybody else, I didn’t get anything special’; I-5). Even those who received support via an EHC plan tended to be disappointed with its outcomes: ‘it’s rubbish... it hasn’t made any difference in my life’ (I-18). Largely, this outlook was attributed to the failure of schools to implement the agreed support: ‘I thought things were going to change with the EHC plan but the school refused to do anything it said to do’ (Survey respondent 58; henceforth S-58). Young people explained that they felt as though their voice was not being listened to: ‘I feel like they were ignoring what I wanted’ (I-3).

Discussing the transition into post-16, our sample of young people reported a lack of support. This was attributed to the emphasis on academic performance in mainstream schools: ‘Sessions at school focused on applying to sixth form. Had I not met the academic requirements, though, there was not much’ (S-6). As a result, young people were unsure of their post-16 options and felt they did not receive the support they needed. Our sample expressed the need for more of an emphasis on general life-skills, without which they felt ill-equipped for their post-16 and post-19 journeys: ‘Life skills I think are quite important... I remember when we all got to university and there were skills I just didn’t know. Some people don’t even know how to cook, you know, how can you live independently if you don’t know these skills?’ (I-5).

The lack of adequate post-16 and post-19 support left many young people feeling disenfranchised and, in some cases, led to them leaving education entirely: ‘I have dropped out of further education because of the sheer stress and trauma I experienced post-16. Had I known what I would have faced I would have dropped out even sooner’ (S-39). Other young people felt the lack of support during this time left them with fewer opportunities than their non-autistic peers, creating a negative self-fulfilling prophecy:

Autism doesn’t affect intelligence but having such poor quality of education for most autistic people means we aren’t given the same chances and tools as our [non-autistic] peers to succeed. It’s then a self-fulfilling prophecy; we are assumed to be stupid solely for our disability, we are then denied an education because of said disability and then called stupid because we didn’t learn things we were never taught. (S-1)

*Sub-theme 2: More positive experiences in specialist settings, but not without challenges.* Many young people who attended specialist educational settings explained

that they felt well supported: *'I don't think the support that we receive here could be improved at all'* (I-19). The wide range of in-house support was also noted: *'You've got speech and language therapy to help you, occupational therapy [and] stuff like that'* (I-18). These young people further recognised the role that their EHC plan played in enabling them to access these settings: *'it helped me with getting in here'* (I-18). Despite these positive sentiments, our sample of young people did note their own, somewhat different, challenges in accessing post-16 support, including the reduction in specialist settings finances (*'special schools have lost like 19% of their budget. . . and that is not a good thing [because] that has cancelled a lot of stuff in the school'*; I7-12<sup>8</sup>) and the lack of integration between the national curriculum and teaching of other important skills (*'We overhear conversations in the office next door where [the staff are] all debating whether it's a curriculum problem or an independence problem and I think there needs to be more of an integrated approach to managing the education'*; I-17). Similar to their mainstream peers who took part in this research, young people in special schools recommended additional life-skills training that is *'more physical practice rather than just the facts of everything and worksheets'* (I7-12).

*Sub-theme 3: The need for continuity of support.* Our participants reflected on the lack of consistency in support over the years: *'Staff at my university had the right skills to help me achieve, but staff before that, no'* (I-15). In some cases, participants referred to EHC plans not being updated as their needs developed, meaning that the plan was not always reflective of participants' needs: *'My EHC plan was never updated between when I was 15 and 20, so after less than a year it was shockingly out of date'* (I-2). Disappointment was expressed at how the EHC plan and accompanying support did not always continue throughout higher education. For example, one participant explained how the key thing that would have made a difference to their post-16 experiences was *'if [my] EHC plan had continued for university'* (S-32). EHC plans were perceived to be particularly useful in challenging times: *'At two parts of my life I became homeless, and I could have been supported through the whole situation [with an EHC plan], but as I was at uni there wasn't support available for outside-of-studying situations like that'* (I-15).

*Sub-theme 4: Limited support outside of education.* Young people reported experiencing limited access to mental health support outside of their educational setting: *'there is almost nothing available to help [with mental health] unless [we] reach crisis point and even then it is usually insufficient'* (S-47). This lack of support was perceived as particularly disappointing since the majority of young people felt that poor mental health was a significant consequence of inadequate support during education: *'educationally the support was really lacking and this led to real struggles with my mental health including alcoholism and suicidal thoughts'* (S-23). A general lack of support was also reported with respect to Local Offers: *'all that they could offer was a local social group for people with autism'* (I-5).

*Theme 2: Parents provide vital support and advocacy.* Young people, from both mainstream and specialist settings, felt that their families were integral in ensuring they got help and support during their post-16 and post-19 journeys: *'Really all the support I've*



ever received has just been family, it's not really been any in education' (I-13). Any support participants had received was perceived to be as a direct result of their parents fighting on their behalf:

This school is very difficult to get into because it requires a lot of proof about how your needs can be met because it's a lot more expensive and difficult for the local authority to justify than sending us to a mainstream secondary school. It took half a year of my parents debating with the local authority to send me to this school. (I-18)

Parental support and advocacy was felt to be vital in securing an EHC plan: 'I know my mum sorted out my EHC plan and she was probably quite influential in getting me [into my specialist provision]' (I-16). Some Local Authorities were seen as reluctant to provide EHC plans: 'if you're diagnosed late, and if you don't have a learning disability, they don't want to give you one' (I-3). The process that parents went through to obtain an EHC plan was described as long and fraught: 'It was just two years of fighting for my mum' (I-18).

In some cases, parental support extended to paying privately for specific support. Those participants with parents who advocated on their behalf reported feeling privileged, and acknowledged that not all families would be able to support or advocate for young people in this way: 'I am fully aware that not everyone is like my mum willing to balance a full-time job with full-time making sure that everything's going well for me' (I-4). Indeed, when a young person did not have this vital parental support or advocacy, they felt disadvantaged:

I did see a big difference in my education when [my social worker] was there to advocate for me vs after she stopped working with me, and I strongly believe if I'd have had a parent, my education would have been much better. (I-2)

*Theme 3: The impact of key stakeholders. Subtheme 1: Educators lack autism awareness and knowledge*—Young people, particularly those attending mainstream settings, felt that educators did not have adequate autism training: 'it was very clear to me even as a 16/17-year-old that sometimes they were just out of their depth and lacked the training in autism' (I-4). As a result, our sample reported that some members of staff did not understand them or their needs: 'My education could have been a lot better if staff had [been] understanding of my needs, and if I was given support from trained support staff' (I-15). In some cases, young people had to explain their needs to the staff that worked with them: 'I myself had, and still have, to provide any information about autism and how my brain works, and it's exhausting' (S-30). This was viewed as especially difficult for those who were unsure of the support that would best suit them: 'I wasn't sure what support I was able to get, which means I only got any support after I'd experienced something that I struggled with' (S-31). The detriment that this had on the young people's educational experiences was acknowledged: '[I] see huge academic and personal differences when I get the right support and I don't' (I-2). Despite this, a minority of students did have positive experiences with the staff. Particularly within specialist settings, students felt that 'their knowledge of autism is incredible. . . Ofsted rated this place outstanding. I can understand why' (I-20).

*Sub-theme 2: The importance of ‘champions’*—Individual educators were often felt to make a positive difference to the young people’s educational experiences:

My education as a whole was awful, I hated it. . . but I had some really nice adults who I think looked out for me more than they should have done. . . I think that they stuck their neck out for me a little bit. (I-21)

Reflecting on what made these champions so helpful, our participants noted that building relationships was crucial: *‘specific teachers who really took the time to get to know me, encourage me and cared about my future [made a difference]’* (S-47). Education professionals with more experience were often felt to provide better support, and the young people suggested that education settings should make use of that experience:

Certain teachers did more than their job’s worth of helping you. The teachers that had been teaching for 20 years tended to be more appreciative of why people were struggling with certain situations. I think it’s clear that people are going to have extra issues, then perhaps more experienced [members of staff] and ones that have a reputation for being quite good at that kind of extra communication, should be assigned to these classes that need extra support. (I-13)

Yet some participants shared that even if there was a key champion they trusted and had good experiences with, they were hesitant to share their concerns or ask for additional support as they did not want to be seen as a burden. Participants also questioned how much help one individual could realistically provide:

I feel like now is the time when I need to be, ‘This is what my needs are’, but at the same time you don’t want to be unnecessarily dramatic. I know that the tutors who have been really open with me have been, like, ‘If there’s anything extra you need, you can always say’, and they’ve been the ones that have really helped; but at the same time it is massively structural, because what can they do? They can’t do anything as individuals. (I-21)

*Theme 4: The importance of self-advocacy.* Young people (from all settings) reported that they were not well-informed about their rights: *‘I have never been told that I even have any rights, so I do not know what these are’* (I-14). Questioning whether the Local Authority deliberately withheld information about their rights and available support from them (*‘councils are legally required to offer certain support once it is requested but if it’s not requested they can loophole out of providing it—if they don’t tell us it exists, we can’t request it’*; I-2), our sample lamented how they *‘weren’t given any information at all to make an informed choice’* (I-2). Participants urged for information about their rights to be made clearer and more easily accessible. Confusion regarding entitlements applied to both EHC plans (*‘I’m not sure exactly what it does but I know it gives me benefits, especially having Asperger’s it probably helps a lot with that. I wouldn’t give it up easily’*; I-16) and Local Offers (*‘I wasn’t aware that something like that existed’*; I-16). For some young people, information about rights and available support was better communicated during higher education. Yet these participants noted that they would have appreciated access to such information during their post-16 journeys and at the point of diagnosis. Being informed about rights was felt to be useful at later life stages too:

My employers at the moment don't know [I'm autistic], and we do a couple of things I don't really like, and I find [it] really overwhelming. But I don't feel comfortable saying [that] because I don't know how they will react to me. I feel like it would be useful to be like, 'I'm legally allowed these things in place'. (I-21)

While most young people spoke about wanting to be better informed, others questioned the practicality of knowing about their rights:

I understand the rights however I don't agree that they actually exist. I've never been listened to about what I feel is right, many times I've had staff try and kick me out of education just because I don't fit into their box of how I should be. They continue to do what they choose rather than listening to me who it's all happening to. (I-15)

## **Discussion**

Using a survey and interviews, we elicited the views of autistic young people (16 to 25 years) about their experiences of transitioning to adulthood following the introduction of the Children and Families Act (Department for Education, 2014a) and associated SEND Code of Practice (Department for Education and Department of Health, 2015). While it takes time for policies to be translated into practice, our findings suggest that 5 years on from the introduction of these reforms, the post-16 educational experiences of autistic young people remain mixed. The young people we spoke to had varied experiences regarding the help and support they received, and how much of a say they had in their post-16 journeys. The types of schooling they accessed appeared to play a role here, with young people in mainstream schools highlighting particular challenges in accessing appropriate support. Parental advocacy was seen as crucial in this regard, as was having key 'champions' in the form of teachers who really knew the young people well. Yet there was an apparent lack of self-advocacy from the young people: they were unaware of the help and support on offer in their local area, as well as what issues they could get support with and what help and support they might be eligible for. Encouragingly, most of our participants were generally happy with their current situation, despite identifying several areas for further improvement. Next, we discuss how these findings relate to existing research. We also consider what they tell us about the impact of the SEND reforms, before identifying recommendations for future research and practice.

A recurring theme within our findings was the very diverse views of our sample regarding their post-16 experiences; a finding that very much aligns with the diversity of autistic educational experiences more broadly (e.g. All Party Parliamentary Group on Autism, 2017). Unpicking this is likely to be complex and may be linked to a number of factors not examined in detail within the current research. This may include the heterogeneity of needs associated with autism (e.g. Hummerstone & Parsons, 2020), factors intersecting with autism (e.g. gender, ethnicity; Carpenter *et al.*, 2019) or the postcode lottery of SEND provision (e.g. Boesley & Crane, 2018). There were, however, some clues within our research as to what might underlie this variability. First, the types of provisions that the young people attended appeared to play a role. Broadly speaking, the experiences of those in specialist provisions (i.e. those who were more likely to have an EHC plan) seemed to be more positive than the experiences of

those in mainstream provisions, with a lack of knowledge of autism and too narrow a focus on academic outcomes emphasised in the latter (see also Goodall, 2018). While challenging experiences of education may also be reported at earlier stages of the educational journey (e.g. Hodges *et al.*, 2020), this is particularly worrying at this later age, when leaving the safety net of school becomes a more imminent reality (e.g. Cribb *et al.*, 2019). A second factor that appeared to play a role in determining how positive the young people were about their post-16 experiences was the level of advocacy that their parents took on. Those who did not have strong parental advocates discussed additional challenges they faced due to having no one to fight their corner. Parental involvement is a key predictor of success for autistic young people (Chiang *et al.*, 2012, 2013) and, indeed, it was this advocacy that appeared to facilitate access to help and support for the young people in our research.

A reliance on parental advocacy is concerning for a number of reasons. First, the effect of constantly fighting for children's needs undoubtedly takes a toll on parental wellbeing (Spiers, 2015). Second, this route to support relies on parents having the time, skills and resources to advocate for their children—many of which require a degree of social or cultural capital (Jegatheesan *et al.*, 2010; Lalvani, 2012). Inequalities are therefore created between families who are and are not able to advocate, rather than support being allocated based on the needs of the young person. The role of individual advocates was further highlighted when the young people spoke about key 'champions' who worked with them professionally—specific individuals who they felt were responsible for their support (cf. Adams *et al.*, 2018). While these champions were very much appreciated, our sample of young people reported that they often held back from seeking help from them, as they did not want to be a burden (also see Crane *et al.*, 2019). Further, high staff turnover made relying on these champions challenging. When considering what made some professionals particularly successful advocates, general knowledge of autism was highlighted as important, but more crucial was having someone take the time to really understand them and their unique needs (also see Crane *et al.*, 2019; Guldberg, 2020). Developing these more relational skills (as opposed to just teaching general knowledge on autism) is key. This recommendation also aligns with the double empathy theory (Milton, 2012; Milton *et al.*, 2018): that when people with different ways of experiencing the world interact, they will struggle to empathise with one another, leading to frequent misunderstandings. The notion of communication as a two-way process, with adaptation needed from both the autistic person and their communicative partner, should underpin training for those supporting autistic young people. This will be essential in ensuring that the voices and perspectives of autistic young people are meaningfully elicited (cf. Guldberg, 2020).

A central aim of the present study was to establish whether, following the SEND reforms, autistic young people felt that they had a say in their post-16 journeys. Research in the United States paints a worrying picture regarding a lack of involvement by young people in their transition planning (Chandaroo *et al.*, 2018). In England, the legal duty for young people to have a say in the decision-making regarding their post-16 education relates mainly to the EHC plan process. Yet, almost half of our participants with an EHC plan did *not* feel they were given a say about what went into it. Similarly, more than a third of our sample (with and without an EHC plan)

did not feel they were given a say about the support they received during their post-16 education. While our participants did report feeling listened to, to a degree, it was evident that they did not really know or understand their rights and entitlements, which further limited their ability to input their views and perspectives. For example, our participants reported that when they were presented with information, it was often not accessible or clear. This is perhaps unsurprising given that parents of children with an EHC plan have also called for more accessible documentation surrounding the EHC plan application process (Adams *et al.*, 2018). Likewise, many participants reflected that they had minimal, if any, involvement in the process of obtaining their EHC plan; recognising that, instead, their parents had fought on their behalf to obtain one. Though a key goal for young people between the ages of 16 and 25 years is to develop independence (Anderson *et al.*, 2018), the lack of clarity around rights and entitlements may be leading to a strong reliance on parents and school champions. There is, therefore, an urgent need to develop effective ways to promote self-advocacy in autistic young people. One way to do this is to create accessible guides or toolkits that help them to better understand their needs, and to inform them about the support they may be entitled to and how to go about obtaining it (cf. Fabri *et al.*, 2016). The need to involve young people in the design and development of resources and services to support them should not be underestimated (see Franklin *et al.*, 2018). Further, we assert that there is a need to start developing advocacy skills early on, rather than waiting until post-16 (cf. Kuo *et al.*, 2018).

In many cases, the success or failure of the SEND reforms is judged by examining outcomes: where do these young people find themselves post-16? It is, perhaps, too early to be able to assess the outcomes of the autistic young people in this research, but it was encouraging that most reported being happy with their current situations (see also Cribb *et al.*, 2019). Clues as to how to make this experience better related particularly to mainstream schools. Those in our study who had attended mainstream provisions felt that the strong focus on academic outcomes meant that if they did not want to follow an academic pathway, then there was no help or support available. This echoes work from the United States, which found that outcomes for autistic adults without a learning disability were *worse* than outcomes for autistic adults with a learning disability. Specifically, Taylor and Seltzer (2011) assessed the occupational and educational activities of autistic young adults and found that those without a learning disability were three times more likely to have no daytime activity, compared to autistic young adults with a learning disability (see also Allan & Coney, 2019). It is important to recognise that staying in education may not be the optimal choice for all individuals, and young people should be supported, irrespective of whether they choose to take a vocational or academic route post-16 (see Seaman & Cannella-Malone, 2016). Further, some of the young people had similar concerns about their specialist provision, where a desire for more practical life-skills training to support their independence was articulated. This again highlights the importance of listening to the voices of young people when making decisions about their education (cf. Guldberg, 2020). As evidenced in this research, pupils may struggle to know exactly what helps them, and may struggle to advocate for the help and support available to them. Yet many do have a voice and opinion on their education, and it is essential that we listen.

This brings us to the key question of the overall impact of the SEND reforms on autistic young people at this crucial developmental stage. Overall, some aspects of the reforms were perceived favourably by our sample of young people, but it was very evident that the radically different system that was promised did not emerge (see Norwich, 2014). What are the reasons behind this? First, it is possible that the reforms were implemented too late to make a real impact on this group. Whilst the Children and Families Act was introduced in 2014, it undoubtedly takes time to fully translate all aspects of any reform into practice. Our participants would have been aged between 10 and 19 years when the reforms were introduced, and may therefore not have experienced all of the policy changes that could be embedded into their educational context. As such, the impact of the reforms may not be as clear for this cohort of young people as it will be for those who succeed them. It was, however, very evident that more needed to be done to support autistic young people post-16, since most services and supports seem to be targeted towards younger children (see also Crane *et al.*, 2018). Second, it may be that autistic young people who are able to articulate their experiences (as per the participants who engaged in this research, given the nature of the data collection techniques employed) do not receive as much help and support as those with more complex needs (e.g. intellectual disability, language impairments). Although we did not directly compare participants who attended mainstream versus special schools, our findings suggest that autistic young people who attended mainstream schools experienced unique challenges; finding themselves too ‘normal’ to warrant help and support, but ‘not normal enough’ to succeed in line with their neurotypical peers (cf. Crane *et al.*, 2019). The toll this takes on their mental health has been well documented (Crane *et al.*, 2019).

Given the qualitative nature of the current study, we were unable to make direct comparisons between the post-16 help and support autistic individuals received in mainstream schools relative to that received in specialist provisions. Future research may seek to address this gap. Nonetheless, our findings suggest that despite the SEND Code of Practice’s aims of prioritising a needs-based approach (Department for Education and Department of Health, 2015), the group of autistic young people in this study did not report this experience. Indeed, participants that had a formal autism diagnosis and accompanying EHC plans reported having greater access to formal support (e.g. in-house therapists) than those without. This is problematic for two reasons. First, existing research suggests that autistic individuals (particularly those who are not struggling academically) often find it difficult to access EHC plans (All Party Parliamentary Group on Autism, 2017; Boesley & Crane, 2018). As such, providing support on the basis of EHC plans is likely to leave many autistic individuals without the support they require. Second, even some of our participants *with* an EHC plan did not receive the support they needed. This is particularly concerning given that individuals have a legal right to the support that is set out in their EHC plan (Department for Education and Department of Health, 2015). Moving forward, it is essential that we move towards a model of supporting *all* autistic people, via person-centred planning, rather than overlooking a sizeable proportion of the autistic population as they do not—on the surface—appear to be in need of help and support (cf. Guldberg, 2020).

Finally, it is important to note the limitations of the current research. First, and most notably, the representativeness of our sample should be discussed. Given the

use of a convenience sample, it is possible that our participants were better networked or more socio-economically advantaged than the autistic population as a whole. Indeed, to be able to participate in the survey, participants would have needed access to a smartphone or computer as well as access to the internet. Further, all of our participants were able to independently complete an extensive online survey and/or take part in an in-depth verbal/written interview. As such, our results only relate to a subsection of autistic young people, and do not reflect the post-16 educational experiences of all autistic young people, including those with more profound intellectual/language impairments. This is a common limitation of research on this participant group, which tends to over-represent the views of autistic people without learning disabilities (e.g. Chiang *et al.*, 2012, 2013; Mitchell & Beresford, 2014; Roux *et al.*, 2015). Second, many of our participants were recruited via school and college partners of the research team (i.e. provisions that have an interest in autism research and improving their practice). As such, it is possible that the educational provisions that some of our participants attended had better initiatives in place for supporting their autistic young people. Further, most participants attended provisions in the South of England, geographically close to the research team, and may not be representative of the experiences of those in other locations. Future research should aim to address this gap, exploring the post-16 educational experiences of autistic young people from across England. Third, our data was cross-sectional in nature, taking just one snapshot of these young people's lives. While our participants were able to retrospectively reflect on changes in their education, longitudinal research following up young people as they move into, and through, post-16 education would be hugely valuable (cf. Cribb *et al.*, 2019). Finally, it is important for future work to triangulate the perspectives of autistic young people with those of others close to them, including parents and/or teachers, to gain a more holistic picture of their educational journeys (e.g. Makin *et al.*, 2017; Hoy *et al.*, 2018; Halsall *et al.*, 2021; Wood, 2021); identifying how to ensure that autistic young people can access help and support, have a say in their education and achieve better outcomes.

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## **Data availability statement**

Research data are not shared.

## NOTES

<sup>1</sup> We use identity-first (i.e. autistic) rather than person-first (i.e. with autism) language, as this is preferred by many autistic people and their families in the United Kingdom (Kenny *et al.*, 2016) and is less associated with stigma (Gernsbacher, 2017) and ableism (Bottema-Beutel *et al.*, 2021).

- <sup>2</sup> Local Offers, introduced as part of the Children and Families Act (Department for Education, 2014a), contain information regarding the help and support available in a person's local area.
- <sup>3</sup> EHC plans are documents that detail a child or young person's education, health and care needs, as well as the formal support that they are legally entitled to. Crucially, EHC plans also provide young people and their families with the legal right to have a say in decision-making surrounding their education.
- <sup>4</sup> Despite plans to make modifications to the survey and interview schedules for autistic young people with additional needs (e.g. co-occurring intellectual disability), the COVID-19 pandemic meant we were unable to make these modifications (e.g. we were unable to make visits to schools to provide support in completing the survey).
- <sup>5</sup> We included young people who self-diagnosed as autistic within this research, given the significant disparities in access to a formal diagnosis for some groups (e.g. Singh & Bunyak, 2019).
- <sup>6</sup> As some of the individual interviews and all the focus groups were conducted within educational provisions, these discussions were constrained by time limitations. This largely accounts for the variable length of the discussions.
- <sup>7</sup> All questions were optional, therefore percentages are calculated as the number of participants who chose this response, out of the total number of those who answered the question. As such, the total number of respondents is included in brackets for each question reported.
- <sup>8</sup> I7-12 represents one of the six autistic young people in the focus group (it was not possible to discern which young person provided the focus group quotes from the recording/transcript).

## References

- Adams, L., Tindle, A., Basran, S., Dobie, S., Thomson, D., Robinson, D. *et al.* (2018) *Education, health and care plans: A qualitative investigation into service user experience of the planning process*. Research Report (London, DfE).
- All Party Parliamentary Group on Autism (2017). *Autism and education in England 2017*. (London, National Autistic Society).
- Allan, M. & Coney, K. (2019) *What happens next? A report on the first destinations of 2017 disabled graduates*. Available online at: <https://www.agcas.org.uk/Latest/launch-of-what-happens-next-2019> (accessed 14 July 2021).
- American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders-5 (DSM-5)* (Washington, DC, APA).
- Anderson, K. A., Sosnowy, C., Kuo, A. A. & Shattuck, P. T. (2018) Transition of individuals with autism to adulthood: A review of qualitative studies, *Pediatrics*, 141(4), S318–S327.
- Beresford, B., Moran, N., Sloper, P., Cusworth, L., Mitchell, W., Spiers, G. *et al.* (2013) *Transition to adult services and adulthood for young people with autistic spectrum conditions*. Working Paper No. DH 2525. Available online at: [www.york.ac.uk/inst/spru/pubs/pdf/TransASC](http://www.york.ac.uk/inst/spru/pubs/pdf/TransASC) (accessed 10 July 2021).
- Boesley, L. & Crane, L. (2018) 'Forget the Health and Care and just call them Education Plans': SENCOs' perspectives on Education, Health and Care plans, *Journal of Research in Special Educational Needs*, 18, 36–47.
- Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J. & Hand, B. N. (2021) Avoiding ableist language: Suggestions for autism researchers, *Autism in Adulthood*, 3(1), 18–29. <https://doi.org/10.1089/aut.2020.0014>
- Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3(2), 77–101.
- Braun, V. & Clarke, V. (2013) *Successful qualitative research: A practical guide for beginners* (London, Sage).
- Braun, V. & Clarke, V. (2019) Reflecting on reflexive thematic analysis, *Qualitative Research in Sport, Exercise and Health*, 11(4), 589–597.
- Carpenter, B., Happé, F. & Egerton, J. (2019) *Girls and autism: Educational, family and personal perspectives* (Abingdon, Routledge).
- Castro, S. & Palikara, O. (2016) Mind the gap: The new special educational needs and disability legislation in England, *Frontiers in Education*, 1. <https://doi.org/10.3389/feduc.2016.00004>.
- Castro, S., Grande, C. & Palikara, O. (2019) Evaluating the quality of outcomes defined for children with Education Health and Care plans in England: A local picture with global implications, *Research in Developmental Disabilities*, 86, 41–52.



- Chandroo, R., Strnadová, I. & Cumming, T. M. (2018) A systematic review of the involvement of students with autism spectrum disorder in the transition planning process: Need for voice and empowerment, *Research in Developmental Disabilities*, 83, 8–17.
- Chiang, H. M., Cheung, Y. K., Hickson, L., Xiang, R. & Tsai, L. Y. (2012) Predictive factors of participation in postsecondary education for high school leavers with autism, *Journal of Autism and Developmental Disorders*, 42(5), 685–696.
- Chiang, H. M., Cheung, Y. K., Li, H. & Tsai, L. Y. (2013) Factors associated with participation in employment for high school leavers with autism, *Journal of Autism and Developmental Disorders*, 43(8), 1832–1842.
- Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A. & Hill, E. L. (2018) Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals, *Journal of Autism and Developmental Disorders*, 48(11), 3761–3772.
- Crane, L., Adams, F., Harper, G., Welch, J. & Pellicano, E. (2019) ‘Something needs to change’: Mental health experiences of young autistic adults in England, *Autism*, 23(2), 477–493.
- Crane, L., Davies, J., Fritz, A., O’Brien, S., Worsley, A. & Remington, A. (2021a) The transition to adulthood for autistic young people with additional learning needs: The views and experiences of education professionals in special schools, *British Journal of Special Education*. <https://doi.org/10.1111/1467-8578.12372>
- Crane, L., Davies, J., Fritz, A., O’Brien, S., Worsley, A. & Remington, A. (2021b) ‘I can’t say that anything has changed’: Parents’ views on the impact of the Children and Families Act 2014 on their autistic children as they transition to adulthood. Preprint. <https://doi.org/10.31219/osf.io/j7ayd>
- Cribb, S., Kenny, L. & Pellicano, E. (2019) ‘I definitely feel more in control of my life’: The perspectives of young autistic people and their parents on emerging adulthood, *Autism*, 23(7), 1765–1781.
- Department for Education (2014a) *Children and Families Act* (London, DfE).
- Department for Education (2014b) *The young person’s guide to the Children and Families Act 2014* (London, DfE).
- Department for Education and Department of Health (2015) *Special educational needs and disability code of practice: 0 to 25 years* (London, HMSO).
- Fabri, M., Andrews, P. C. S. & Pukki, H. K. (2016) Using design thinking to engage autistic students in participatory design of an online toolkit to help with transition into higher education, *Journal of Assistive Technologies*, 10(2), 102–114.
- Franklin, A., Brady, G. & Durell, S. (2018) *Defining quality and rights based Education, Health and Care Plans (EHCPs) for disabled children and young people* (Coventry, Coventry University).
- Gaona, C., Palikara, O. & Castro, S. (2019a) ‘I’m ready for a new chapter’: The voices of young people with autism spectrum disorder in transition to post-16 education and employment, *British Educational Research Journal*, 45(2), 340–355.
- Gaona, C., Castro, S. & Palikara, O. (2019b) The views and aspirations of young people with autism spectrum disorders and their provision in the new Education Health and Care plans in England, *Disability and Rehabilitation*, 42(23), 3383–3394.
- Gernsbacher, M. A. (2017) Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma, *Journal of Child Psychology and Psychiatry*, 58, 859–861.
- Goodall, C. (2018) ‘I felt closed in and like I couldn’t breathe’: A qualitative study exploring the mainstream educational experiences of autistic young people, *Autism & Developmental Language Impairments*, 3. <https://doi.org/10.1177/2396941518804407>.
- Guldberg, K. (2020) *Developing excellence in autism practice: Making a difference in education* (London, Routledge).
- Halsall, J., Clarke, C. & Crane, L. (2021) ‘Camouflaging’ by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators, *Autism*. <https://doi.org/10.1177/13623613211012819>.
- Hellawell, B. (2017) A review of parent–professional partnerships and some new obligations and concerns arising from the introduction of the SEND Code of Practice 2015, *British Journal of Special Education*, 44(4), 411–430.

- Hodges, A., Joosten, A., Bourke-Taylor, H. & Cordier, R. (2020) School participation: The shared perspectives of parents and educators of primary school students on the autism spectrum, *Research in Developmental Disabilities*, 97, 103550.
- Hoy, K., Parsons, S. & Kovshoff, H. (2018) Inclusive school practices supporting the primary to secondary transition for autistic children: Pupil, teacher, and parental perspectives, *Advances in Autism*, 4(4), 184–196.
- Hummerstone, H. & Parsons, S. (2020) What makes a good teacher? Comparing the perspectives of students on the autism spectrum and staff, *European Journal of Special Needs Education*. <https://doi.org/10.1080/08856257.2020.1783800>.
- Jegatheesan, B., Miller, P. J. & Fowler, S. A. (2010) Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families, *Focus on Autism and Other Developmental Disabilities*, 25(2), 98–109.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. & Pellicano, E. (2016) Which terms should be used to describe autism? Perspectives from the UK autism community, *Autism*, 20(4), 442–462.
- Kuo, A. A., Crapnell, T., Lau, L., Anderson, K. A. & Shattuck, P. (2018) Stakeholder perspectives on research and practice in autism and transition, *Pediatrics*, 141(4), S293–S299.
- Lalvani, P. (2012) Parents' participation in special education in the context of implicit educational ideologies and socioeconomic status, *Education and Training in Autism and Developmental Disabilities*, 47(4), 474–486.
- Makin, C., Hill, V. & Pellicano, E. (2017) The primary-to-secondary school transition for children on the autism spectrum: A multi-informant mixed-methods study, *Autism & Developmental Language Impairments*, 2. <https://doi.org/10.1177/2396941516684834>.
- Milton, D. E. (2012) On the ontological status of autism: The 'double empathy problem', *Disability & Society*, 27(6), 883–887.
- Milton, D., Heasman, B. & Sheppard, E. (2018) Double empathy, *Encyclopedia of Autism Spectrum Disorders*. [https://doi.org/10.1007/978-1-4614-6435-8\\_102273-1](https://doi.org/10.1007/978-1-4614-6435-8_102273-1).
- Mitchell, W. & Beresford, B. (2014) Young people with high-functioning autism and Asperger's syndrome planning for and anticipating the move to college: What supports a positive transition?, *British Journal of Special Education*, 41(2), 151–171.
- Norwich, B. (2014) Changing policy legislation and its effects on inclusive and special education: A perspective from England, *British Journal of Special Education*, 41(4), 403–425.
- Norwich, B. & Eaton, A. (2015) The new special educational needs (SEN) legislation in England and implications for services for children and young people with social, emotional and behavioural difficulties, *Journal of Emotional and Behavioural Difficulties*, 20(2), 1741–2692.
- Office for National Statistics. (2021, February 18). Outcomes for disabled people in the UK: 2020. Available online at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020> (accessed 14 July 2021).
- Palikara, O., Lindsay, G. & Dockrell, J. E. (2009) Voices of young people with a history of specific language impairment (SLI) in the first year of post-16 education, *International Journal of Language & Communication Disorders*, 44(1), 56–78.
- Palikara, O., Castro, S., Gaona, C. & Eirinaki, V. (2018) Capturing the voices of children in the Education Health and Care plans: Are we there yet?, *Frontiers in Education*, 3. <https://doi.org/10.3389/feduc.2018.00024>.
- Prime Minister's Strategy Unit (2005) *Improving the life chances of disabled people*. Available online at: <https://core.ac.uk/download/pdf/4156824.pdf> (accessed 14 July 2021).
- Reid, B. (2007) *Moving on up? Negotiating the transition to adulthood for young people with autism* (London, National Autistic Society).
- Robertson, C. (2012) Special educational needs and disability co-ordination in a changing policy landscape: Making sense of policy from a SENCo's perspective, *Support for Learning*, 27(2), 77–83.

- Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A. & Anderson, K. A. (2015) *National autism indicators report: Transition into young adulthood* (Philadelphia, PA, A. J. Drexel Autism Institute, Drexel University).
- Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T. & Ford, T. (2019) Selection bias on intellectual ability in autism research: A cross-sectional review and meta-analysis, *Molecular Autism*, 10(1), 1–10.
- Rydzewska, E. (2012) Destination unknown? Transition to adulthood for people with autism spectrum disorders, *British Journal of Special Education*, 39(2), 87–93.
- Sales, N. & Vincent, K. (2018) Strengths and limitations of the education, health and care plan process from a range of professional and family perspectives, *British Journal of Special Education*, 45(1), 61–80.
- Seaman, R. L. & Cannella-Malone, H. I. (2016) Vocational skills interventions for adults with autism spectrum disorder: A review of the literature, *Journal of Developmental and Physical Disabilities*, 28, 479–494.
- Singh, J. S. & Bunyak, G. (2019) Autism disparities: A systematic review and meta-ethnography of qualitative research, *Qualitative Health Research*, 29(6), 796–808.
- Spiers, G. (2015) Choice and caring: The experiences of parents supporting young people with autistic spectrum conditions as they move into adulthood, *Children & Society*, 29(6), 546–557.
- Stobbs, P. (2014) Chapter 3. Overview of previous national SEND achievements and their fit with current SEND policy directions, *Journal of Research in Special Educational Needs*, 14(2), 128–132.
- Taylor, J. L. & Seltzer, M. M. (2011) Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood, *Journal of Autism and Developmental Disorders*, 41(5), 566–574.
- Wehman, P., Schall, C., Carr, S., Targett, P., West, M. & Cifu, G. (2014) Transition from school to adulthood for youth with autism spectrum disorder: What we know and what we need to know, *Journal of Disability Policy Studies*, 25(1), 30–40.
- Wittemeyer, K., Cusack, J., Guldberg, K., Macnab, N., Howlin, P., Hastings, R. *et al.* (2011) *Educational provision and outcomes for people on the autism spectrum* (London, Autism Education Trust).
- Wood, R. (2021) Autism, intense interests and support in school: From wasted efforts to shared understandings, *Educational Review*, 73(1), 34–54.

## SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

**Appendix S1.** Survey Questions.

**Appendix S2.** Section One: About you.