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"We are different, that's a fact, but they treat us like we're different-er"

Understandings of autism and adolescent identity development

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Background

Early adolescence is a period of developmental change which includes the move to a more complex school environment and the development of individual identity (Kroger, 2004)

During adolescence young people establish an individual identity; at the same time they typically seek to fit in with recognised social and cultural groups

(Blakemore and Mills, 2014; Kroger, 2004)

In the UK diagnosis of autism in the absence of intellectual disability is often not made until late childhood or beyond

(Crane et al 2015)

Integrating the idea of “being autistic” forms part of the process of identity development

(Bottema-Beutel & Smith 2013, Humphrey & Lewis 2008, Morgensen & Mason, 2015)



Background

For autistic young people, there are marked increases in social, communication and daily living skills but also higher rates of mental health difficulties, poor quality of life and higher rates of school exclusions (Inceasu et al 2012, Hebron and Humphrey 2014, McGovern & Sigman 2005, Moore, 2016)

During adolescence increased awareness of difference and the stigma attached to autism may contribute to negative outcomes for autistic young people (Humphrey and Lewis 2008)

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 and Troxwell-Whitman, 2019; Cage et al., 2018; Hull et al., 2021; Mandy, 2019).

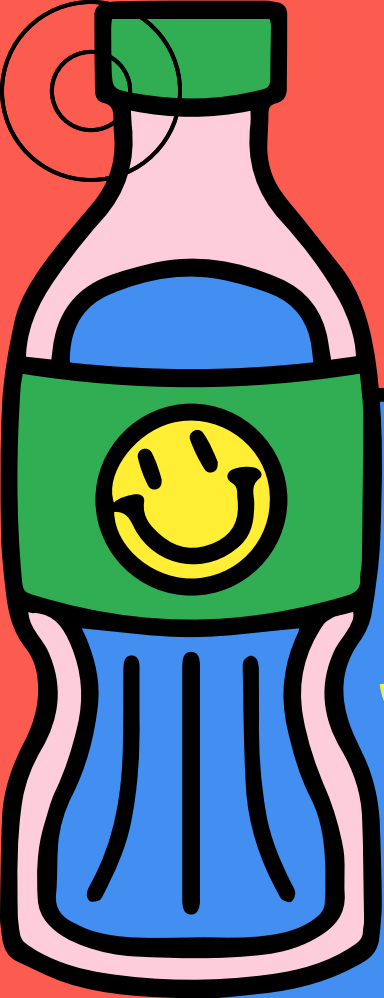


Background

Studying ways in which autistic young people understand their diagnosis and negotiate identity could inform understanding of mental health and wellbeing in this group.

However relatively few studies directly include the perspectives of autistic young people themselves

(Ramussen & Pagsberg 2019)



Study aims

1. How do autistic young people and others in their social environment understand autism?
2. How do these understandings relate to young people's identity development in early adolescence?
3. How do these understanding relate to young people's school experiences in mainstream settings.



Methodology

Data drawn from ongoing longitudinal study investigating experiences of autistic young people in mainstream schools from year 6-11.

14 families were recruited to the study via the Specialist Autism Teaching team based at the city council

Ethical approval granted by York St John University

Semi structured interviews with the young person, their parent and a teacher at annual intervals

Data analysed using inductive thematic analysis with a contextualist approach

Results

Identifying with Autism

Negotiating
difference


Changing
understandings
over time

Social
camouflaging

Social construction of Autism

The autism
label

Individuality
and sameness
in Autism



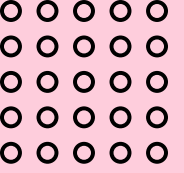
**Theme 1a:
Negotiating
difference**

Well, me and my friend (name) we're quite different. We don't 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" (Young person, Y6)

"I think he is just struggling with the idea of having Aspergers. He spoke to me a long time last night saying how different he feels... He said I wish you had not told me" (Parent, Y7)

"I just want to be treated like normal. I don't want to be treated like there is something, like I have Asperger's" (Young person Y6)

"..he had chosen to have that (a locker within the inclusion unit) and then very quickly decided he didn't want to. He didn't want to be different" (Parent Y7)



Theme1b:

Changing understandings over time

“it affects us all...its sort of a learning curve for us all” (Parent, Y6)

”Understanding autism....Year 6 its suddenly hit him. He has quite a lot of out of the blue meltdowns.....He’s expressed he doesn’t understand why he got this, why he has caught this...I think its just dawned on him now that this is not going away” (Teacher, Y6)

“I explain that its just like two different brains, one is like a Microsoft computer and one an apple computer, and you all get to the same outcome but its just that you think differently” (Teacher Y7)

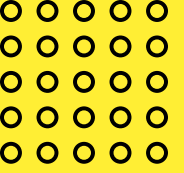


Theme 1c: Social camouflaging

“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” (Parent, Y8)

“From my experience I’ve got several students at school who present really well at school and then go home and its absolutely chaotic....you know, it could be the stress that we’re minimizing, that kind of floods out” (Teacher, Y7)

“I mentioned to him about if there was anyone he'd like to invite round and he said he would not want to do that, that this was a different place, and he did not want to mix them.....he doesn't want [peers] to know all about him” (Parent Y7)



Theme 2a

The autism label

‘the autism people at (secondary school) are a bit of a target to bullies’
(Young person, Y8)

Young person (Y9) : *“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?”*

Young person: *“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”*

‘she’s not on the major spectrum....she’s on the lower spectrum’
(Parent, Y8)



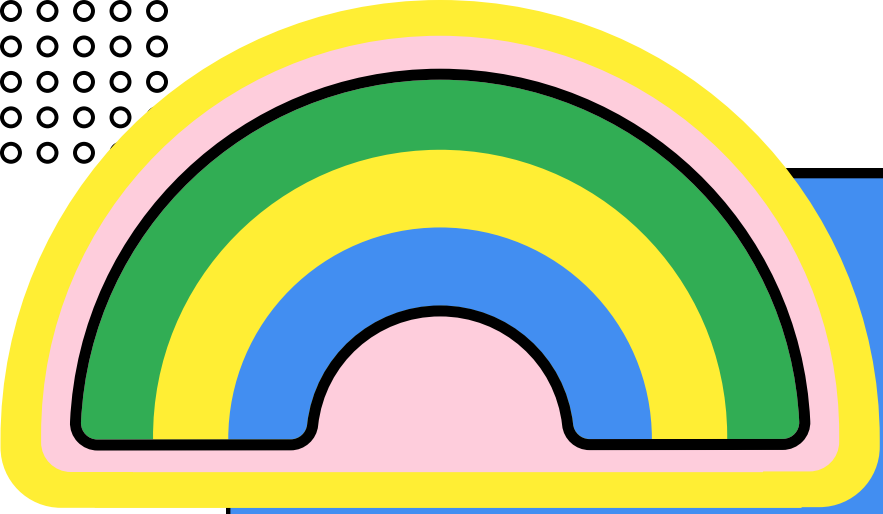
Theme 2b

Individuality and sameness in autism

“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?’” (Teacher, Y8)

“They said ‘oh there's another autistic child in the class, we’re used to autism’, but every child is unique and they never got his uniqueness” (Parent, Y7)

“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” (Parent Y6)



Discussion

Young people's understanding of what 'being autistic' means unfolds in the broader context of early adolescent development.

In describing themselves young people used terminology aligned with prevalent socio-cultural discourses of autism – both the medical model and neurodiversity models and often in overlapping ways.

'Normal' and 'mainstream' were how young people said they would like to be treated by others, but this was not what they experienced in school. Several young people described being bullied because of the autism label.

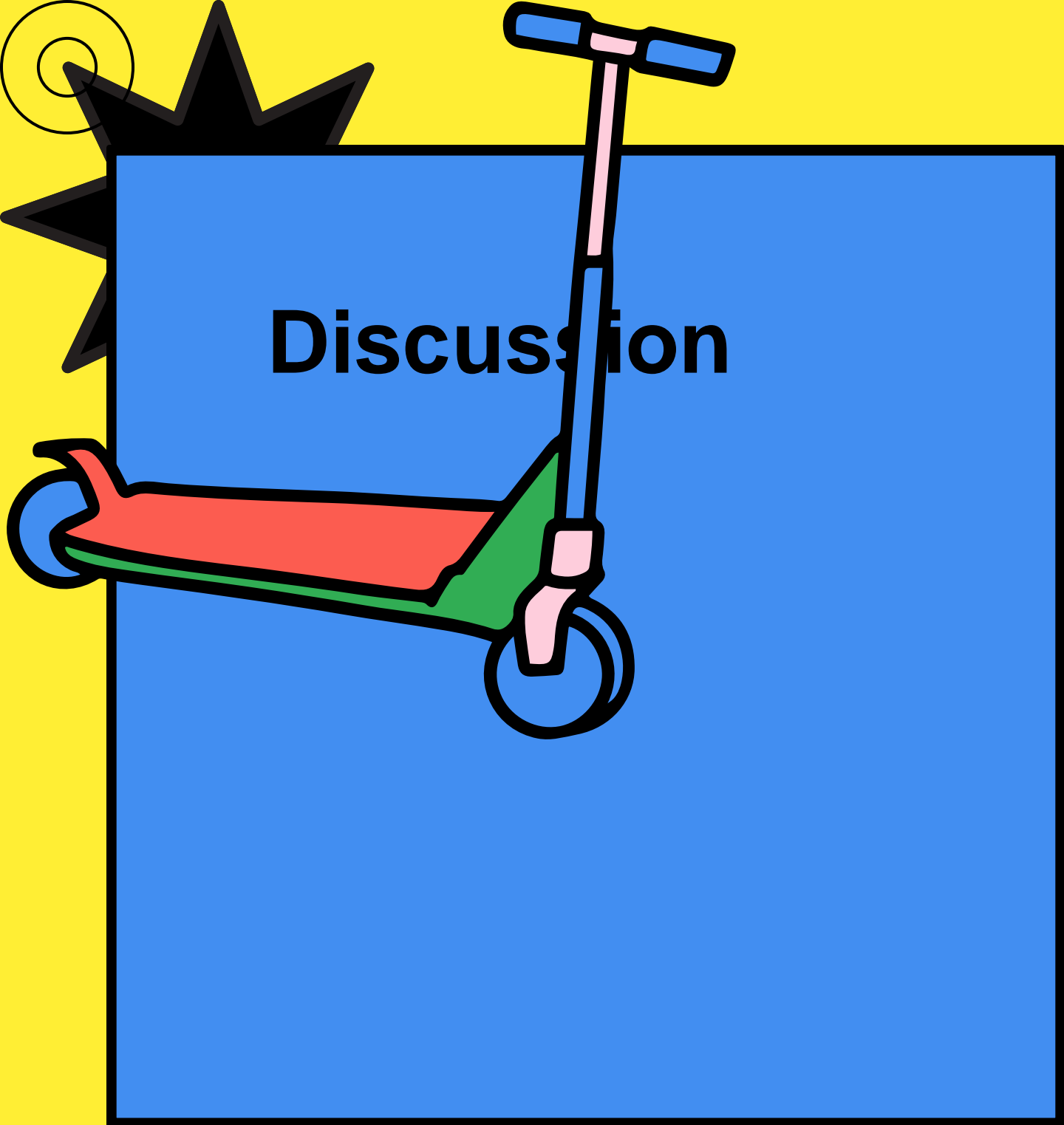


Discussion

Several young people engaged in social camouflaging in order to avoid 'appearing autistic' at school and this included the rejection of support

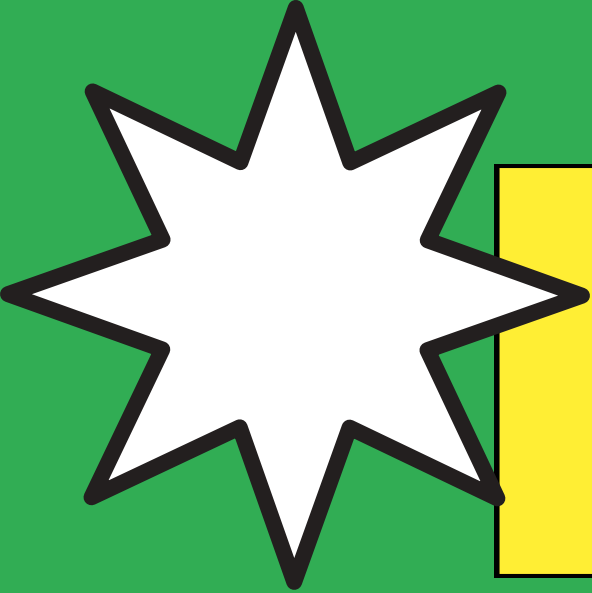
Some teachers assumed autistic young people were a homogenous group with similar support needs and occasionally doubted the validity of the diagnosis if young people did not present 'typically'

There were examples of teacher interventions that could encourage social camouflaging



Discussion

Parent and teachers seem to be negotiating the competing discourses of autism and use language that can be linked to both. This may unintentionally encourage social camouflaging.



Suggestions for practice/further research

An alternative approach to school support

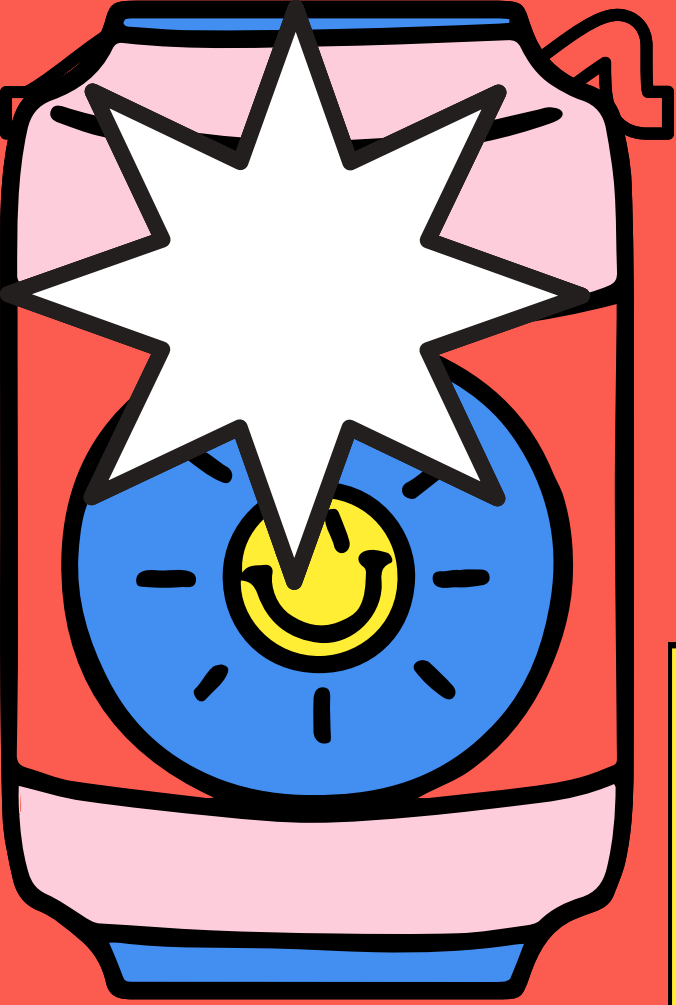
Whole school interventions aimed at:

- **Increasing understanding of autism and its heterogenous nature**
- **Increased awareness of social camouflaging**
- **Acceptance of diversity in the wider school community**

Enhanced post diagnostic support for young people and families

To include:

- **Opportunities to reflect on the diagnosis with others**
- **Consideration of the best ways for families to talk about autism**



Questions?

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