Do autistic individuals experience understanding in school? A retrospective mixed-methods study.

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Abstract

Autistic pupils report negative school experiences in terms of peer and teacher relationships. One possible explanation could be a lack of understanding of the autistic pupil by classmates and teachers. We investigated autistic and non-autistic adults' perceptions of how well they were understood in school in a survey and interviews. The autistic group reported significantly less understanding from both classmates and teachers, and being significantly better understood by autistic peers than by non-autistic classmates. Semi-structured interviews revealed that having a diagnosis and shared interests with others facilitated understanding. Further resources are needed for pupils and teachers to better understand autistic pupils and this study points towards the potential value of providing opportunities for autistic pupils to be together.

Keywords: autism spectrum disorder; education; peer support; teachers; school experience

Despite the increasing number of pupils on the autism spectrum¹ now enrolled in mainstream schools, the inclusion process for this population is complex and poorly understood (Davis et al., 2004; Humphrey & Parkinson, 2006). Autistic children report poor quality teacher relationships (Al-Sharbati et al., 2015; Humphrey & Lewis, 2008a; 2008b) and these have been linked with higher rates of disruptive behaviour in the classroom (Robertson, Chamberlain & Kasari, 2003). Exclusion rates are twenty times higher for autistic than non-autistic pupils in the UK (Barnard, Prior & Potter, 2000). Many teachers report that they do not have the necessary training to support autistic pupils adequately (Lindsay, Proulx, Thomson & Scott, 2013; McGregor & Campbell, 2001). Perhaps as a result, high levels of anxiety and teacher burnout have been reported among mainstream teachers of autistic pupils (Barnard et al., 2000). Another key aspect is peer relationships. The available research shows that pupils on the autism spectrum have fewer friends (Humphrey & Symes, 2011) and experience higher levels of loneliness (Bauminger & Kasari, 2000) and more peer rejection compared with their non-autistic peers (Humphrey & Lewis, 2008a; 2008b; Symes & Humphrey, 2010). It is well established that peer isolation is a considerable risk factor for being bullied (Murray-Harvey & Slee, 2010). When compared with non-autistic peers and those with other special educational needs, autistic children typically experience higher levels of victimisation, including violence (Humphrey & Symes, 2010a; 2010b; Ung et al., 2016; Wainscot, Naylor, Sutcliffe & Williams, 2008).

Studies have reported that non-autistic adults judge the friendships of peers with high autistic traits as less satisfying and engage in more negative behaviours toward them (Faso, Corretti, Ackerman & Sasson 2016). Moreover, non-autistic people give more negative interpersonal ratings of autistic adults based on “thin slices” of information (Sasson et al., 2017; Stagg,

¹ Following Kenny et al. (2016) and Gernsbacher (2017) we use identity-first language or the phrase “on the autism spectrum” throughout this article.

Slavny, Hand, Cardoso & Smith, 2014). Emergent work also shows that non-autistic people struggle correctly to interpret the mental states, emotions and body language of autistic people (Cassidy, Mitchell, Chapman & Ropar, 2015; Sheppard, Pillai, Wong, Ropar & Mitchell, 2016). Thus, one possibility is that peer relations might be more positive when autistic pupils have the opportunity to socialise with other autistic people (Sinclair, 2010). No direct research has examined this, but one study conducted among 18-25 year old autistic adults revealed a common theme of ‘not quite fitting in’ which originated from the school years (Portway & Johnson, 2005).

Here we investigate, retrospectively, whether autistic people feel they were understood at school, specifically comparing their thoughts about autistic peers and non-autistic classmates, as well as how they were understood by teachers. We hypothesise that autistic adults will report lower levels of understanding from classmates and teachers, compared with non-autistic adults. We further hypothesise that autistic adults will report higher levels of understanding from autistic peers than from non-autistic classmates and teachers. Follow-up interviews in a sub-group of autistic people will explore the school experience in more depth.

Methods

Participants

Survey participants were 162 autistic and non-autistic adults, aged 18-89 years old (see Table 1). Within the autistic group, 51 participants reported having a diagnosis from a medical professional, while 15 participants self-identified as autistic. A sub-set of 13 survey respondents who volunteered for follow-up were later invited for interview. We selected people who were either recent or distant school leavers (see Table 2) in order to capture a spread of perspectives.

Table 1: Survey Participant Descriptives

		Total sample <i>n=162</i>	Non-autistic group <i>n=96</i>	Autistic group <i>n=66</i>
Gender <i>count</i>	Male	43	28	15
	Female	111	67	44
	Other*	8	1	7
Age <i>Mean (SD)</i> <i>Min-Max</i>		38.8 (14.0) 18-89	39.0 (15.2) 18 – 89	38.5 (12.1) 18 – 66

* other includes both “prefer not to say” and “not listed” gender categories

Table 2: Interview Participant Descriptives

		Total sample <i>n=13</i>	Recent school leavers <i>n=6</i>	Distant school leavers <i>n=7</i>
Gender <i>count</i>	Male	5	0	5
	Female	8	6	2
Age <i>Mean (SD)</i> <i>Min-Max</i>		40.4 (15.9) 18 – 65	25.8 (4.9) 18 – 31	52.9 (9.7) 40 – 65
Age at diagnosis <i>Mean (SD)</i> <i>Min-Max</i>		35.5 (16.5) 7 – 62	20.3 (16.9) 7 – 27	48.6 (7.9) 7 – 62
Education setting				
	Mainstream school	12	6	6
	Special school	0	0	0
	“It’s complicated” ^	1	0	1

^ This wording was provided in the survey to enable autistic people to report quickly and easily when their school experience did not fall neatly into either of the other categories provided.

Design

The survey analysis compared two groups of participants with and without an autism diagnosis. The dependent variables were ratings of understanding by three person-types: non-autistic classmates; teachers; and (for autistic participants only) autistic peers. Survey data were enriched by information about school experiences collected during the interviews.

Materials

The survey directed participants to reflect on their perceived experiences aged 14-15 years. There were four sections: 1) demographics, 2) understanding by non-autistic classmates, 3) understanding by teachers and 4) (autistic participants only) understanding by autistic peers. Sections 2-4 asked participants to respond to statements using a five-point rating scale from Definitely Agree to Definitely Disagree. Statements represented four types of understanding as follows: *I feel that other pupils in my school understood my emotions; I feel that other pupils in my school understood my actions; I feel that other pupils in my school responded positively towards me; I feel that other pupils in my school were helpful towards me.* The same statements were repeated for each person-type (classmates, teachers and peers). The “autistic peer” understanding category included a “Not applicable” answer section in case autistic participants had not known other autistic peers in school, which was coded as missing data.

The interview script (see Supplement) was designed to explore factors relating to the experience of being understood in school. Follow-up probes were used to help participants elaborate on their answers when required. Interviews were recorded on a Sony ICD-B140 4GB dictation machine before being transcribed. A debriefing form was emailed to participants at the end of the interview.

Procedure

Participants were recruited at [REMOVED FOR BLIND REVIEW] campus locations using posters, and online via autism-related websites and via Twitter. The survey was administered online and following completion of the survey, autistic participants were asked whether they wanted to take part in a follow-up interview. Participants who consented were interviewed either face-to-face or via Skype (we also offered a live webchat option but this was not used). The interview took between 30 and 60 minutes to complete.

Ethical approval was obtained from the [REMOVED FOR BLIND REVIEW] Ethics Committee. For both phases participants were required to reflect on their school experiences. It was emphasised that participants could withdraw at any time and information about suitable mental health and autism support organisations was provided.

Analysis Methods

We use the term “Classmate” when reporting all participants’ ratings of understanding by non-autistic pupils. We use the term “Peer” when reporting the autistic sample’s ratings of understanding by other autistic pupils.

Cronbach’s alphas were calculated for the four “understanding” statements in each person-type category: these ranged from .804 to .929 indicating very good internal reliability (Tavakol & Dennick, 2011; Vale, Silcock, Rawles & Vale, 1997). Ratings for each statement were summed to provide a total “understanding score” for each person-type (classmates, teachers and – where applicable – peers). The score ranged from 0-20 with higher scores representing greater perceptions of being understood. ANOVA and independent-samples t-tests were used to compare understanding between and within groups dependent on person-type. For autistic participants who gave ratings of Peer understanding, a one-way repeated measures ANOVA was used to analyse differences in understanding (non-autistic peers vs. autistic peers vs. teachers).

Interview transcripts were analysed using thematic analysis by the first author, following Braun and Clarke’s (2006) recommended six phases, with the aim of identifying patterns of information within the data without adopting a rigid theoretical framework for interpretation. Transcripts were annotated to provide initial codes, these were discussed with the last author and then combined into sub-themes and finally over-arching themes. Quotations from

participant transcripts are used to illustrate themes and related sub-themes. Y marks the quotes from recent autistic school leavers, and O marks those from older school leavers. The second letter stands for the participant ID: for example, “Y.A” represents a quote from a recent school leaver coded as participant A.

Results

Survey Results

A repeated-measures ANOVA on group (autistic vs. non-autistic) and person-type (Classmate vs Teacher) revealed a main effect of group, $F(1,160) = 128.32$, $p < .001$, $\eta^2 = .445$, such that autistic people reported less understanding on the whole, compared with non-autistic people. In addition, there was a main effect of person-type, $F(1,160) = 137.40$, $p < .001$, $\eta^2 = .097$, such that participants reported being less well understood by Classmates than by Teachers. There was no group by person-type interaction: both groups had a similar mean difference between their understanding ratings for Classmates and Teachers. Data are shown in Figure 1 below.

Follow-up independent t-tests were used to check whether autistic participants rated understanding more poorly for each person-type separately. These revealed a significant difference with a large effect size in reported understanding from Classmates, $t(169.056) = -11.039$, $p < .001$, $d = 1.7$, with lower understanding reported by the autistic group ($M = 7.34$, $SD = 3.23$), compared with the non-autistic group ($M = 13.66$, $SD = 4.28$). There was also a significant difference with a large effect size in reported understanding from Teachers $t(160) = -9.123$, $p < .001$, $d = 1.5$, which was again lower in the autistic group ($M = 8.82$, $SD = 4.10$), than the non-autistic group ($M = 14.67$, $SD = 3.95$).

Additional paired sample t-tests were conducted to compare ratings of Classmates versus Teachers, in each group separately. Autistic participants reported significantly less understanding from Classmates than from Teachers, $t(65) = -3.108$, $p < .01$. Likewise, non-autistic participants' reported significantly less understanding from Classmates than from Teachers, $t(95) = -2.613$, $p < .05$.

A sub-sample of the autistic group ($n = 28$) provided data on understanding by autistic Peers at school. A one-way repeated measures ANOVA on ratings of understanding by the autistic group only, revealed a significant main effect of Person-type, $F(2, 54) = 6.88$, $p < .01$, $\eta^2 = .203$. Follow up analyses revealed that Peers ($M = 11.32$) were reported as significantly more understanding than Classmates ($M = 7.89$; $p < .01$). There were no significant differences in understanding between Classmates and Teachers, nor between Peers and Teachers (both $p > .25$).

Interview Results

Three main themes were apparent for all participants, regardless of how long ago they left secondary school. These were *Impact of Diagnosis*, *Autism Awareness* and *Shared Interests*.

Impact of Diagnosis captures how having, or not having, a diagnosis changed school experiences. All but one of the autistic participants received their diagnosis in adulthood, after leaving school. Many expressed that not having a diagnosis hindered their classmates' and teachers' ability to understand them and worsened their school experiences. Out of the 13 participants, seven reported having experienced mental health issues prior to receiving an autism diagnosis, including depression, anxiety or eating disorders. After receiving a diagnosis many reported increases in self-awareness and understanding from others: *"Now that I am able to say that I have this condition and this is what it means for me, it does help a lot... It meant I could say to my tutors, 'This is my condition and this is what I need' other than feel like I am drowning, like I can't ask for help"* (Y.B) On the other hand, three participants reported issues with regards to their autism diagnosis being believed by their fellow peers: *"Half (of people who I have told about the autism diagnosis) have been very surprised and even sort of doubt it..."* (O.C) and *"For the people who grew up with me who saw me as kind of me just being a bit lazy and useless find it hard for them to get their heads around it"* (O.F).

Mourning for time spent without diagnosis emerged as a sub-theme. Many participants expressed disappointment that they were not diagnosed sooner and believe that it would have helped them in school: *"It all goes back to if I had been diagnosed... I allow myself to be wistful because my life would been so different"* (O.G). For the older autistic participants, the effects of not having an autism diagnosis had continued into the work environment: *"I had so much trouble when I was made redundant and had to go into a more sort of normal working environment, sort of office working environment and I started to fall apart. Too many people, too much noise"* (O.C.). Others reported instances of camouflaging in school where they attempted to mask their autistic traits before receiving a diagnosis: *"I created these different personalities around each sort of group or person. I would be that personality. I would try and assimilate into that group for a small amount of time"* (Y.B).

The majority of participants reported that a lack of *Autism Awareness* hindered their school experiences to a large degree. This was reported as negatively influenced interactions with peers and teachers, with a few reflecting on how more understanding would have improved such interactions: *“I think if there had been awareness of what autism was at the time, I wouldn’t have been labelled as a naughty, disruptive pupil by teachers. I would have received more kindness and support from the teaching staff and my peers”* (O.B).

In addition, over half of the participants, regardless of school leaving age, cited instances of how a lack of understanding negatively impacted their academic potential: *“All of the emphasis was on the negatives, not positives through school. Nobody ever said to me, ‘You’ve got a lot of potential’ ... I do feel that my whole education was a lost opportunity really”* (O.B). In some cases, these two sub-themes were intimately linked: *“I missed so much school because of it. It would be hours out of my day sometimes, recovering from being overwhelmed and teachers not understanding or appreciating it wasn’t something I was doing to skive out of class* (O.G).

The *Shared Interests* theme reveals how shared or common interests influenced autistic participants’ school experiences. Eight out of the 13 participants across the two groups reported that having a shared interest benefited understanding. These often provided a foundation or means of social interaction with their non-autistic peers: *“Most of my close friends are still musicians and if I meet up with them, that’s pretty much all we talk about ... The shared interests thing was very much the foundation of any relationships and friendships I had”* (O.C). For participants who had interacted with other autistic people, they reported that shared interests helped to enable those friendships: *“We were both engaged in very similar things like debating and music, although we had different tastes. There would be a lot of discussion there. We both would be able to communicate quite well with that”* (Y.A).

Discussion

In this mixed-methods project, our aim was to investigate autistic adults' experiences of feeling understood in school, and how they compared with those of non-autistic adults. As predicted, the autistic group felt significantly less well understood than the non-autistic group and this applied to both classmates and teachers. Understanding was also influenced by the diagnostic status of other pupils: for those autistic participants who had autistic peers in school, levels of reported understanding were higher for these peers than for classmates.

Our interview analysis was limited by the fact that virtually all of the participants interviewed had received an autism diagnosis after leaving school. These participants felt that not having an autism diagnosis whilst at school hindered understanding from classmates and teachers, and that greater autism awareness would have enhanced both interactions with others and academic achievement. All reported that receiving a diagnosis had increased understanding from others on the whole, though we also uncovered some evidence of dismissal diagnostic status by both friends and health professionals. Consequences of lack of understanding including difficulties finding the right work environment after school, and feeling a need to camouflage. *Shared Interests* came to light as a protective factor in terms of understanding, with many reporting that it provided the foundation for social engagement.

Our results correspond with previous research indicating that autistic pupils are subject to worse school experiences in terms of peer and teacher relationships compared with non-autistic counterparts (Humphrey & Lewis, 2008a, 2008b; Symes & Humphrey, 2010). It has been argued that by including autistic children in mainstream education they will have greater opportunities to develop social skills, while their non-autistic peers become more accepting of neurodiversity (Boutot & Bryant, 2005; Kasari & Rotherham-Fuller, 2007). Researchers have emphasised the important role that non-autistic peers play in the success of this inclusion process (Ochs, Kremer-Sadlik, Solomon & Sirota 2001) but we also know that non-autistic

people are disposed to make negative judgements of autistic people (Sasson et al., 2017; Stagg et al., 2014).

These data combined with our new evidence indicate that autistic pupils may gain from the opportunity to spend time with autistic peers. Indeed, one study which conducted interviews with nine autistic students at an autism specialised college reported feeling that only other autistic people truly understood autism and that this conferred a sense of belonging (Jones, Huws & Beck, 2013). This corresponds with previous studies indicating that autistic adults feel better understood by others on the autism spectrum post diagnosis (Jones, Goddard, Hill, Henry & Crane, 2014; Rosqvist, 2012). The importance of such factors should not be under-estimated: recent data indicate that feelings of belonging provide a significant protective factor against negative mental health outcomes in autistic people and people with high self-reported autistic traits (Cassidy, Bradley, Shaw & Baron-Cohen, 2018; Pelton & Cassidy, 2017).

Relative to the non-autistic group, autistic participants also reported being significantly less understood by their teachers in school. Many teachers report receiving little autism training prior to teaching autistic pupils (Able, Sreckovic, Schultz, Garwood & Sherman, 2014; Lindsay et al., 2013; McGregor & Campbell, 2001; Robertson et al., 2003). Moreover, recent research conducted with non-autistic college students has demonstrated that a greater knowledge of autism relates to reduced stigma towards people on the autism spectrum (Gardiner & Iarocci, 2014; Gillespie-Lynch et al., 2015; Nevill & White, 2011; White, Hillier, Frye & Makrez, 2016). Provision of training to increase autism knowledge may improve relationships between teachers and their autistic pupils relationships, and thus school experiences.

Limitations

It is unclear to what extent these survey data can be generalised. Not all of our sample had a confirmed medical diagnosis of autism, and the surveyed group was majority-female. In

addition, less than half of the autistic group had contact with autistic peers at school, reducing our sample size for these sub-analyses. Furthermore, our survey required autistic and non-autistic adults to report retrospectively on their school experiences. However, our data correspond strongly with existing literature reporting on negative school experiences and emergent findings of poor interpersonal-relations between autistic and non-autistic people. We add to this literature with an empirical investigation of self-reported experiences, enhanced by interviews and thematic analysis. Future studies should replicate this methodology with a sample of pupils currently in school, and directly explore the impact of teacher and classmate training.

Conclusion

Successful interactions within and beyond school require the co-operation of both parties, not just the autistic person. Autistic people report being poorly understood in school, but perceive that they are better understood by other autistic peers than by non-autistic classmates. Being understood by others is a non-trivial component of academic achievement, social relationships and wellbeing. For autistic pupils to feel understood requires that they have a diagnosis, that people around them understand what that diagnosis means, and that they have opportunities to spend time with other autistic people. Much work is needed to deliver these elements in schools.

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Supplementary material: Interview Script

1. In relation to autism, what kind of language do you use to describe yourself? Can I use that language?
2. When were you diagnosed with an autism spectrum condition?
3. Who diagnosed you?

Thinking about your time at school, when you were aged about 14-15 years old. You might want to anchor your thoughts about that period by thinking

- a) What was the year that you had your 15th birthday?*
 - b) Where were you living at that time?*
 - c) Did anything special happen that year, like a family holiday?*
4. How would you describe your experience in secondary school?
 - a. What kind of school was it?
 - b. What sort of contact did you have with other autistic or neurodivergent people
 5. Can you please describe your relationships with peers without autism in school?
 6. Can you please describe your relationships with peers with autism in school?
 7. What factors do you feel hindered your peers' ability to understand you?
 8. What factors do you feel helped your peers understand you?
 9. How you feel that others understand you now that you have left school?