

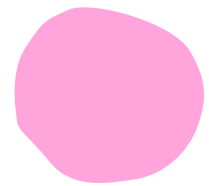
"I felt like an ant back then, that they could just stand on at any time and completely crush": An autistic young persons retrospective story of mainstream schooling.

Sue Mesa

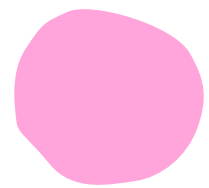
 @sue_mesa @YSJOT



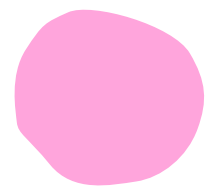
About me



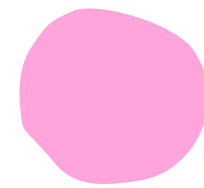
I am a Senior Lecturer in Occupational Therapy at York St John University



My clinical background is in adult learning disabilities



My research is related to school experiences of autistic young people and is positioned within the neurodiversity paradigm



I am a part time PhD student supervised by Dr Lorna Hamilton and Dr Trish Hobman, funded by YSJ and The Constance Owens Trust



Thesis - AIMSS:
Autism Inclusive Mainstream Secondary Schooling

Study 1: A longitudinal narrative analysis - how school experiences influence identity

Study 2: Scoping review of existing school-based neuro affirmative interventions

Study 3: A participatory study - coproducing school-based intervention



Background

75% of parents state school does not meet their child's needs (NAS, 2021)

More likely to experience bullying (Schroeder et al., 2014)

Three times more likely to be excluded from school (Timpson, 2019)

70% of autistic children are diagnosed with a mental health condition (Autistica, 2019)

Quality of life is much lower than neurotypical peers across the adult lifespan (Van Heijst & Geurts 2015)

Higher rates of mental ill health in adulthood (Lai et al., 2019)

A disproportionate number of deaths by suicide are autistic people (Autistica, 2019)

29% of autistic adults are in paid work (ONS, 2021)



Background

- Longitudinal study with data collection from Year 6-9
- Fifteen families recruited via the Autism Specialist Teaching Team at York City Council
- Semi structured interviews and a series of quantitative measures conducted with young people, parents and teachers at annual intervals



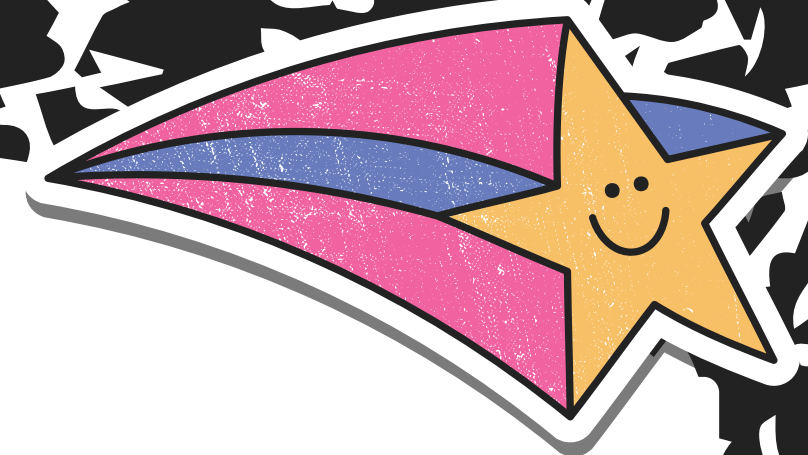
“We are different, that’s a fact, but they treat us like we’re different-er”:
Understandings of autism and adolescent identity development

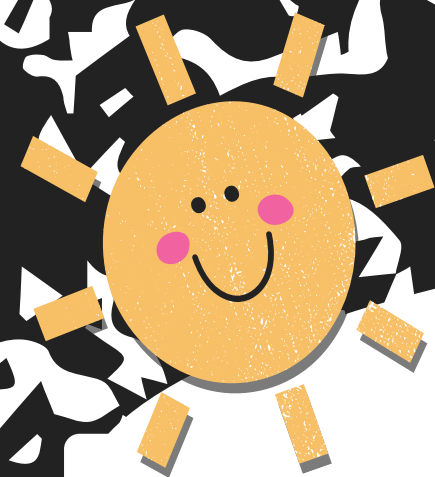
Sue Mesa and Lorna G. Hamilton

Abstract
Purpose – A key development in early adolescence is the active construction of individual identity; for autistic young people, integrating the idea of “being autistic” forms part of this process. The purpose of this paper is to explore identity development from a contextualist perspective, foregrounding young people’s experiences within mainstream educational settings.
Design/methodology/approach – A longitudinal, qualitative methodology was used: semi-structured interviews were conducted annually with 14 autistic young people, their parents and teachers between school years 6 and 9.
Findings – Young people felt different from their neurotypical peers and their acceptance of their diagnosis changed over time as they managed their developing personal and public identities. In pursuit of being treated “normally,” many camouflaged their differences at school, which sometimes involved opting out of school-based support. Adults described their own understandings of autism and discussed the responses of others in the school environment to autistic differences.
Originality/value – The influence of sociocultural discourses of autism on young people’s identity development is discussed and implications for both school based and post-diagnostic support for young people and their families explored.
Keywords Autism, Qualitative research, Schools, Identity, Adolescent development
Paper type Research paper

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(Mesa & Hamilton 2021, 2022)





Study 1 Aims

To understand how identity develops in autistic adolescents over the whole of their secondary education

To understand how secondary school experiences influence identity development



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Study 1 Method

Using an accessible information sheet, and parents as gatekeepers, recruited four young people from the Mesa & Hamilton (2022) longitudinal study. Keen to privilege their story.

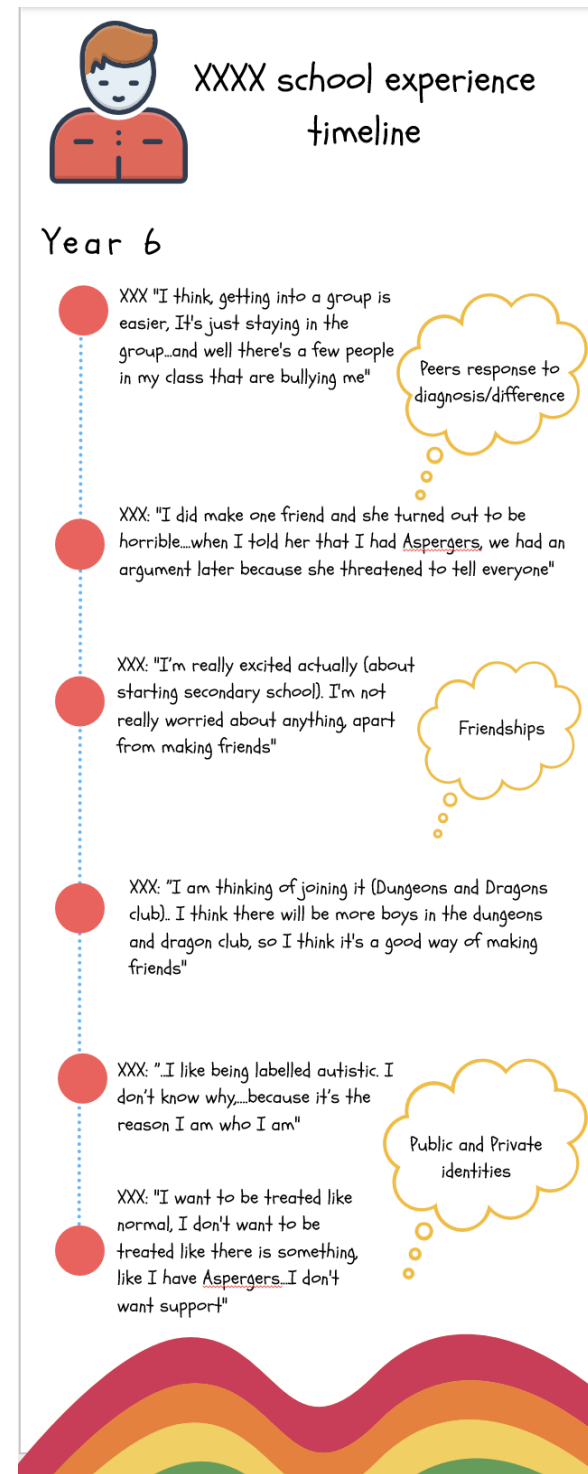
A retrospective narrative inquiry interview at the end of Year 11 related to their whole secondary school experience.

Narrative inquiry seeks to go beyond the surface, moving from the 'what' of a story to the 'why's and what stories tell us about society (Riessmann, 2008)

Narrative inquiry can give voice to those who are silenced or storied in stigmatizing ways (Anderson-Chavarria, 2022; Milton, 2014) and their narratives can be used to promote social change (Squire et al., 2008).



Preparation for interview



A week before the interview they were sent:

1) An interview guide to reduce anxiety about what to expect (Ashworth et al., 2021).

2) A choice of visual timeline - intentionally flexible and individualised method to support story telling (Cascio & Racine, 2018)

- A pre prepared visual timeline of a selection of their quotes from year 6-9 interviews and blank pages for year 10 & 11
- A completely blank timeline for each year

Participants were invited to review timelines ahead of the interview, discuss with parents if they want to, record their thoughts about it in any way they would like to.

James

British white male

Lives with mum and two younger siblings

Diagnosed as autistic in Year 4.

Taught Year 7 solely in a small group within the inclusion space with increasing time from Year 8 spent in mainstream classes

Periods of non-attendance from Year 9 onwards and several periods of school exclusion

Did not meet government benchmark of 5 good GCSE



Rejected by peers for being different



Illustration by Eliza Fricker: Missing the Mark 2024

"I didn't want any attention, I just wanted to be invisible then, so I just kept silent....Cos I was afraid, I was afraid of what everyone thinks about me, I didn't like being judged....I didn't like, even like a little glimpse at me, someone could literally look at me for like I don't know, a second, and I'd just completely meltdown"

"If someone is being horrible, I would never speak out about it... I was just keeping everything all to myself, I didn't want to be seen as some vulnerable kid that's easy to pick on"

Researcher: "Did you feel vulnerable?"

"I felt like an ant back then, like everyone was giant crowding over me and I was just this little ant that they could just, stand on, at any time, and just completely crush me"

Not understood, accepted or affirmed by teachers



I need help, it's all too much.

Let's do some social skills training.

We could move you to another class away from them both?

Illustration by Eliza Fricker: Missing the Mark 2024

"Teachers thought they understood me, but they couldn't even figure out 2% of me, like they just did not get me..... they didn't understand autism as well as they said they did"

"The teachers didn't want me"

"They think I'm the baddy. Me getting into trouble for sticking up for myself"

"I just didn't get with the teachers, I would end up having like massive arguments with em and ... I was just so sick of it, the teachers wouldn't do anything with this bullying, and ... they just sort of like sit there and watch it almostso I just ended up just like, if they aren't going to care about me why should I care about them, and what they tell me to do"

Lack of school belonging influences wellbeing

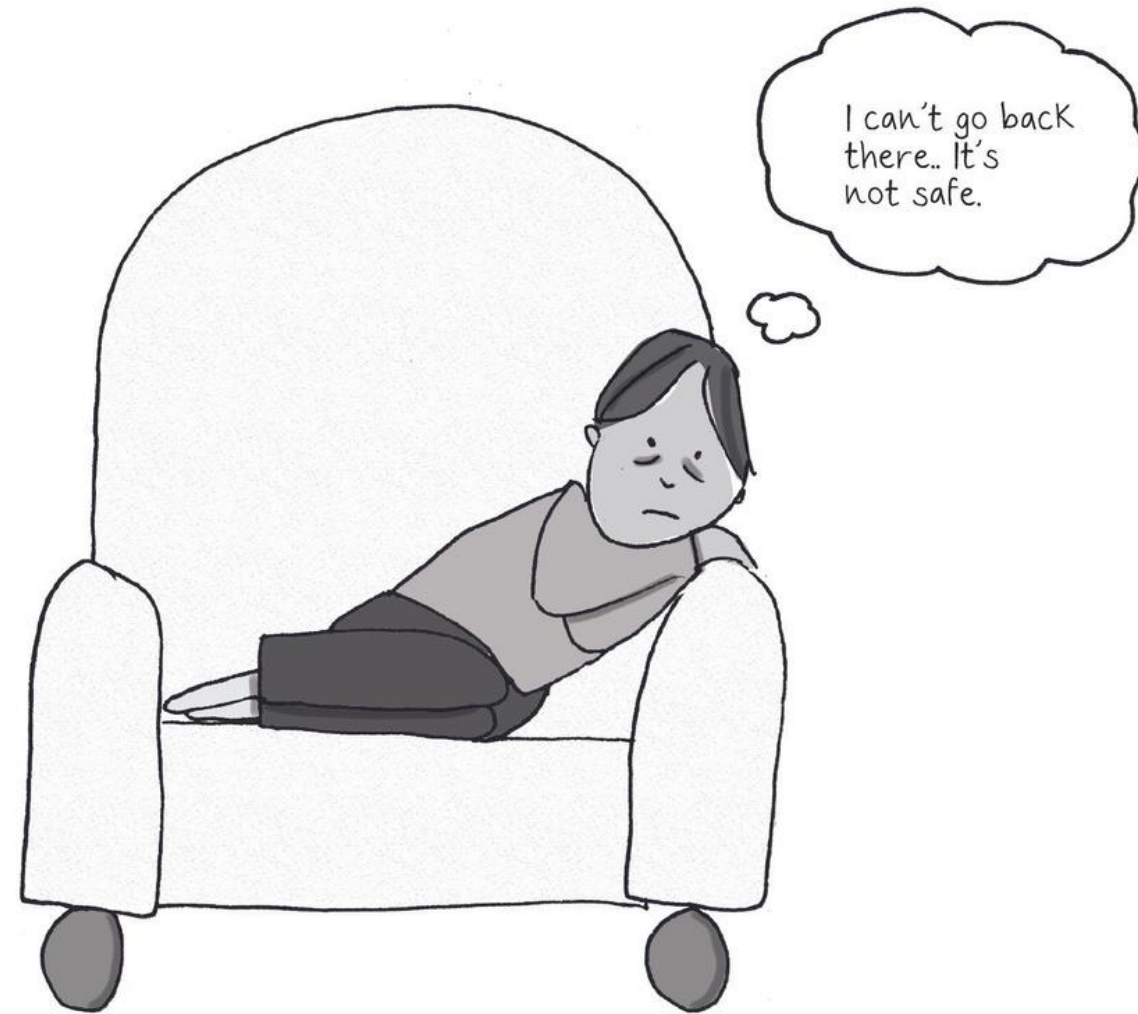


Illustration by Eliza Fricker: Missing the Mark 2024

"I thought I didn't have anyone, I thought I didn't have no friends ... I started getting really depressed, like sleeping in all day ... or like never getting sleep. I just completely shut myself out...and then ... Year 10, the bullying was getting even more worse and basically ... I started self-harming... I was just completely out of it"

"I don't really like to think about my school years that much cos, I ... was just a complete bomb site really, erm I mean, I can't really say that now, cos, I'm just still an emotional mess"

"I'm just...still sort of recovering from what I went through."

Lack of social connection impacts developing identity

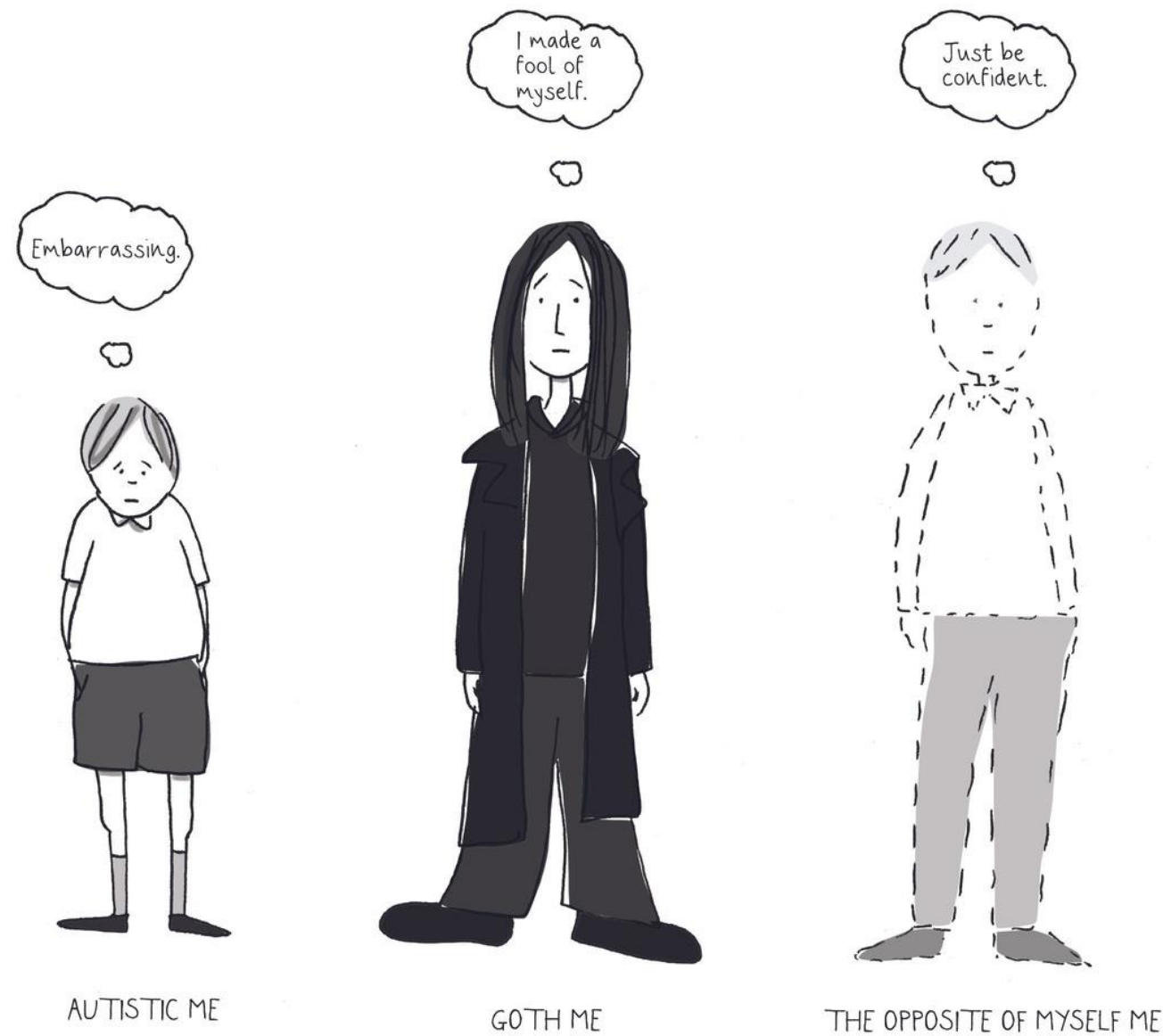


Illustration by Eliza Fricker: Missing the Mark 2024

"I used to call it the A.....
I was so embarrassed"

"I was one of those cringy goth
kids, I don't know what I was
thinking, I just made a fool of
myself"

"As soon as I walked in, actually I was a little bit
nervous, cos I thought I don't want to have no one
again... so I had to, you know, be confident, I just
had to put my head up.....I'm like the complete
opposite of myself now."

"I think the thing is, they
didn't really like weird
students...because I was a
bit weird then.... and I think
that's why I got bullied "

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Discussion

Desire for and conscious effort to form social relationships (Kapp et al 2019, Cage et al 2016)

Victimisation influences masking and mental health (Bernadin et al 2021, Botha & Frost 2020, Chapman et al 2022).

Deficit orientated understandings of autism are dominant in school culture (Fricker 2023, Wharmby 2023, Pearson & Rose 2023, Wood 2023).

Autism as an identity hasn't been affirmed in school, either personally or in a collective way (Botha et al 2022)

Other explored identities have not created any kind of 'in group' experience from which he can build a positive sense of self (Jankowski et al 2014, Tajfel and Turner 1979)





Reflections on OT practice

Changing perspectives within the profession - calls for us to reflect on ableism and work towards disability affirmative and strengths-based practice (Chen & Patten 2021, Dallman et al 2022, Hammel 2022, Patten 2022, Vine 2024)

Many occupational therapy interventions are aligned with a medical model framing (Leiger 2016, O'Brien & Kuhanek 2020, Kuhanek 2020) and interventions from this perspective may have unintended consequences (Dallman, 2022)

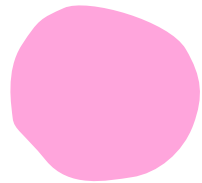
Autistic adults advocate for children's occupational therapy that supports autistic identities rather than trying to "fix" children, changes environments or tasks, and supports self-advocacy and autonomy (Sterman, 2023)

Assessment of high and low functioning environments (Patten 2022)

Universal interventions (Hutton et al 2014)



Strengths and limitations



In depth work with rich data, which centers the voice of autistic young people that is largely missing from the literature



Small sample size



Questions/comments



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