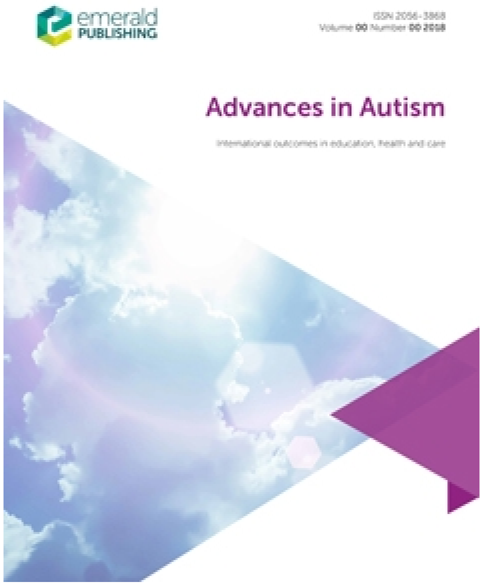
Mesa, Sue ORCID logoORCID: https://orcid.org/0000-0001-5933-3270 and Hamilton, Lorna G. ORCID logoORCID: https://orcid.org/0000-0003-0526-8252 (2021) "We are different, that's a fact, but they treat us like we're different-er": Understandings of autism and adolescent identity development. Advances in Autism.



"We are different, that's a fact, but they treat us like we're different-er": Understandings of autism and adolescent identity development.

Journal:	*Advances in Autism*
Manuscript ID	AIA-12-2020-0071.R1
Manuscript Type:	Research Paper
Keywords:	Autism, Identity, Qualitative research, Adolescent development, Schools

Introduction

Young people go through major biological, psychological and contextual changes in early adolescence, including puberty and the transition from primary to secondary education (Simmons & Blyth, 1987). The move into a larger, more complex school environment coincides with a key developmental period for identity construction, and typically an increased focus on the peer group over the family (Erikson, 1963; Kroger, 2004). For autistic young people, this developmental period may present challenges, as the social complexities of adolescence interact with the strengths and difficulties associated with autism (Humphrey & Lewis, 2008). For many, social communication and daily living skills develop markedly during this period (McGovern & Sigman, 2005; Smith, et al, 2012). However, research also indicates a heightened prevalence of mental health difficulties and poor quality of life in comparison with the general population (Cottenceau et al. 2012; Hebron & Humphrey, 2014; Simonoff et al. 2012). Further, in the UK context up to one in five autistic young people has been excluded from mainstream school on at least one occasion (Moore, 2016). During adolescence, increased awareness of difference and of the stigma attached to autism may contribute to negative outcomes for autistic young people (Humphrey & Lewis, 2008). The current study examines understandings of autism among autistic young people, their parents, and teachers, as they relate to identity construction and school experiences through the early years of mainstream secondary education.

A central concern of adolescence is the establishment of an individual identity; at the same time young people typically seek to fit in with recognised social and cultural groups (Blakemore & Mills, 2014; Kroger, 2004). The differences in social interaction characteristic of autism can lead to an assumption that identity is not a central concern and/or may be poorly developed. However, qualitative work indicates that autistic young people engage in identity construction within social contexts, positioning themselves in relation to cultural norms and expectations (Baines, 2012; Ringland, et al. 2016). In an interview study, while autistic adolescent boys often found self-description difficult, some described themselves in terms of core characteristics associated with autism (Cridland, at al. 2015a). In a participatory study, autistic teenagers articulated the complex ways in which their diagnosis shaped both personal and public identity (Morgensen & Mason, 2015). It appears, therefore, that identity construction is a concern for many autistic young people and that negotiating the idea of “being autistic” is an important part of this developmental process. Importantly, the ways in which others within the social environment orient to autistic individuals impacts identity negotiation (Bottema-Beutel & Smith, 2013; Ochs, et al. 2001).

Discourses of autism prevalent in the sociocultural contexts in which young people grow up are likely to influence identity construction (Brownlow, 2010). Within the medical model, autism is primarily conceptualised in terms of deficit with a focus on amelioration towards normative standards (see O’Neil, 2008 for a critique). The neurodiversity movement instead frames autism as integral to individual identity, highlighting the role of person-environment fit in the presentation of neurodevelopmental conditions (Baker, 2011). Both discourses are evident in the way young people talk about themselves (Humphrey & Lewis, 2008). Many autistic and non-autistic people appear to adopt a hybrid “deficit-as-difference" conception of autism (Kapp, et al. 2013). The terminology used to describe autism has seen a shift in recent years away from “person-first language” (e.g., person with autism) towards "identity-first" language (e.g., autistic person). Identity first language was indicated in a large-scale UK survey to be preferred by a majority of the autistic community (Kenny et al., 2016). For autistic young people, then, identity construction involves navigating multiple, often competing, discourses of autism.

Diagnosis of autism in the absence of intellectual disability is often not made until late childhood or beyond in the UK (Crane et al., 2015); individual responses to diagnosis are complex and likely to evolve over time. For young people and their families, diagnosis has several advantages, including access to support and increased understanding of difference from others. However, it can also lead to stigma and discrimination, and can be perceived as being of limited utility due to the heterogeneous presentation of autism (Calzada, et al. 2012). Asked to explain what autism meant to them, older autistic adolescents often framed the diagnosis as difficult to accept initially, with differing degrees of acceptance over time (Huws & Jones, 2008). The authors conclude that "whether being told that they had autism was perceived as a positive or negative event, it would appear that all participants had to some degree, reworked their identity" (Huws & Jones, 2008, p. 105). Some young people resist autism as a public identity, reluctant for their diagnosis to affect the way others perceive them, while accepting it as fundamental to personal identity (Morgensen & Mason, 2015). The decision as to whether, when and how to disclose diagnosis can therefore be complex; autism, once publicly disclosed, can be a "totalising" social identity, dominating other individual narratives (Gilling, 2012). However, autistic communities - often in online spaces- increasingly offer young people the opportunity to embrace autism as a positive collective identity (Bagatell, 2007; Brownlow, 2010; Ringland et al. 2016).

Young people's experiences at school shape identity development (Gilling, 2012; Humphrey & Lewis, 2008). In retrospective interviews, autistic young adults and their parents tended to describe the transition from childhood to adolescence as a stressful time, marked by ostracisation and bullying, as social demands increase within the school context (Portway & Johnson, 2003). A desire to avoid negative responses from others can lead young people to mask behaviours that could mark them out as autistic, a phenomenon known as "social camouflaging" that is associated with identity confusion and mental health difficulties (Cage & Troxwell-Whitman 2019; Cage, et al. 2018; Hull et al. 2021, Mandy, 2019). Increased understanding of autism in wider school communities is likely to reduce negative experiences for autistic pupils; however, access to specialist training for school staff is variable (Roberts & Simpson, 2016).

Studying the ways in which autistic young people understand their diagnosis and negotiate identity can inform understanding of mental health and wellbeing in this population. However, relatively few developmental studies of autism directly include the perspectives of autistic young people themselves (Rasmussen & Pagsberg, 2019). There is increasing acknowledgement in autism research of the need for qualitative studies that foreground the experiences of individuals (Bölte, 2014). The current study aimed to address the following research questions by triangulating interview data from young people, their parents, and teachers:

1. How do autistic young people and others in their social environments understand autism?
2. How do these understandings relate to young people's identity development in early adolescence?

3. How do these understandings relate to young people’s school experiences in mainstream settings?

Method

Ethical approval was granted from the School of XXX at XXX University (Approval Code: RECPSY00019).

Participants

The data reported here are drawn from an ongoing multi-informant longitudinal study investigating the school experiences of 14 autistic young people, between Year 6 (ages 10-11) and Year 9 (ages 13-14) in various mainstream educational settings in a city in the north of England. All families identified themselves as White British and socio-economic status using the National Statistics Socio-economic Classification categories, (ONS 2020) ranged from L3 higher professional occupations to L14.2 long-term unemployed. Families were recruited in three cohorts, via a specialist autism teaching team at the local council. Inclusion criteria were: (1) young person had a diagnosis of autism/Asperger’s Syndrome; and (2) was in a mainstream educational setting and about to transition (or had very recently transitioned) to secondary school.

Parents provided informed consent for their own and their child’s participation. Information on the study was also provided in age-appropriate written form and young people gave verbal assent to participate; one young person did not wish to take part in interviews at any time point. Parents and young people jointly identified a teacher who had worked closely with the young person in that academic year. The teacher provided their own consent.

In total we conducted 36 interviews with 13 children, 36 interviews with 31 teachers, and 38 interviews with 14 mothers and 2 fathers. Most families joined the study when their child was in Year 6; four joined shortly after transition to secondary school in Year 7. Table I summarises the demographic characteristics.

<Table I about here>

Data Collection Procedures

Semi-structured interviews were conducted with young people, their parent(s), and teachers, at annual intervals. Semi-structured interviews offer the flexibility to focus on the specific issues and experiences that are meaningful to individuals, within an overarching schedule informed by the research aims (Smith, 1995). In planning the interviews, we were guided by the recommendations set out by Cridland et al. (2015b) for conducting qualitative research with autistic individuals and their families. For example, we prepared clear interview guides that were differentiated by participant (young person, parent, teacher) and school year group, focusing on key domains of daily lives at school (e.g., classroom learning, peer interactions, physical school environment). Young people were given the option of participating in interviews with or without a familiar adult present, in order to mitigate the unfamiliarity of the situation. Young people and parents were interviewed in the family home, school setting, or university according to preference; all teachers were interviewed in the school setting. Interviews were conducted by researchers with experience of working with autistic young people (Cridland et al., 2015b).

In interviews with young people, we took care to phrase questions in an age-appropriate manner, avoiding non-literal language. The mean interview time for young people was 23 minutes, for teachers, 19 minutes and parents, 34 minutes. Interviews were audio-recorded and transcribed verbatim using standard orthographic transcription by research assistants. All identifying information was redacted from interview transcripts.

Data Analytic Approach

We analysed the data using inductive thematic analysis with the aim of giving an account of the individual experiences of the young people and the meaning that they, their parents and teachers attach to those experiences. We adopted a contextualist analytic approach, foregrounding the impact of the social contexts in which the young people live – specifically family homes, school environments and broader sociocultural context – on these experiences and understandings (Braun & Clarke, 2013; Tebes, 2005). Contextualism takes a middle ground between strong essentialist and constructionist epistemological positions. It acknowledges that, while individual experience is inevitably subject to interpretation and therefore not an objective “reality”, it nonetheless appears “real” to the individual (Willig, 2008).

We adopted the protocol for conducting thematic analysis set out by Braun and Clarke (2006). Both authors listened to audio recordings of interviews repeatedly, and iteratively read accompanying transcripts, taking note of ideas and comparing notes regularly. We generated initial codes systematically across the full dataset, reviewing each other’s coding and resolving disagreements through discussion. At this stage, we extracted those sections of the full dataset containing codes that were relevant to the research questions for the current study. We then began the process of collating codes that were identical or closely related from across the reduced dataset into initial themes, using a thematic map to visualise the analysis.

We identified provisional sub-themes that were supported by a limited amount of data and either discarded them, or integrated with other, related themes. When refining the themes, we re-read the interview data, to identify disconfirming cases and ensure that the thematic structure adequately reflected the whole dataset. We named the themes and sub-themes, developed working definitions of their meaning, and analysed the data assigned to each theme in further depth, integrating insights from existing research literature to our analysis. At the final stage, we identified excerpts from the data to illustrate the thematic structure of our analysis.

Analysis

An overview of the thematic structure is presented in Figure 1. Throughout the analysis, pseudonyms are used (see Table 1) and the time point at which the interview was conducted is indicated in brackets (e.g., Y6 = Year 6).

<Figure 1 about here>

Theme 1: Identifying with Autism

1a: Negotiating difference

Almost all participants identified feeling ‘different. For some, an autism diagnosis had been exonerating in explaining the basis of their perceived difference and they had positively integrated the idea of ‘being autistic’ into their personal identity. Jenny (Y6) said “*everything sort of like clicked”,* explaining further:

> *“I’d rather be different and have a reason for it, than not be different. I’d rather be different and have a label for it, because a lot of people say labels are a bad thing.… I like being labelled autistic, I don’t know why… Because it’s the reason why I am who I am.”* (Jenny, Y6)

In describing their experiences of difference, some young people drew on an autistic group identity. Lee (Y7) used the phrases “*the autism people*” and “*people like me*”. Identification with other autistic young people helped them make sense of their difference favourably, at least to some extent:

> *“Well me and my friend [name], we’re quite different [from others]. We don’t really like storybooks; we prefer fact books and statistics. And we’re really similar and we almost feel as if we’re outcasts, but we also feel really good because we’re different and I like that.”* (Richard, Y6)

Some young people publicly identified as autistic, talking openly about their differences. Justin's parent (Y6) said, "*he owns it"* and that he had recently introduced himself with "*my name is Justin, I'm ten and I'm autistic*". Gerry's teacher (Y6) described how he had delivered a training session about autism to his peers at primary school and he had *"felt very proud of it as he was telling them about how he is".* Conversely, others perceived difference negatively:

> *"I think he's just struggling with the idea of having Asperger's as well. … He spoke to me for a long time last night saying how different he feels … He said to me I wish you had not told me."* (Tim's parent, Y7)

Likewise, Jonathan's parent (Y6) described him wanting to "*be like anybody else, he doesn't want the label".* This was described further:

> *"We have to call it the 'A'…You cannot mention the word autism at all times, or he'll just start shouting and kicking off".* (Jonathan's parent, Y6)

Despite differing responses to diagnosis, a commonality was the desire to be treated as 'mainstream', like everyone else. Jenny (Y6) said, *"I want to be treated like normal. I don't want to be treated like there is something, like I have Asperger's".*

Several young people had declined support at school, including additional transition visits, use of identified inclusion spaces, and teaching assistant support, sometimes with acknowledgement that it would have been helpful. David's parent (Y7) said he had told his teaching assistant to "*go away*", because he felt support identified him as being different and "*made him look weak*". Archie (Y7) felt that accepting support would *"probably ruin my already practically non-existent social standing even further".* Parents and teachers reported further examples of young people's reluctance to accept support:

> *"There was an option for him to have a locker within the [specialised autism] unit and he chose to have that and very quickly decided he didn't want to. He didn't want to be different"*. (Tim's parent, Y7)

...

> *"I see this with a number of young people I work with, where they recognise their own differences and they don't want to look any different. And they are a really tricky group of young people to work with, because any strategies you try to put in place to support them, they perceive as making themselves look different so they are unwilling to engage."* (Simon's Specialist Autism Teacher, Y8)

1b: Changing understandings over time

The meanings young people attached to the diagnostic label changed over time. Some were described as having sudden points of realisation; others showed increasing or decreasing acceptance of 'being autistic' with age. Jonathan's parent (Y6) reported that he was initially accepting of the diagnosis but has since "*realised*" and had become "*embarrassed*". Likewise, his teacher identified a change when they started planning for secondary school transition:

> *"Understanding autism, that's the thing that, Year 6 it's suddenly hit him. He has had quite out-of-the-blue meltdowns, crying proper tears… which we've never seen before… He's expressed he doesn't understand why he got this, why he has caught this and we've explained that he hasn't caught anything ... everybody is special and unique and you too. So we've had to read books about famous people who are autistic who've actually made great things of*

> *their lives….I think it has just dawned on him now that this is not going away, I've got this forever'* (Jonathan's teacher, Y6)

In Y7, Jonathan had been uncomfortable being referred to as 'autistic', but when asked about his diagnosis in Y8 said "*Yeah, I'm getting there … I'm 50%*". Conversely, Jenny had shared her diagnosis in Y7 but felt she had consequently been treated differently, and in Y9 she reported she had made a new friendship group, from whom she had chosen to keep her diagnosis hidden.

Adults tried to support acceptance of diagnosis by presenting autism as an inherent part of the person, or by framing difference in a constructive way. Jonathan's parent (Y7) said she kept reiterating to him that autism is "*who you are. That's just your personality".* Simon's teacher used the analogy of different operating systems attributed to neurodiversity advocate, Steve Silberman (2016):

> "*I explain that it's just like two different brains, one is like a Microsoft computer and one is an Apple computer, and you all get the same outcomes but it's just that you think differently."* (Simon's teacher, Y7)

...

Justin's parent (Y6) reflected that acceptance and understanding of autism was a family project. As a family, they had bought books and been to talks as "*it affects us all'* and *"it's sort of like a learning curve for all of us".*

1c: Social camouflaging at school

Many young people, even those who construed their diagnosis positively, were keen to keep it private. Parents reported that their child would 'act' at school in order to convince others that they were 'like everybody else'. They also described the impact of camouflaging at school on emotional wellbeing and behaviour. Justin's parent (Y6) said “*because he has held it together all day at school, when he is home, he is a total wreck”.* Other parents also described distressed behaviour:

> *“He is storing it up and he is controlling himself and managing himself and by the time he gets home his self-management is lost and the smallest thing, you know if that fell on the floor, that would be enough for a flying rage,”* (Alistair's parent, Y6)
>
> ...
>
> *“He acts fine, so he goes under the radar a lot, so they actually find him ‘normal’ to a degree and then he comes home, and everything basically erupts.”* (Jonathan’s parent Y8).

Some teachers were aware that there were differences in how young people presented at school and home but, in contrast to parents, did not identify the school environment as a stressor:

> *“From my experience I’ve got several students at school who present really well at school, and then they go home and it’s absolutely chaotic.... You know, it could be the stress that we’re minimising, that kind of all floods out.”* Simon’s teacher (Y7).

In Y8, following exclusion from school, Simon’s teacher expressed surprise that suddenly things “*seemed to go pear-shaped*" as staff had thought he was managing well and had planned to reduce support. However, during the previous year Simon’s parent (Y7) had described him being “*really reclusive ...[he] just locks himself away in his bedroom”* after school. Simon’s case illustrates how social camouflaging can contribute to poor wellbeing and educational outcomes for young people; staff in Simon's school environment were unaware of the challenges he was experiencing in Y7 and reported that his transition from primary school had gone 'really well'. By Y8 Simon had moved to a specialist educational setting after several exclusions from his mainstream school.

Many young people preferred to keep home and school clearly separated. Young people could 'be themselves' at home, but homework blurred the home/school boundary. Richard (Y7) said "*I think maybe we should add 20 minutes to school or something instead … It makes me feel angry … It makes me feel like I'm at school. I think when you're at home it should mean you're at home."* Bertie's parent (Y9) reported that he would "*have a 25-minute meltdown over a 15-minute piece of homework."*

Some children extended this self-imposed boundary to friendships. Evan's parent (Y7) said, "*I mentioned to him about if there is anyone he'd like to invite round and he said he would not want to do that, that this was a different place and a different environment, that he would not want to mix them".* They had understood this in the context of Evan being 'secretive' about his special interests and his desire to keep precious possessions hidden, as "*he doesn't want [peers] to see all that and know all that about him".* Taken together, these accounts suggest that young people often experience the home environment as a sanctuary, where the 'mask' worn at school, under social pressure to 'fit in', can be dropped.

Theme 2: Social construction of autism

2a: The autism label

Parents talked about autism as a ‘label’ which provided a route to support, but was perceived negatively by others, leading to adverse consequences for young people. For some, this had made the decision to seek diagnosis difficult:

> *“We had reservations about going through the process of diagnosis. Yes, I know that ... he can access services and things and if people understand then they can make accommodations for him, but there are negative things that come with a diagnosis as well. It’s a label and you know.... is he going to be treated differently because of that?”* Evan’s parent (Y6)

Neurotypical peers were described as viewing autism unfavorably. Sometimes awareness of the diagnosis, or that the young person accessed support, resulted in bullying. Richard (Y7) said “*the autism people at [secondary school] are a bit targets to bullies,”* and Bertie (Y8) said “*They call me [autism unit name]. Sometimes they say get back to the [autism unit] and I just don’t really like it.”* Jonathan reported bullying had intensified in Y9, and he felt it happened because people saw him as *“freaky and they are just the type of people that hate different.”*

Parents had concerns about whether the diagnostic label negatively influenced teacher assessment of academic ability. Related to her school record Jenny’s parent (Y7) said, “*I hope it doesn’t say autistic or Asperger’s and they’ve just immediately blackmarked her.”* A teaching assistant for Richard (Y8) reported that they had to advocate for him to be moved up an academic set, as he had been placed in an insufficiently challenging class, which they attributed to his diagnosis. Jenny (Y9) said that some teachers had lower expectations of her compared to her peers. She explained further:

Jenny: *"They treat me like a cute cat ... They treat us like we're not human, like we're less, I don't know how to put it really."*

Researcher: *"That they treat you differently to other children?"*

Jenny: *"Yeah like ... we are different, that's a fact, but they treat us like we're different-er. Like we're more different to other people than we actually are."*

Some parents and teachers reported being mindful that the provision of support could have adverse consequences for inclusion. Jonathan's teacher (Y7), referring to small group teaching, said, "*they almost become defined by it."* Bertie's parent (Y7) reported school staff had tried to reduce his use of ear defenders so that he stood out less. Likewise, Gerry's teacher (Y6) said, *"If he's got someone with him and if he's got toys, I think he'll get picked on. It's the nature of children, isn't it?"*

Parents' concern about the impact of labelling influenced their choices about their child's education more broadly. Jonathan's parent (Y7) when discussing the option of a school that offered autism enhanced provision said that they "*wouldn't dream of putting him there,"* as they did not want him to be treated differently. Similarly, Evan's parents (Y6) declined a residential school trip as it "*might kind of expose his differences."*

Adults often constructed autism hierarchically based on perceived severity, contrasting 'extreme autism' with Asperger's Syndrome, which was referred to as 'mild'. Evan's parent (Y6) reflected that Evan, who had a diagnosis of Asperger's Syndrome, would have been considered just "*a bit of a geek"* in previous generations. Several parents highlighted their child was 'not as autistic' as others: "*She's not on the major spectrum... She's on the lower spectrum."* (Jenny's parent, Y8). In contrast, neurotypical children were often referred to as 'normal'.

2b: Individuality and sameness in autism

Autism was presented as highly variable, but participants also anticipated there would be a degree of commonality among autistic young people, with some referred to as 'typically autistic'. In developing their own understanding of autism, some parents tried to distinguish behavior that was 'typically autistic':

> *"It is difficult to know what is autism and what is him just being an eleven-year-old boy."* (Simon's parent, Y6)

Where a young person did not present as 'typically autistic', there were expressions of doubt about the validity of the diagnosis. David's parent (Y7) reported that teachers did not believe he was autistic, which prevented access to a timely diagnostic assessment. Correspondingly, following Simon's exclusion from school in Y8, his teacher reflected that "*he didn't display at all as being autistic. He seemed very sociable, mixed with his friends … and I was saying 'are we sure he is autistic?'"*

Despite the variability in presentation, several teachers felt autism as a category was 'so well defined,' which facilitated identification of support strategies. However, the need for teachers to see autistic young people as individuals was stressed by parents and specialist teachers:

> *"They said oh there's another autistic child in the class, we're used to autism, but every autistic child is unique, and they never got his uniqueness." (David's parent, Y7)*

…

> *"It would be nice to put it in a little box and say right this is how this child with autism presents but it's never like that ... 'Oh yeah we've had an autistic child before its fine'. You think, you've not had that one, it's not the same, you know you would never say that about a neurotypical child."* (Simon's Specialist Autism Teacher, Y8)

Parents discussed the potential benefits of autistic young people interacting with each other at school, because they would be similar:

> "*I think it will also be nice for him to be around other children which are autistic, because at the moment he's the only one... He's not used to being around other people like him."* (Gerry's parent Y6)

Discussion

This study examined understandings of autism among autistic young people, their parents, and teachers, related to identity construction and school experiences. For the young people in this study, understanding what ‘being autistic’ meant and their acceptance of it, changed and unfolded in the broader context of their early adolescent development as they ‘grew up’ with the diagnosis (Hurlbutt & Chalmers, 2002; Huws & Chalmers, 2015). The extent to which ‘autism’ was integrated into their developing identities was mediated by the responses of others in their social environments (Bagatell, 2007; Humphrey & Lewis, 2008).

In describing themselves, young people used terminology aligned with prevalent socio-cultural discourses of autism - both medical and neurodiversity models- often in overlapping ways (Humphrey & Lewis, 2008; Kapp et al. 2013). The idea of ‘normality’ was used as a benchmark from which young people described themselves as deviating. Difference was conceptualised negatively by many, a finding consistent with other studies of autism (Hebron & Humphrey, 2014; Humphrey & Lewis, 2008), but also characteristic of the desire to fit in associated with early adolescent development more broadly (Blakemore & Mills, 2014). ‘Normal’ and ‘different’ were largely presented as binary categories, with both autistic and neurotypical people characterised as homogenous groups. In this sense, autism was sometimes understood as a ‘totalising identity’ (Gilling, 2012), with limited appreciation of the multiple layers of difference and similarity between individuals.

Autism was similarly a ‘totalising identity’ for teachers, who assumed that autistic young people would be a relatively homogenous group with similar support needs and sometimes doubted the validity of the diagnosis if the person did not present as expected. Contrastingly, parents and specialist teachers identified the need for teachers to see each young person's individuality (see also Larcombe et al., 2019) This discrepancy suggests that some teachers lack understanding of the heterogenous nature of autism and have limited expertise to offer individualised support (Larcombe et al. 2019; Van Herwegen et al. 2019). In the absence of sufficient knowledge, they sometimes draw upon societal stereotypes about how autistic people behave (Humphrey & Lewis, 2008).

Participants described teachers as sometimes underestimating young people’s abilities and typically developing peers as responding to the autism label in more overtly negative ways (Baines, 2012; Mogensen & Mason, 2015). Congruent with other studies several had experienced bullying (Hebron & Humphrey, 2014; Humphrey & Lewis, 2008). Research suggests bullying is associated with limited understanding of autism (Larcombe et al. 2019; Symes & Humphrey, 2012), an example of the ‘double empathy problem’ (Milton, 2012).

Several young people, engaged in social camouflaging to avoid ‘appearing autistic’ at school (Huws & Jones, 2015; Mogensen & Mason, 2015). Research suggests that social camouflaging is a response to stigma and is used to avoid bullying and discrimination, but is costly to mental health (Hull et al., 2017, Cage & Troxell-Whitman, 2019; Hull et al. 2021). Consistent with this, parents in this study, described how social camouflaging took a toll on young people’s mental health, and it is notable that a third of the young people were excluded from school following behavioural misdemeanours and/or referred to mental health services. Keen at al. (2016) identified that mental health difficulties in autistic young people are associated with poorer educational outcomes. These findings therefore underline the importance of increased awareness of social camouflaging in school as part of efforts to increase positive educational outcomes (Mandy, 2019) and improve mental health.

Cooper et al. (2017) suggest that opportunities to experience group belonging and develop a positive social identity may offer protection against mental health difficulties. Parents in this study discussed the perceived benefits of autistic young people interacting in school, to develop a group identity and some young people positively discussed their shared difference with autistic friends. Stevenson et al. (2016) found that facilitating opportunities for autistic young people in a special school, to reflect on their diagnosis together, helped develop understanding of autism as a difference to be accepted, which ‘thickened’ their identity. However, our study raises the question of whether such peer support mechanisms could be facilitated in mainstream settings, where young people may be reluctant to engage with activities that makes their difference visible.

Parents and teachers in this study, also seem to be negotiating the competing socio-cultural discourses of autism (Baron-Cohen, 2019; Kapp et al., 2015). They positioned ‘difference’ positively, but like young people, also used language that indirectly, and likely unintentionally, communicated negative conceptualisations of autism. For example, when parents refer to neurotypical children as ‘normal,’ the young person might infer that they are ‘abnormal.’ Similarly, when parents express concern that engaging in extracurricular school activities or accessing specialist support may expose their child's ‘difference,’ this may inadvertently suggest that difference is better hidden. Several parents also described autism hierarchically, positioning their child on a scale as ‘not as autistic as others’. While the intention may be to support children to perceive their diagnosis more favourably, it could reinforce the idea that being ‘more’ autistic is undesirable.

Many of these examples can be understood as parents seeking to protect their child. However, it is possible that the conflicted messages result in unintentional pressure for young people to ‘act normally’ and camouflage their difference (Bagatell, 2007). Parents are similarly subject to and part of a neurotypically-dominated social world, in which negative characteristics associated with autism are foregrounded and positive attributes hidden (Brownlow, 2010). Post-diagnostic support in the UK has been identified by families and professionals as inadequate (Crane et al 2016; Crane et al 2018; Rogers et al., 2016), which leaves parents limited opportunity to explore the diagnosis, its impact on their family, and ways to talk about difference. Perhaps then, opportunities for young people to reflect on their diagnosis should extend to parents too.

There were examples of teacher interventions that could also encourage social camouflaging. Attempts to limit the use of successful supports such as ear defenders and fiddle toys in order to reduce the visibility of difference, indirectly communicates that difference is undesirable. Whilst these interventions aim to safeguard young people from difficulties with neurotypical peers, the focus on changing the behaviour or appearance of the autistic person to help them ‘fit in,’ originates from a deficit-orientated perspective (Brownlow, 2010).

An alternative approach would be grounded in the social model of disability (Oliver, 1990), situating the ‘problem’ with peer relationships within the wider social context. Interventions would focus on increasing understanding of autism and acceptance of diversity in the wider school community, which research indicates can promote more positive judgements (Sasson & Morrison, 2019). This may require a cultural shift for schools, which currently offer support mostly in the form of one-to-one classroom input. It would also require consideration of who facilitates whole-school interventions, given that demands on teachers are perennially high, they do not always know how to promote peer acceptance and inclusion (Lindsay et al., 2013) and autism training is not widely available (Roberts & Simpson, 2016).

Strengths of this study include its longitudinal design, which allows analysis of identity development and school experiences over time. The multi-informant data collection further enables consideration of young people's perspectives in relation to those of important others in their social environment. Limitations include a low response rate to recruitment letters (~10%) and consequent small sample, which included only one female adolescent. The school experiences discussed are specific to one local authority area in the north of England and should not be viewed as representative at a national level. However the analytic structure may be transferable to other studies. Finally, the dataset included some missing interviews (Table I) due to constraints on the time of participating families and teachers.

Conclusion

The current study enhances understanding of identity construction in young adolescents with autism and the influence of mainstream school experiences on this process. To promote positive identity development and wellbeing in autistic young people, two recommendations for further research and practice are made. School-based interventions could focus on the whole-school system to increase understanding of autism and acceptance of diversity, in order to promote a better person-environment fit for autistic young people. Extended post-diagnostic support for young people and families to include opportunities to reflect on the diagnosis with others, and exploration of the best ways to talk about autism is also recommended.

References

Bagatell, N. (2007), Orchestrating voices: Autism, identity, and the power of discourse. *Disability & Society,* Vol. *22* No.4, pp413-426. https://doi.org/10.1080/09687590701337967

Baines, A.D. (2012), Positioning, strategizing, and charming: How students with autism construct identities in relation to disability. *Disability & Society,* Vol. 27 No. 4, pp547-561. https://doi.org/10.1080/09687599.2012.662825

Baker, D.L. (2011), *The politics of neurodiversity: Why public policy matters.* Boulder, CO: Lynne Rienner.

Baron-Cohen, S. (2019), *The concept of Neurodiversity is dividing the autism community. It remains controversial – but it doesn't have to be*. Scientific American. https://blogs.scientificamerican.com/observations/the-concept-of-neurodiversity-is-dividing-the-autism-community/

Blakemore, S.-J., & Mills, K.L (2014), Is adolescence a sensitive period for sociocultural processing? *Annual Review of Psychology,* Vol.65, pp187-207. https://doi.org/10.1146/annurev-psych-010213-115202

Bottema-Beutel, K., & Smith, N. (2013), The interactional construction of identity: An adolescent with autism in interaction with peers. *Linguistics & Educatio*n, Vol 24, pp197-214. https://doi.org/10.1016/j.linged.2012.12.002

Braun, V., & Clarke, V. (2006), Using thematic analysis in psychology. *Qualitative Research in Psychology,* Vol. 3, pp77-101.

Braun, V., & Clarke, V. (2013), *Successful qualitative research: A practical guide for beginners.* London: Sage.

Brownlow, C. (2010), Presenting the self: Negotiating a label of autism. *Journal of Intellectual & Developmental Disability,* Vol. 35 No. 1, pp14-21. https://doi.org/10.3109/13668250903496336

Cage, E., Di Monaco, J. & Newell, V. (2018), Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism & Developmental Disorders,* Vol. 48, pp473-484. https://do.org/10.1007/s10803-017-3342-7

Cage, E., & Troxwell-Whitman, Z. (2019), Understanding the Reasons, Contexts and Costs of Camouflaging for Autistic Adults*. Journal of Autism and Developmental Disorders,* Vol. 49 No. 3, pp 1899-1911. https://doi.org/10.1007/s10803-018-03878-x

Carrington, S., & Graham, L. (2001), Perceptions of school by two teenage boys with Asperger syndrome and their mothers: a qualitative study. *Autism,* Vol. 5 No. 3, pp37-48. https://doi.org/10.1007/s10803-011-1238-5

Calzada, L.R., Pistrang, N., & Mandy, W.P.L. (2012), High-functioning Autism and Aspergers Disorder: Utility and Meaning for Families. *Journal of Autism and Developmental Disorders,* Vol. 42, pp230–243. https://doi.org/10.1007/s10803-011-1238-5

Cooper, K, Smith, LGE & Russell, A (2017), 'Social Identity, Self-Esteem, and Mental Health in Autism', *European Journal of Social Psychology*, Vol. 47 No. 7, pp 844-854. https://doi.org/10.1002/ejsp.2297

Cottenceau, H., Roux, S., Blanc, R., Lenoir, P., Bonnet-Brilhault, F., & Barthélémy, C. (2012), Quality of life of adolescents with autism spectrum disorders: Comparison to adolescents with diabetes. *European Child & Adolescent Psychiatry,* Vol. 21 No. 5, pp289–296. https://doi.org/10.1007/s00787-012-0263-z

Crane, L., Chester, J.W., Goddard, L., Henry, L.A., & Hill, E. (2015), Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism,* Vol. 20 No.2, pp53-162. https://doi.org/10.1177/1362361315573636

Crane, L., Chester, J., Goddard, L., Henry, L.A., Hill, E.L. (2016), Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: The International Journal of Research and Practice.* Vol. 20 No. 2, pp153–162. https://doi.org/10.1177/1362361315573636

Crane, L,. Batty, R,. Adeyinka, H., Goddard, L,. Henry, L., & Hill, E.L. (2018), Autism diagnosis in the United Kingdom: perspectives of autistic adults, parents and professionals. *Journal of autism and developmental disorders.* Vol. 48 No. 11, pp3761-3772. https://doi.org/10.1007/s10803-018-3639-1

Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A. (2015a), The perceptions and experiences of adolescent boys with autism spectrum disorder: A personal construct psychology perspective. *Journal of Intellectual & Developmental Disability,* Vol. 30 No. 4, pp354-367. https://doi.org/10.3109/13668250.2015.1070814

Cridland, E.K., Caputi, P., Jones, S.C., & Magee, C.A. (2015b). Qualitative research with families living with autism spectrum disorder: Recommendations for conducting semistructured interviews. *Journal of Intellectual & Developmental Disability,* Vol. 20 No. 1, pp 78-91. https://doi.org/10.3109/13668250.2014.964191

Dillon, G., & Underwood, J. (2012), Parental perspectives of students with autism spectrum disorders transitioning from primary to secondary school in the United Kingdom. *Focus on Autism and Other Developmental Disabilities*, Vol. 27, pp111–121 https://doi.org/10.1177/1088357612441827

Erikson, E.H. (1963). Youth: Fidelity and diversity. In E.H. Erikson (Ed.). *Youth: Change and challenge* (pp1-23). New York: Basic Books Inc.

Gilling, J. (2012). "When powerfulness isn't so helpful": Callum's relationship with autism. *Educational & Child Psychology,* Vol. 29 No. 2, pp32-40.

Hebron, J., & Humphrey, N. (2014). Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: A comparative study. *Journal of Research in Special Educational Needs,* Vol. 13 No 1, pp22-32. https://doi.org/10.1111/j.1471-3802.2012.01246.x

Humphrey, N., & Lewis, S. (2008). 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism,* Vol. 12 No. 1, pp23-46. https://doi.org/10.1177/1362361307085267

Hurlbutt K, & Chalmers L. (2002) Adults With Autism Speak Out: Perceptions of Their Life Experiences. *Focus on Autism and Other Developmental Disabilities*. Vol. 17 NO. 2, pp103-111. https://doi.org/10.1177/10883576020170020501

Huws, J.C., & Jones, R.S.P. (2008), Diagnosis, disclosure, and having autism: an interpretive phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual Disabilty.* Vol. 33 No. 2, pp99-107. https://doi.org/10.1080/13668250802010394

Huws, J.C., & Jones, R.S.P. (2015), 'I'm really glad this is developmental': Autism and social comparisons – an interpretative phenomenological analysis. Autism, Vol. 19 No. 1, pp84-90. https://doi.org/10.1177/1362361313512426

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017), "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. Journal of Autism and Developmental Disorders, Vol. 47 No. 8, pp2519– 2534. https://doi.org/10.1007/s10803-017-3166-5

Hull, L., Levy. L,. Lai., M,. Petrides. K.V., Baron-Cohen, S., Allison, C., Smith, P., & Mandy, W. (2021). Is Social Camouflaging associated with anziety and depression in autistic adults? Molecular Autism. Vol. 12. https://doi.org/10.1186/s13229-021-00421-1

Kapp, S.K., GIllespie-Lynch, K., Sherman, L.E., & Hutman, T. (2013), Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology,* Vol. 49 No. 1, pp59-71. https://doi.org/10.1037/a0028353

Keen, D., Webster, A., Ridley. G., (2016) How well are children with autism spectrum disorder doing academically at school? An overview of the literature. *Autism,* Vol. 20, No. 3, pp 276–94. https://doi.org/10.1177%2F1362361315580962

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,* Vol. 20 No. 4, pp442 - 462. https://doi.org/10.1177/1362361315588200

Kroger, J. (2004). *Identity in adolescence: The balance between the self and other.* New York: Routledge.

Larcombe, T.J., , T.J., Joosten, A.V., Cordier, R. & Vaz, S. (2019), Preparing children with autism for transition to mainstream school and perspectives on supporting positive school experiences. *Journal of Autism and Developmental Disorders.* Vol. 49, pp3073-3088. https://doi.org/10.1007/s10803-019-04022-z

Lindsay, S., Proulx, M., Thompson, N., & Scott, H. (2013), Educators' challenges of including children with autism spectrum disorders in mainstream classrooms. *International Journal of Disability, Development and Education.* Vol. 60, pp374-362. https://doi.org/10.1080/1034912X.2013.846470

Mandy, W. (2019). Social camouflaging in autism: Is it time to lose the mask? *Autism,* Vol. 23 No.8, pp1879-1881. https://doi.org/10.1177/1362361319878559

McGovern, C.W., & Sigman, M. (2005), Continuity and change from early childhood to adolescence in autism. *Journal of Child Psychology & Psychiatry,* Vol 46 No. 4, pp401-408. https://doi.org/10.1111/j.1469-7610.2004.00361.x

Milton, D. 2012. “On the Ontological Status of Autism: The ‘Double Empathy Problem’.” *Disability and Society Vol. 27 No. 6,* pp883–887 https://doi.org/10.1080/09687599.2012.710008

Moore, C. (2016). *School report, 2016.* London: The National Autistic Society.

Morgeson, L., & Mason, J. (2015), The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder. *Sociology of Health & Illness, Vol. 37 No.* 2, pp255-269. https://doi.org/10.1111/1467-9566.12208

Office of National Statistics (2020). *SOC 2020 Volume 3: The National Statistics Socio-economic Classification.* ONS

https://www.ons.gov.uk/methodology/classificationsandstandards/standardoccupationalclassificationsoc/soc2020/soc2020volume3thenationalstatisticssocioeconomicclassificationnssecrebasedonthesoc2020#category-descriptions-and-operational-issues

Ochs, E., Kremler-Sadlik, T., Solomon, O., & Sirota, K.G. (2001).,Inclusion as social practice: Views of children with autism. *Social Development,* Vol. 10 No 3, pp399-419. https://doi.org/10.1111/1467-9507.00172

Oliver M (1990) *The Politics of Disablement*. London: Macmillan Publishers.

O’Neil, S. (2008), The meaning of autism: Beyond disorder. Disability & Society, Vol*. 23 No* 7, 787-799. https://doi.org/10.1080/09687590802469289

Portway, S., & Johnson, B. (2003), Asperger syndrome and the children who ‘don’t quite fit.’ *Early Child Development & Care,* Vol. 173 No 4, pp 435-443. https://doi.org/10.1080/0300443032000079113

Rasmussen, P.S., & Pagsberg, A.K. (2019), Customizing methodological approaches in qualitative research on vulnerable children with autism spectrum disorder. *Societies, Vol. 9 No. 4,* p75. https://doi.org/10.3390/soc9040075

Ringland, K.E., Wolf, C.T., Faucett, H., Dombrowski, L., & Hayes, G.R. (2016),“Will I always be not social?”: Re-conceptualising sociability in the context of a Minecraft community for autism. *CHI ‘16: Proceedings of the 2016 Conference on Human Factors in Computing Systems, pp*1256-1267. https://doi.org/10.1145/2858036.2858038

Rogers, C., Goddard, L., Hill, E.L., Henry, L.A., Crane, L. (2016), Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom. *Autism: The International Journal of Research and Practice.* Vol. 20 No. 7, pp820–831 https://doi.org/10.1177/1362361315611109

Roberts, J., & Simpson, K. (2016), A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education,* Vol. 20 No. 10, pp1084-1096. https://doi.org/10.1080/13603116.2016.1145267

Sasson, N. J., & Morrison, K. E. (2019), First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. Autism, Vol. 23 No. 1, pp50–59. https://doi.org/10.1177/1362361317729526

Silberman, S. (2016). NeuroTribes: *The legacy of Autism and how to think smarter about people who think differently.* Crows Nest Australia: Allen and Unwin.

Simonoff, E., Jones, C.R.G., Pickles, A., Happé, F., Baird, G., & Charman, T., (2012), Severe mood problems in adolescents with autism spectrum disorder. *Journal of Child Psychology & Psychiatry,* Vol. 53 No. 11, pp1157 - 1166. https://doi.org/10.1111/j.1469-7610.2012.02600.x

Simmons, R.G., & Blyth, D.A. (1987). *Moving into adolescence: The impact of pubertal change and school context.* New York: Aldine de Gruyter.

Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harré, & L. Van Langenhove (Eds.), *Rethinking methods in psychology* (pp9-26). London: Sage.

Smith, L.E., Maenner, M.J., & Seltzer, M.M. (2012), Developmental trajectories in adolescents and adults with autism: The case of daily living skills. *Journal of the American Academy of Child & Adolescent Psychiatry, Vol. 51 No.* 6, pp622-631.

https://doi.org/10.1016/j.jaac.2012.03.001

Stevenson, K., Cornell, K., & Hinchcliffe, V. (2016), ‘Let's Talk Autism’ - a school-based project for students to explore and share their experiences of being autistic. *Support for Learning,* Vol. 31 No.3, pp208-234. https://doi.org/10.1111/1467-9604.12130

Symes, W,. & Humphrey, N. (2012), Including pupils with autistic spectrum disorders in the classroom: The role of the teaching assistants. *European Journal of Special Needs Education*. Vol. 27, pp517-532.

https://doi.org/10.1080/08856257.2012.726019

Tebes, J.K. (2005), Community science, philosophy of science, and the practice of research. *American Journal of Community Psychology,* Vol. *35*, pp213-230. https://doi.org/10.1007/s10464-005-3399-x

Van Herwegen, J., Ashworth, M., & Oalikara, A. (2019),Views of professionals about the educational needs of children with neurodevelopmental Disabilities. *Research in Developmental Disabilities. Vol.* 91, pp1-14.

https://doi.org/10.1016/j.ridd.2019.05.001

Willig, C. (2008), *Introducing qualitative research in psychology: Adventures in theory and method.* Buckingham: Open University Press.

Figure 1: Thematic Map

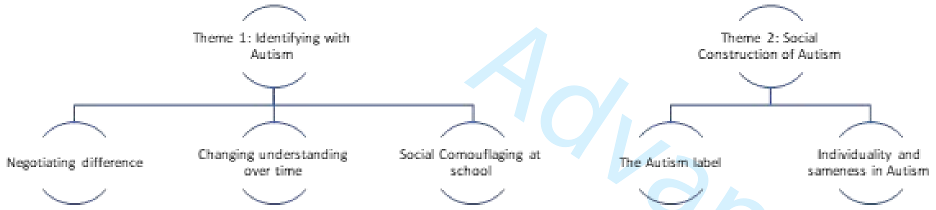


Table I: *Participant Characteristics*

Cohort	**Pseudonym**	**Gender**	**School years for which interview data available**	**Additional information**	**Parent/s interviewed**
1	Simon	M	Y7, Y8 *	Moved to a specialist education setting following school exclusions. Referred to mental health services.	Mother
1	Tim	M	Y7, Y8, Y9	Moved to a specialist education setting following school exclusions.	Mother
1	Bertie	M	Y7, Y8, Y9		Mother
2	Richard	M	Y6, Y7, Y8 *	Family unavailable in Y8. Teacher unavailable in Y7, Y9.	Mother
2	Jonathan	M	Y6, Y7, Y8, Y9	School exclusions. Referred to mental health services. Teacher unavailable in Y9.	Mother
2	Gerry	M	Y6, Y7, Y8 *		Mother
2	Jenny	F	Y6, Y7, Y8, Y9	Referred to mental health services. Teacher unavailable in Y9.	Mother and Father
3	Evan	M	Y6, Y7, Y8 *		Mother and Father
3	Justin	M	Y6, Y7, Y8 *		Mother
3	Jacob	M	Y6, Y7, Y8 *		Mother
3	Alistair	M	Y6, Y7, Y8 *		Mother
3	Lee	M	Y6, Y7, Y8 *		Mother
3	David	M	Y7, Y8 *	School exclusions. Teacher unavailable Y8.	Mother
3	Archie	M	Y7 *		Mother

*Data collection ongoing