BETHANY COPPING BSc Hons MSc

EXPLORING STORIES OF AUTISTIC ADOLESCENTS

Section A: Autistic Adolescents: Navigating Identity Development

Word Count: 7,408

Section B: Stories of young people of the Global Majority and their families after receiving a diagnosis of Autism: exploring the interplay of culture, neurodiversity and other aspects of identity

Word Count: 7,746

Overall Word Count: 15,154

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2024

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

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Summary

Section A: This is a meta-ethnography exploring autistic adolescent identity development using a narrative identity framework. A systematic literature search and meta-ethnographic synthesis of 15 relevant qualitative studies was conducted. Seven third-order constructs were developed from 25 underlying second-order constructs identified within the research. These were, meaning-making - my autistic identity; personal processes; self in time; meaning making - stories of those around me; social connection and relationships; navigating autism in a ‘neurotypical’ world; and societal narratives. The findings indicate how autistic adolescents develop and co-construct their identity through their stories of themselves and the stories of those around them and wider society. The review proposes a framework for future identity research. Clinical and research implication are considered.

Section B: This is a narrative analysis study looking at the stories of young people of the global majority and their families after an autism diagnosis. Nine interviews were conducted, four with young people, and five with their parents. Findings highlighted the unique stories people of the global majority tell after receiving an autism diagnosis. Of particular note were barriers to services, cultural and faith narratives, increased bullying and stigma. Clinical implications are discussed for creating culturally sensitive services, increased community presence and challenging dominant medical narratives of autism.

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Abstract

Narrative identity proposes that personal narratives are formed over time with the telling and re-telling of stories. The aim of this review was to explore the stories of identity development in autistic adolescents by synthesising the relevant qualitative literature. A systematic literature search and meta-ethnographic synthesis of 15 qualitative studies was conducted. Seven third-order constructs were developed from 25 underlying second-order constructs identified within the research. These were, meaning-making - my autistic identity; personal processes; self in time; meaning making - stories of those around me; social connection and relationships; navigating autism in a ‘neurotypical’ world; and societal narratives. The findings indicate how autistic adolescents develop and co-construct their identity through their stories of themselves and the stories of those around them and wider society. The review proposes a framework for future identity research.

Key words: Autism, identity development, narrative identity, meta-ethnography,

Introduction

Autism spectrum disorder (ASD) is a clinical diagnosis defined as persistent difficulties with social communication and social interaction and restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013). Characteristics are present from a young age but may not be apparent due to reduced social demands or individuals hiding who they naturally are or changing their behaviour to match those around them; known as camouflaging or masking (Belcher et al., 2022). Often, medically focused and deficit-focused language has been used to describe those with autism. However, more recently, there has been a shift in the discourse to encompass and celebrate neurodiversity. For the purpose of this report, the terms ‘autism’ and ‘autistic’ will be used to reflect the identity-first language that the autism community advocates for and will not refer to autism as a ‘disorder’, which implies impairment rather than difference.

Adolescence is an important developmental period marked by profound transformation in identity, self-concept, and social interaction (Kroger, 2006). The World Health Organisation (WHO) define the period of adolescence as the phase of life between childhood and adulthood, from ages 10 to 19; however, a more meaningful definition which accounts for individuality and cultural variability focuses on the developmental tasks expected to be achieved during this life stage (Curtis, 2015). Identity is a complex and abstract concept that can be challenging to define. Identity development is a dynamic process that happens over the lifespan and begins in adolescence (Erikson, 1968). This process is influenced by external factors like the social worlds and communities we navigate, alongside internal processes (Yoder, 2000). Adolescence is associated with attempts to determine societal placement (Waddell, 2002). Childhood and early adolescence involve recognising values and beliefs held by family (Steinberg, 1990). A common process in adolescence is moving away from family and parental figures to establish independence and autonomy (Erikson, 1968), which often places increased importance on peer friendships and acceptance, including a shift towards adopting peer beliefs (e.g. Brechwald & Prinstein, 2011; Brown & Larson, 2019; Music, 2010). Social relationships become increasingly more important as adolescents increase their capacity for emotional perspective taking (Choudhury et al., 2006). During mid-adolescence, individuals begin to reflect on the extent to which their beliefs match those of their family and social networks (Collins & Steinberg, 2006). Steinberg and Monahan (2007) found that, across different ethnicities and genders, susceptibility to peer pressure peaks at age 14 and then declines, suggesting an increased resistance to adopting the values of others in later adolescence. Additionally, societal values also contribute to adolescent identity formation (Erikson, 1968); therefore, adolescents' societal context may shape how they see themselves.

Narrative Identity

McAdams' narrative identity theory (McAdams & McLean, 2013) introduces the idea that individuals construct their identities through the development of life stories, which is a narrative unfolding over time (Polkinghorne, 1988). This concept has been found across cultures (Bruner, 1986; Sarbin, 1986). Nelson & Fivush (2020) posit that while aspects of autobiographical memory and life stories begin in childhood, narrative identity emerges alongside structural thinking, problem-solving, and cause-and-effect abstract reasoning skills in adolescence. Building a narrative identity involves connecting life events by attributing meaning to memories, making sense of that in the present day, and projecting to future hopes and goals (McAdams, 1995; Singer, 2004). Therefore, this is a constructed story told with emotionally curated memories that change over time, with memories becoming more or less salient and shaped by the stories others tell us. McAdams' theory encourages exploration of how these narratives influence adolescents' self-perception, social interactions, and future aspirations.

Autism as a context

Previous research highlights the role of context in identity formation (Adam & Marshall; Yoder, 2000). For adolescents, the narrative of their lives may involve weaving together experiences, challenges, and successes to create a coherent and meaningful self-narrative. Navigating the intricacies of identity development for autistic adolescents may pose unique challenges as they grapple with questions related to their sense of self, belonging, and autonomy. Potential differences in social interactions and forming peer relationships may impact how they establish a narrative identity.

Additionally, Goffman's theory of stigma (1963) offers insights into the challenges faced by autistic adolescents with autism in managing their identities within societal norms. Stigmatised for differences in social communication and behaviour, they may encounter prejudiced attitudes that can impact their self-esteem and social integration. The stigma associated with autism may lead to identity concealment or masking as adolescents employ impression management strategies to fit into social contexts (Chapman et al., 2022; Hull et al., 2017). This may lead to a delicate balance between the authentic expression of self and the demand for social conformity in the lives of autistic adolescents. Consideration of how autistic adolescents navigate these challenges, striving for a sense of identity and purpose within the context of their unique neurodevelopmental profile, has not previously been synthesised. Research on autism and identity development is continually developing as the narrative of autism shifts away from the medical model of deficits to models of neurodiversity and inclusion.

Aims

This review aimed to investigate:

1) What are the stories of identity development in autistic adolescents?
2) What impact do others have on identity development in autistic adolescents?
3) How does this fit with developing a narrative identity?

Methodology

This review evaluated qualitative research in peer-reviewed journal articles and unpublished dissertations to answer the research questions posed. The review was completed in four stages; a systematic search of the literature, a critical appraisal, a synthesis using a meta-ethnographic approach informed by Noblitt and Hare (1988), and the findings were synthesised to propose a theoretical model of narrative identity development.

Systematic literature search

The exclusion and inclusion criteria for the review are defined in Table 1. The aim of the review was to evaluate research exploring the formation of identity in autistic adolescents through first-person accounts. Only studies employing a qualitative methodology were included in the review to support this approach. Studies using content analysis were only included when accompanied by qualitative quotes to understand the stories being told.

Table 1

Inclusion and exclusion criteria

Inclusion criteria

- Studies that specifically focused on autism in adolescence from a first-person experience
- Studies where most participants were between the ages of 10 to 19.
- Studies that considered the influence of autism on identity or understanding of the self
- Studies that used a qualitative analysis methodology
- Studies in the English language

Exclusion criteria:

- Studies not reported in the English language.
- Studies from parental experience only
- Studies where participants with autism were in the minority or where it did not distinguish between participants with autism and other conditions.
- Studies with no qualitative data reported.

Search strategy

The literature search was conducted in October 2023 and consisted of a search of four databases: Medline, PsychArticles, PsychInfo. and Web of Science. The key terms were searched for in titles and abstracts (see Table 2). No limits were placed on the date range of the literature. Filters were added to return studies written in English and qualitative studies only. This search was accompanied by an additional search of literature cited in the relevant studies and through a search using Google Scholar.

Table 2

Literature search terms

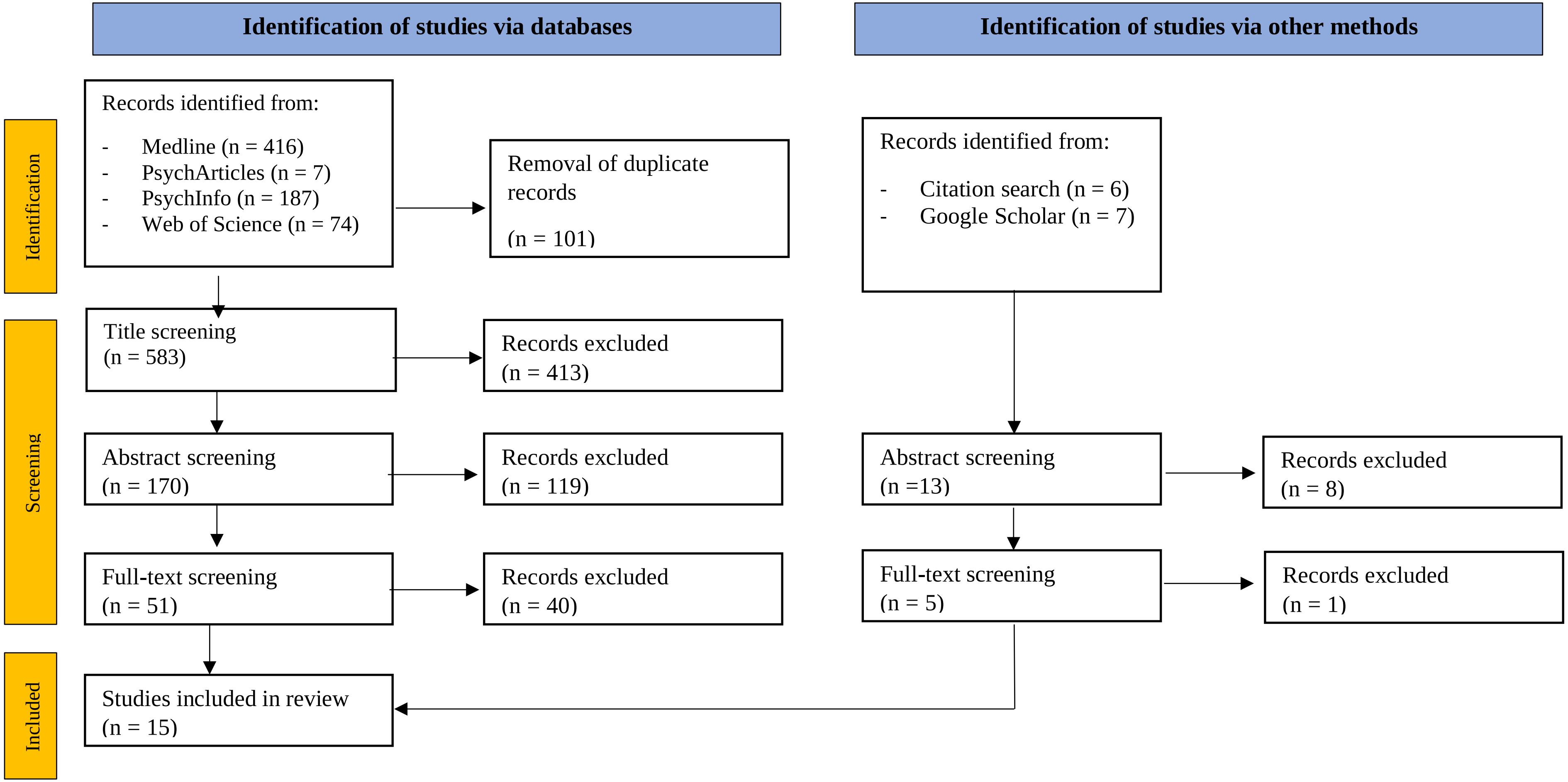
Search terms used (combined with AND)	Search of
Autis* or ASC or ASD or neurodivergent or Aspergers	Titles and abstracts
Identi* or self	Titles and abstracts
Adolescen* or young-adult or teenager or emerging-adult or youth	Titles and abstracts

*denotes wildcard search

The literature search process is displayed in Figure 1. The search returned 697 records, of which 101 were duplicated. The remaining 596 records were screened by title against the exclusion criteria and a further 413 were excluded. Abstracts of the remaining 183 papers were then screened, and a further 127 were excluded. Fifty-six articles were read in full, 15 of which were included in the final review.

Figure 1

Systematic literature search process (PRISMA flow diagram)



Critical appraisal

The quality of these studies was assessed using the Critical Appraisal Skills Programme tool (CASP, 2018, see Appendix A). This is a ten-question checklist and is the most widely used tool for assessing quality when synthesising qualitative health-related research (Long et al., 2020). In looking to understand more about the role of intersectionality factors in identity development, prioritising research with ethnically and culturally representative samples was considered important. The underrepresentation of minoritized ethnic groups within health research has been an established issue (Redwood & Gill, 2013); therefore, an additional category was added to supplement the 10 CASP quality questions assessing whether there was ethnically diverse recruitment within the studies.

Synthesis

Meta-ethnography highlights the differences and similarities across studies and aims to bring an interpretive lens to offer a new level of theoretical or conceptual insight (Sattar et al., 2021). Therefore, this was felt to be the method to best fit the research aims. The methodology employed within this review is grounded in the approach developed by Noblit and Hare (1988), which has seven steps laid out in Table 3. The approach to synthesis was inductive. No existing concepts or themes were used to develop constructs. As the view of autism is always evolving, and the move to neurodiversity narratives over medical model narratives is championed, the decision was made to translate the papers in date order, starting with the most recent. Of the two papers published in 2023, the Tesfaye et al. (2023) paper was chosen over Morgan (2023) as the index paper due to its higher quality, larger sample size, and more diverse participants.

Table 3

Summary of analytical approach, based on the seven stages of meta-ethnography as outlined by Noblit and Hare (1988).

Step	Key Task

Step 1	**Suitability of the meta-ethnographic approach was assessed -** The area of interest was identified, and the aims of the review compared to the aims of meta-ethnography.
Step 2	**Defining the scope of the review** Definitions of key terms considered, and inclusion and exclusion criteria were developed. Studies were then selected for inclusion and their quality assessed.
Step 3	**Reading the studies** The studies were read and re-read to become familiar with the characteristics of each study and identify key themes. The process of reading the studies proceeded from the most recent study (Tesfaye et al. 2023) and progressed in descending date order to Cridland et al. (2015).
Step 4	**Determining how the studies relate** Salient themes were listed from each paper for an overview to be able to compare to other papers and understand the themes arising. Participant quotes (first-order constructs) and researcher interpretations of themes and concepts (second-order constructs) were identified across studies from these lists. This was an iterative process with themes being continuously revised.
Step 5	**Translation of studies into one another** Constructs and themes identified from the papers were compared and translated into each other from the fifteen studies, starting with the index paper (Tesfaye et al., 2023). This was done by compiling first and second order constructs from the index paper, followed by recording similar themes in other papers, and additional themes not found in the index paper.
Step 6	**Synthesising the studies** Three stages of synthesis were undertaken: - reciprocal synthesis: similarities across studies were reviewed to refine the preliminary constructs identified. This was done by reviewing the first order

	and second order constructs in the context of their studies to confirm similarities and interpretations with other studies. A table was made (Appendix B) of collate first and second order constructs into third order constructs. This was done by the primary researcher and then reviewed by the research supervisor. - refutational synthesis: conflicting second-order constructs were identified and where needed were reordered and the third-order constructs were renamed to allow for these differences. Differences of opinion were considered important to include due to the subjective experience of being autistic. Therefore, these were included within constructs rather than eliminated. - line of argument synthesis: offers a meaningful narrative around the third-order constructs identified. With the third order constructs developed, they were revised alongside narrative identity research to develop a line of argument synthesis.
Step 7	**Reporting of findings** – Data was summarised, and the strengths and limitations are reported on. Recommendations were made before the report was concluded.

Noblit and Hare (1988) state that the reviewer's perspective is considered central to the outcomes. Therefore, it is important to consider the author's reflexive position. A perspective on autism as a difference rather than a deficit is central to the first author's position. In addition, the perspective of contextualism was taken, which emphasises the importance of considering the context when interpreting phenomena. This position acknowledges that an individual's experience appears real to them and is shaped by to the context they are in. It considers that an individual's understanding of autism, and how this fits with their identity, will be shaped by their cultural and community narratives, alongside their autism assessment and feedback experiences.

Results

Description of studies

After assessing eligibility, fifteen studies published between 2015 and 2023 were included (see Table 4). Seven of the studies were conducted in the UK, five in the USA, and the remaining in Japan, Australia and Canada. The review studies included 204 young people aged between 10 and 24 (49 female, 132 male, 3 transgender females, 5 transgender males, 1 gender fluid person and one non-binary person). One study did not report gender, and Tesfaye et al. (2023) seemingly incorrectly reported the number of participants, stating 31 participants, 6 female and 26 male, which does not add up correctly. Two of the studies also included additional participants, such as teachers or parents. Three of the studies were unpublished, and twelve were sourced from peer-reviewed journals.

Overall, despite there being three studies which focused on females only, there were more male than female participants, which is typical of studies considering autism, given the disparity in diagnosis (Roman-Urrestarazu et al., 2021).

Table 4

Overview of the studies analysed (in order of publication date)

Study no.	Author	Year	Location	Source	Sample size and demographic information	Experiences researched	Research aims	Data Collection and Approach to analysis	Study conclusions
1	Tesfaye et al.	2023	Canada	Peer reviewed journal	31 participants (6 female, 26 male) aged 11 to 18 years. 74% white, 9.7% Arab/West Asian, 3.2% South East Asian, 6.5 South Asian, 3.2 Black, 3.2% Mixed ethnicity.	Autism in adolescents with all language and intellectual levels. Diagnosis given between 2:0 and 4:11 years.	To understand the experiences and perspectives of autistic adolescents in their home, school and community environments.	Interview; Thematic analysis	Autistic adolescents have interests in forming social connections, aspirations for their future and a desire to achieve independence. Barriers identified were stressful school environments, bullying, mental health issues, lack of tailored support and stigma.
2	Morgan	2023	UK	Peer reviewed journal	10 participants (10 female) aged 14 to 19 years. Ethnicity not specified.	Autism in females.	How do adolescent girls, diagnosed with autism in adolescents, construct their self-concepts and social identities.	Blog posts and semi-structured interviews; Discourse analysis	Three discourses were found: diagnostic, individualistic and normativity. These were used to construct the self as a “legitimised autistic”, “a person with support needs” as “uniquely individual”, “in the process of becoming” and as a “self hiding from a hostile world”. Social identities were

									based on constructs of "fitting in" and "sticking out".
3	Chapman e al.	2022	UK	Peer reviewed journal	20 participants (10 female, 10 male) aged 13 to 19 years. Ethnicity not specified.	Autism in adolescents, no intellectual disability.	1. How do autistic teenagers describe their experiences of masking? 2. How do autistic teenagers describe the relationship between their experiences of masking and mental health?	Semi-structured interview; Thematic analysis	Masking is associated with mental health difficulties and is driven by the social oppression of autistic people.
4	Mesa & Hamilton	2022	UK	Peer reviewed journal	13 young people (gender not reported) aged 10 – 14. All White British. 31 teachers and 16 parents also took part.	Autism, accessing a mainstream secondary school	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?	Interview wi th yp, parents and teachers; Thematic analysis	Young people felt different from their neurotypical peers. 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
5	Riccio	2021	USA	Peer reviewed journal	19 participants (1 female, 18 male), aged 14 to 19 years. 9 White, 5 Hispanic or Latino, 5 Black, 3 Asian/Pacific Islander, 1 Alaskan Native, 5 Mixed.	Autism,	1. Do parents' decisions about disclosing their child's autism diagnosis to their child impact their child's autism understanding in adolescence? 2. Do parental perceptions of autism influence their child's perception of autism? 3. Does parental disclosure	Interviews and surveys; Content analysis	Adolescents whose parents voluntarily disclosed their autism diagnosis to them described autism and themselves more positively than adolescents who did not experience voluntary disclosure.

						influence adolescents’ self-descriptions?			
6	Hanai et al.	2021	Japan	Peer revied journal	17 participants (4 female, 13 male) aged 13 to 24 years. No ethnicity specified.	3 participants with ADHD and 14 participants with Autism, all without Intellectual Disabilities	To describe the self of adolescents with ASD or ADHD by focusing on their subjective experiences.	Semi-structured interviews; Constant comparison analysis	Adolescents realised sense of self through interaction with others. Three concepts were found: “Interest in self and self-realization”, “Intentionality and self-transformation”, “Unrealized/unnoticed self”
7	Barber	2020	USA	Dissertation	10 participants (5 transgender males, 3 transgender females, 1 as gender fluid, 1 non-binary), aged 14 to 19 years. All White.	Gender diversity in autism	1) How do gender diverse youth with ASD perceive that formal and informal school structures influence their perceptions of safety and support in school?, 2) How these students perceive that formal and informal school structures influence their perceptions of feeling unsupported in their gender identities in school?, 3) How do these students perceive that their gender identities and those of other students could be better supported in school?	Interview; Thematic analysis	Gender diverse youth with autism benefit from formal and informal structures of support at school. Participants did not feel that their autistic identity was linked with their gender identity.

8	Berkovits et al	2019	USA	Peer reviewed journal	38 participants (5 female, 33 male) aged 15. 60% Caucasian/Non-Hispanic, 15.8% Hispanic, 23.7% Black/Asian/Other	Autism	To elicit and describe the experiences of adolescents with ASD in order to further understanding of adolescent perceptions of the diagnosis and what "being on the spectrum" means for them	Interview and quantitative measures; Qualitative (content?) analysis	Adolescents perceived their autism diagnosis as having negative implications, which may contribute to negative social-emotional outcomes.
9	King et al.	2019	UK	Peer reviewed journal	5 participants (5 male) aged 13 to 15. No ethnicity stated.	Autism in males	To use photo-elicitation interviews to explore the nature of self-understanding in adolescent boys diagnosed with an ASC.	Photo elicitation and interview; IPA	Themes of self in action, self extended in time and self in relation to others. *Themes* captured how participants understood themselves in terms of their actions and abilities, in the context of their past and future and in relation to others.
10	Kofke	2019	USA	Dissertation	4 participants (4 female) aged 14-15. All white.	Autism in females	1. What are the perspectives of adolescent autistic students who identify as female, girl, or young woman on their experiences learning and using social skills in high school? and, 2. How does the ongoing work of learning social skills at school, through instruction and otherwise, contribute to students' perspectives on the development of an autistic/disability identity?	Interview; IPA	Female students learned concepts about socialising while at school and used these skills in their daily lives. Students discussed the importance of friendships, dealing with sensory needs at school, the masking impulse, marking autistic identity and the intersection of gender.

11	Gaffney	2017	UK	Dissertation	6 participants (6 female) aged 14-20. No ethnicity stated.	Autism in females	To find out how girls / young women who have an autism spectrum disorder (AS) diagnosis view this diagnosis and what can be learned from hearing their voices. Research Questions: · How do adolescent females with an autism diagnosis make sense of this diagnosis? · How does the autism diagnosis impact on their sense of self?	Interview ; IPA	Themes emerged were Understanding Autism, Acceptance or rejection, and Self and Autism.
12	Cage et al.	2016	UK	Peer-reviewed journal	12 participants (11 male, 1 female) aged 12-15. 7 White British, 1 White Other, 1 White & Black African, 1 British Asian & East African, 1 White/Asian, 1 White British/Asian. 5 school staff also interviewed.	Autism without intellectual disability	To examine reputation concerns in autistic adolescents	Semi-structured interview; Thematic analysis	Autistic adolescents were sometimes concerned about their reputation, although many reported that they did not want to be cool, and wanted to be accepted for being different. Difficulties with coping with unpredictability contributed to their understanding of social rules.
13	Stevenson et al.	2016	UK	Peer-reviewed journal	8 young people (3 females, 5 males) Ages and ethnicity not stated.	Autism	To find ways to make it acceptable to talk about autism; to share the process used and also, due to the richness of material, and therapeutic value of the project, to analyse the main	Video content and podcasts; Thematic analysis	A therapeutic media project was used to facilitate discussion about what autism meant for participants. Themes emerged around making sense of diagnosis, experiences of difference and transition to

					4 adults were also interviewed.		themes that emerged from the project		adulthood. Strategies to negotiate identity and manage diagnosis were found.
14	Jones et al	2015	USA	Peer reviewed journal	10 participants, (8 male, 2 female) aged 13 to 20 years. No ethnicity stated	Autism	To better understand how adolescents with ASD identify with and make meaning of their diagnosis through a phenomenological exploration of their disability narratives	Semi-structured Interview; Descriptive phenomenology	Themes that emerged were formation of an ASD narrative, social construction of the label, and confusion whether ASD is a disability. Results indicated the need for a reduction of social stigma associated with ASD and disability labels.
15	Cridland et al	2015	Aus	Peer reviewed journal	8 participants (8 male) aged 12 to 16. No ethnicity stated. 8 families were also interviewed.	Autism in males	Understand the perceptions and experiences of adolescents with ASD from a personal construct psychology perspective.	Semi-structured interview; Thematic analysis	Personal construct methodology was found to be helpful for helping understand autistic adolescents. Themes included complexity of the adult social realm, identity development, development of flexible processing styles, sense-making in multi-faceted situations, and understanding and managing psychical and emotional changes associated with puberty.

Quality appraisal

The fifteen studies were assessed for quality using the quality appraisal tool outlined. The full results of this can be found in Table 5. The highest-scoring paper was from Tesfaye et al. (2023), and the lowest was from Stevenson et al. (2016). All of the studies provided clear aims of their research and a justification for why they considered the research important. Qualitative methodology was felt to be appropriate in all studies. The suitability of the design by Stevenson et al. (2016) was contested in this review. The design was unclear in the write-up, and it appeared that the themes of the video would then influence the themes of the podcast discussion, but there was little acknowledgement of this. Regardless of these reservations, the study was considered high quality in other areas, therefore it was included in the review.

Recruitment appeared appropriate in all but two studies, which were considered partially appropriate; however, in reporting on ethnicity, eight papers did not report the ethnicity of participants, three papers included white participants only, and four papers reported participants with a range of ethnicities.

Data collection was well described and considered sufficient across all studies. Two papers used alternative data collection methods other than interviewing. Morgan (2023) used blog posts, and Stevenson et al. (2016) used videos and podcasts.

A relative weakness was found in ethical issues, with the two studies not listing any ethical approval process and five papers only reporting the ethics board that approved the study. When interviewing young people with communication differences, more detail describing capacity, consent, safeguarding procedures and how the young person could opt out is invaluable to quality assessing ethical processes. Additionally, researcher reflexivity was reported on in six studies, partially in two studies and not considered in seven studies. It was therefore unclear in most papers the influence of researcher assumptions on the data and whether any steps were taken to address this.

Data analysis, findings, and the value of the study were generally well described in most of the studies and partially described in some others. A wide range of analytical processes were used, including thematic, discourse, constant comparison, interpretive phenomenological, and descriptive phenomenological analysis. One paper was also included that had used content analysis as it also contained qualitative quotes (Berkovits et al. 2019).

Synthesis of the findings

Twenty-five second-order constructs were identified and conceptualised under seven third-order constructs. If themes appeared particularly salient in the papers they occurred, and relevant to the review, they were included, and no limit set for how many times it must appear in other papers. The third-order constructs were: meaning-making - my autistic identity; personal processes; self in time; meaning making - stories of those around me; social connection and relationships; navigating autism in a ‘neurotypical’ world; and societal narratives. Table 6 provides a summary of the third-order constructs, their constituent themes, and which studies contributed towards them.

Table 5

Assessment of study quality using CASP appraisal criteria for quality assessment

Author	Aims	Methods	Design	Recruitment	Ethnically and culturally diverse recruitment	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value	No. of yes
Tesfaye et al (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11
Morgan (2023)	Yes	Yes	Yes	Partially	Can't tell	Yes	Yes	Partially	Yes	Yes	Yes	8
Chapman et al (2022)	Yes	Yes	Yes	Yes	No	Yes	No	Partially	Partially	Yes	Yes	7
Mesa & Hamilton (2022)	Yes	Yes	Yes	Yes	No	Yes	Partially	Partially	Yes	Yes	Partially	7
Riccio (2021)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Partially	Partially	8
Hanai (2021)	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Partially	Yes	Yes	Yes	8
Barber (2020)	Yes	Yes	Yes	Yes	No	Yes	Yes	Can't tell	Yes	Yes	Yes	9
Berkovits et al (2019)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	10
King et al. (2019)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Partially	Yes	Yes	Yes	9
Kofke (2019)	Yes	Yes	Yes	Yes	No	Yes	Yes	Can’t tell	Yes	Partially	Yes	8
Gaffney (2017)	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Partially	Yes	
Cage et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	No	Partially	Partially	Yes	Partially	7
Stevenson et al. (2016)	Yes	Yes	Partially	Partially	Can’t tell	Yes	Partially	Yes	Partially	Yes	Yes	6
Jones et al (2015)	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Partially	Partially	Yes	Yes	7
Cridland et al (2015)	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Partially	Yes	Yes	Yes	8
Total Met	15	15	14	13	4	15	6	5	11	10	10	
Total partially met	0	0	1	2	0	0	2	8	4	3	3	
Total not met	0	0	0	0	11	0	7	2	0	0	0	

Table 6

Overview of third order constructs and underlying themes

	Tesfaye et al (2023)	Morgan (2023)	Chapman et al (2022)	Mesa & Hamilton (2022)	Riccio (2021)	Hanai (2021)	Barber (2020)	Berkovits et al (2019)	King et al. (2019)	Kofke (2019)	Gaffney (2017)	Stevenson et al (2016)	Cage et al. (2016)	Jones et al (2015)	Cridland et al (2015)	No. of papers
Meaning making – my autistic identity																**14**
Autism makes me who I am	x		x							x		x		x	x	6
I am different	x	x		x		x		x	x	x	x	x				9
Understanding autism	x	x								x	x	x		x		6
Intersecting identities			x				x			x						3
Rejection of diagnosis				x	x			x			x			x		6
Personal processes																**6**
Cognitive challenges								x		x					x	3
Routine and unpredictability	x		x			x							x			4
Stimming			x					FO								2
Emotional processes	x		x			x		x				x			x	6

Table 6 continued

	Tesfaye et al (2023)	Morgan (2023)	Chapman et al (2022)	Mesa & Hamilton (2022)	Riccio (2021)	Hanai (2021)	Barber (2020)	Berkovits et al (2019)	King et al. (2019)	Kofke (2019)	Gaffney (2017)	Stevenson et al (2016)	Cage et al. (2016)	Jones et al (2015)	Cridland et al (2015)	No. of papers
Self in time																**10**
Future selves	x	x				x		x	x		x	x				7
Acceptance of autism over time		x		x								x		x		4
Past selves			x			x			x							3
Autonomy	x	x				x						x				4
Meaning making – stories of those around me																**14**
Stories of stigma and bullying	x	x	x	x				x				x		x	x	7
Stories of family		x	FO		x			FO	x		x	x				7
Masking & fitting in		x	x	x		x				x			x			6
Feeling dismissed	x	x				x										3
Social connection & relationships																**12**
Group belonging		x	x	x		x			x	x		x	x	x	x	9
Seeking relationship	x					x				x	x		x			5
Navigating social interactions			x								x		x		x	5

Table 6 continued

	Tesfaye et al (2023)	Morgan (2023)	Chapman et al (2022)	Mesa & Hamilton (2022)	Riccio (2021)	Hanai (2021)	Barber (2020)	Berkovits et al (2019)	King et al. (2019)	Kofke (2019)	Gaffney (2017)	Stevenson et al (2016)	Cage et al. (2016)	Jones et al (2015)	Cridland et al (2015)	No. of papers
Navigating autism in a neurotypical world																**10**
Access to support	x	x		x			x							x		5
Sensory needs	x		x			x		x		x			x			5
Environment as an enabler	x					x	x		x							4
Societal narratives																**7**
Disability narratives		x			x		x							x	FO	5
Community narratives		FO	x									FO				3

*x denotes appearance as a second order construct, FO denotes appearance as a first-order construct

Meaning-making - my autistic identity

This third-order construct describes how adolescents make sense of their autism identity. Fourteen of the studies featured young people navigating what autism meant to them. There appeared to be a distinct theme of ‘autism makes me who I am’ where participants recognised that autism made up a part of themselves (Chapman et al., 2022; Cridland et al., 2015; Jones et al., 2015; Kofke 2019; Stevenson et al., 2016; Tesfaye et al., 2023).

> “*I wouldn’t change the fact that I have autism because it’s who I am. And I think if I really did change that it would be really bad because I’d be changing a part of me*” (Tesfaye et al., 2023; p5).

This was often linked to unique characteristics and strengths participants had associated with autism, like increased creativity or cognitive benefits like a better memory (Tesfaye et al., 2023).

> “*Well. The brain, when my brain, you know there’s the left side of the brain, the right side of the, brain the hemispheres?...Left side of the brain’s all about work and logical things…Right side of the brain’s all about creativity and stuff…In my brain my autism makes it so that my right side of the brain is always dominated over the left side...So, I’m more prone to using the right side of my brain rather than the left side of my brain (Kofke, 2019p. 94)*”,

‘Autism makes me who I am’ was interwoven with the second-order construct of ‘I am different’. Nine papers mentioned participants making comparisons to their peers and seeing themselves as different from ‘normal’. Difference was sometimes seen as positive and a strength (Berkovits et al., 2019; Mesa & Hamilton, 2022; King et al., 2019;), negative (Hanai et al., 2021), both (Kofke 2019; Stevenson et al., 2016), or neutral (Gaffney, 2017; Morgan, 2023; Tesfaye et al., 2023).

For some, it was difficult to accept the perceived difference and they rejected their diagnosis (Berkovits et al., 2019; Gaffney, 2017; Jones et al., 2015; Mesa & Hamilton, 2022; Riccio, 2021).

Participants spoke about their understanding autism in six papers (Gaffney, 2017; Jones et al., 2015; Kofke 2019; Morgan, 2023; Stevenson et al., 2016; Tesfaye et al., 2023), and this varied greatly across participants. Some showed understanding and had done further research themselves, some showed awareness of the spectrum, and some showed little understanding beyond being told they had it.

Three papers highlighted intersectional factors influencing identity (Barber, 2020; Chapman et al. 2022; Kofke, 2019). Chapman et al. (2022) highlighted class and Kofke (2019) highlighted gender as other intersectional factors that can interact with autism identity.

Barber's participants were all gender diverse with autism, who felt like their gender identity was not linked to them being autistic, although one person highlighted:

> "*Well, from things I have researched on my own through online things, it seems like people with autism and people who are a bit more neurodiverse usually are more likely to have gender dysphoria, from what I read at least. Not sure if it's actually true or not, but I definitely think since I have autism, it might make a bit more likely for me to identify as transgender*".

Table 7 provides examples of first-order and second-order constructs used in the development of this third-order construct (see Appendix B for the full extraction table). This third-order concept was formed from fourteen of the fifteen papers; major contributing studies were Tesfaye et al (2023) and Gaffney (2017), which were considered high quality and Stevenson et al., (2016) and Jones et al (2016), which were considered moderate quality. These four papers were published over a range of years and did not reflect a change in adolescents' perspectives over time.

Table 7 *Meaning making of my autistic identity – example first and second-order constructs*

Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Tesfaye et al. (2023)	"I wouldn't change the fact that I have autism because it's who I am. And I think if I really did change that it would be really bad because I'd be changing a part of me. So I'd say make it easier that I can have friends" (p.1147)	Although they identified many challenges linked to autism traits or perceived autism traits, they recognized that being autistic was part of their identity. Youth indicated that rather than changing who they are as autistic individuals, they would prefer barriers in their environment, or specific behaviors with which they struggle, to change. Hence, youth conveyed that they were "OK" with their autism diagnosis, but they wanted being autistic to be easier…. Participants also identified positive aspects of being autistic. Similar to the challenges, some advantages were directly linked to clinical autism features (e.g. developing knowledge and skills by focusing on specific interests), while other advantages were related to cognitive abilities (e.g. having a good memory, being "smarter," and seeing situations uniquely or creatively). P1147	Autism makes me who I am
Stevenson et al (2016)	"I wouldn't want to change it, I'm perfect the way I am. I don't want to change who I am" (p.225)	… the theme of accepting autism also came up for many students (p.225)	
Tesfaye et al. (2023)	"Ahm, like a lot of times, autistic people's brains work differently . . . Like, if you look at it, a neuro-typical brain and an autistic brain you won't find anything different by individually looking at them. It's just the paths of how things	Autistic Identity. Youth described autism in complex and nuanced ways. There was no overwhelming preference for describing being autistic as either negative or positive. Many of the participants described the	I am different

	transmit in a neuro-typical brain and an autistic brain are different. It’s kind of like how people, it’s kind of like Canadian and American people write back and forth and Chinese [people] write up and down.” (p.5)	diagnosis as a human variation stemming from differences in brain function (p.1147)	
Mesa & Hamilton (2022)	“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 lables are a bad thing… I like being labelled autistic, I don’t know why…because it’s the reason I am why I am.” (p.9)	‘an autism diagnosis had been exonerating in explaining the basis of their perceived difference and they have positively integrated the idea of ‘being autistic’ into their personal identity’ (p.9)	
Jones et al. (2015)	‘When asked whether there were any other ways he learned about autism, Chris said: ‘Studies and therapy, and a whole bunch of suspicion of why the heck am I doing this sort of stuff. Plus, my curiosity at why I have such a hard time at school.’	Chris expressed that he knew so much about autism because of his lived experience and interest in understanding his unique behaviors and need for supports.	Understanding autism
Stevenson et al (2016)	‘I don’t get it. So now I’m thinking my brain is not developed properly. Does it mean my brain? The wires in my brain are not connected? That’s what, I’m confused now.’‘So now it’s a lot different but it’s still new. No-one knows exactly how autism is affected, no-one knows how it affects you and no-one knows why it’s given to you.’‘Lots of kids like me who have got it, don’t know what it is, they tell you you’ve got it, but you don’t know what it is. (p.220)	Quite often in the interviews (especially when discussing causes of autism) there was a sense of confusion for the students	

Berkovits et al (2019)	It’s terribly sad when I have to go through this, cause no one wants to have Asperger’s (p.837)	42.1% of adolescents described a variety of perceived burdens related to having a diagnosis of ASD.	Rejection of diagnosis
Gaffney (2017)	. . . I wish that sort of, I wish, that I don’t have it and don’t want to know, I don’t like saying that I have it, cause for me it don’t feel comfortable saying it, it feels something not right. When I speak with people who don’t have anything wrong with them it feels awkward and all that for me.	Kerry has always had a negative response towards her diagnsosis… she does not want autism in her life	
Chapman	I remember trying to act calm or normal in a posh, rich area… so like imagine this everyday person, you know, you see them on the street. Now imagine them in a restaurant. A rich one. Just like being awkward. With the handkerchief on his lap (p.10) ‘	Teenagers also alluded to ways in which being autistic intersected with other aspects of their identity in specific contexts’ (p.10)	Intersectional identities
Kofke (2019)	Well. I’ve heard that autistic women, like myself, tend to be kind of shy. You know. Or they might be a bit irritable…Kind of like me…considering the fact that I don’t really understand, like the difference between autistic women and autistic men quite yet. Like I guess ah. Not sure. I just, I just know. I’m not an expert, you know. I’m just going based off of what I’ve seen. You know…But you know, I think. I don’t think these things are exclusive to women though. I think ah, I think autistic guys might be shy or antisocial, or they might be really irritable, like me. (p.135)	There was an intersectional component to these student’s social lives at school and how that impacted their school experience …. This theme focused on the impact of their understandings of their gender as a female, girl, or young woman and any intersections with autism. Each student conceptualized identifying with their gender differently. They felt autism or neurodivergent traits, which affected each person differently, regardless of gender. (p.70).	

Personal processes

This third-order construct refers to the individual cognitive and emotional processes young people with autism are managing in their day-to-day lives. Three papers referred to the process of dealing with cognitive challenges associated with autism (Berkovits et al., 2019; Cridland et al., 2015; Kofke 2019), which included rigid thinking styles and difficulties with executive function.

The need for routine and dislike of unpredictability was highlighted in four papers (Cage et al., 2016; Chapman et al., 2022; Hanai et al., 2021; Tesfaye et al., 2023). Young people found coping with change difficult, and tasks becoming familiar was helpful in easing anxiety

> *"If it's something where I'm going every day, school particularly, it gets easier. So lessons are better. I don't have to worry about that kind of stuff at school. Occasionally it comes back though usually if I'm talking about something new. If it's something rehearsed like public speaking it's actually not that bad because it's rehearsed. That's why because I've done drama before and I don't really have a problem with projection because it's a rehearsed idea"* (Chapman et al., 2022, p.9).

Two papers referred to the process of 'stimming' (self-stimulatory behaviour), which is s the repetition of physical movements, sounds, words, moving objects, or other behaviours, feeling good and leading to cognitive and emotional relief (Berkovitz et al., 2019; Chapman et al. 2022).

Six papers referred to emotional processes, which included feeling and coping with different emotions (Berkovits et al., 2019; Chapman et al., 2022; Cridland et al., 2015; Hanai et al., 2021; Stevenson et al., 2016; Tesfaye et al., 2023). Chapman et al., (2022) highlighted how challenges autistic adolescents have to deal with in everyday life can have a direct impact on mental health:

> *"One participant spoke about how the exhaustion and impact of masking took a profound toll on their mental health and how at times this led to suicidal thoughts and feelings (p.13).*

Table 8 provides examples of first-order and second-order constructs used in the development of this third-order construct. Six papers contributed to this construct, spanning 2015-2023. Chapman et al. (2022) and Berkovitz et al. (2019) were key contributing studies, which were considered moderate and high quality, respectively.

Table 8

Personal process – *example first and second-order constructs*

Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Cridland et al (2015)	He gets very fixed on an idea. It can be very frustrating at times but it can be good at other times…If he has an idea on something…he will stick to that even if you tell him it is wrong… (Brother, Family 2) [He] thinks he is right all of the time and that is his downfall…sort of contradicts everything you say. He's a real challenger; he will challenge you on everything. (Father, Family 6)	The majority of family members (n = 15/19) discussed the adolescents' tendency to have rigid thought processing styles rather than developing flexible processing. Common areas of rigidity included retaining an opinion despite conflicting evidence, following rules without exception, difficulty accommodating change, and perfectionism (p.359)	Cognitive challenges
Kofke (2019)	She described that she would "want to do it with a passion" and then she found she "can't bring myself to do it at all."	Ernie discussed what she termed issues with "executive dysfunction" where she either could not start a school project, despite thinking about and had desire to start the project. … Alternatively, she had a hard time stopping her work on a project that she was intently focused on and did not want to complete it. In these examples, Ernie was describing what it was like to have autistic inertia, a common phenomenon among autistic people. (p.155)	
Cage et al. (2016)	"I do not like people leaving and then coming. It kind of confuses me. I just like it being all the same people, the same always"	Coping with the unpredictability of everyday life (page 17)	Routine and unpredictability
Hanai et al. (2021)	When I became a high school student, my relationships also changed anew, and I worried about getting involved with people	In many cases, when participants experienced environmental changes, they became to think about themselves.	

	in a new environment. How do I get used to the environment? I had to look at myself as necessary. (p1671)		
Chapman et al. (2022)	Everything in my brain just vanishes for a second, and I feel like I'm able to just process everything and all I think about really is the running. I don't care what happened. I just want to run run run run run… it all just vanishes, it all just melts away suddenly. Because all I really want in life is to be free.	When these participants were able to express themselves freely, particularly though stimming, they described an immense emotional, sensory and cognitive release	Stimming
Berkovits et al., (2019)	I sometimes talk to myself and make weird sounds. I sometimes repeat things other people say. And it just, it naturally makes me feel good."	N/A	
Tesfaye et al., (2023)	Interviewer: When you are feeling sad, how do you usually deal with that emotion? Participant: I ignore it. Interviewer: That's OK. OK. So when you are feeling nervous, how do you usually deal with that emotion? Participant: I go to bed. (p.1150)	Experiences of stress and anxiety Throughout the interviews, experiences related to anxiety and stress were consistently raised by participants. As mentioned earlier, both school and the future were identified as primary stressors; however, manifestations of anxiety and stress arose across all of the subjects discussed. In a minority of cases, participants described depression and helplessness…. In addition, many youth expressed that they did not have strategies for coping with anxiety or stress, stating they often "endure" these periods or ignore them: (p.1149)	Emotional process
Chapman et al. (2022)	"For some people, it will be easier to not exist rather than to exist. There have been countless times in my life where I have felt that and it has taken me great courage to keep on existing" (p.13)	One participant spoke about how the exhaustion and impact of masking took a profound toll on their mental health and how at times this led to suicidal thoughts and feelings	Emotional processes

Self in time

This third-order construct encompassed how participants made sense of their identity over time. This included looking to past experiences and reflecting on how they had come to understand themselves (Chapman et al. 2022; Hanai et al, 2021; King et al., 2019). Many participants referred to their hopes and worries about the future (Berkovits et al., 2019; Gaffney, 2017; Hanai et al., 2021; King et al., 2019; Stevenson et al., 2016; Tesfaye et al., 2023). Participants often had ambitions about going to university, different career paths, becoming their best selves, or living independently and having relationships. Some were worried about coping with the pressures of this and whether they would find someone who would want a romantic relationship with an autistic person

> *"I don't know if I'll be able to marry anyone, because who wants to marry a guy who has Asperger's? And if I marry someone I'm going to have to tell them I have Asperger's… I can never really have a child because there could be the fear of, you know, having, putting another person with Asperger's in the world."* (Berkovits, 2019, p836).

The skill of autonomy was mentioned in four papers and was linked to building and developing independence skills in the present time, which could lead to coping in the future (Hanai et al., 2021), Morgan, 2023; Stevenson et al., 2016; Tesfaye et al., 2023).

For others, four papers referred to the acceptance of autism into their personal stories over time (Jones et al., 2016; Mesa & Hamilton, 2022; Morgan, 2023; Stevenson et al., 2016),

> *"Like I was in denial with this whole thing since freshman year. I started to agree during my junior year. I started to see all of the signs and was like yeah I have it."* (Jones et al., 2016, 1496).

Table 9 provides examples of first-order and second-order constructs used in the development of this third-order construct. Ten papers contributed overall to this construct, spanning several years (2015-2023). Morgan (2023) and Stevenson et al. (2016) were key contributing studies, which were considered high quality and moderate quality respectively.

Table 9

Self in time – example first and second-order constructs

Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
King et al. (2019)	I remember this day and it was really, really funny. We were driving to school and it was really icy, this road that was a bit of a shortcut, and we [Dad and I] call it cat road because we see lots of cats and it was actually quite scary because it was really icy and dad accidentally crashed into the back of this van. (p.237)	Self-extended in time For some participants, reflecting on the past contributed to self-understanding. Rory recalled a series of specific events including a birthday celebration, a difficult situation that lead to the development of a close friendship, a "funny story" relating to a family friend and a "scary" car crash. (p.237)	Past selves
Chapman et al (2022)	"I don't really like talking about what they [my social skills] were like at the time because it's really embarrassing because. Because I used to board and partly why I left boarding is because the care team kept talking to me about what I used to be like. And, I kept saying, please could you stop talking about what I used to be like? I'm really ashamed of the person I used to be… Like because I'm not the idiot I was then. Like I never thought about anything'	Participants spoke about feeling ashamed of their past social skills, behaviour or expression of distress.	
Morgan (2023)	"I also realised that I'm going to have this my whole life and I began to stress about the future - will I be able to cope in a job?" (p.189)	A majority of participants talked about their future self, the ways they were trying to improve themselves, or fears about the future as an autistic person… Participants spoke or wrote about academic qualifications and future careers as destinations they were focussed on	Future selves

		working towards, or of skills they were working hard to learn… However, a further challenge for autistic adolescents is how to manage the potential dissonance between constructing the self as a person with support needs alongside a future self who will have a job, career and independent life beyond the immediate family, as is so often the normative ideal in western cultures. (p.188)	
King et al. (2015)	If I don't do it [music practice] I'm going to be stuck and then there's no point in me carrying on is there? Not if you've got nothing to show what you've done and if [I do] by year 11 or maybe year 10 I would be able to teach people how to play the trumpet.	Holding in mind a future possible self appeared to help participants make important decisions and provided motivation. Having established his identity as a musician, Henry hoped to attend a prestigious music school and pursue a career as a music teacher. Holding this future in mind reinforced his commitment to current musical endeavours.	
Tesfaye et al. (2023)	Interviewer: Who will make the important decisions [in your life]? Participant: Probably my parents [. . .] I'd go to more places, like maybe instead of making my parents go do the groceries, I would probably go do it. (p.1149)	Seeking autonomy. It was clear that many youth wanted to gain autonomy, particularly in the sense of being able to make independent decisions about matters that affect them.	Autonomy
Hanai et al. (2021)	I had some pets, they were mine, so I had to take care of them. My parents told me it was about time for you to work. Well, I hate to be told so, … and I did my best [to find a job]. (D/24, f)	Participants imagined what they wanted to be, such as being on their own and independent from their parents.	
Morgan (2023)	I feel that l have learnt to accept myself and will continue to learn to be my best self . . .but l don't	A discourse of individualism is used in participants' constructions of the self in the process of "becoming" a hoped-for future self.	Acceptance of autism over time

	think the world is ready to be understanding and supportive.(p.188)	A majority of participants talked about their future self, the ways they were trying to improve themselves, or fears about the future as an autistic person. Journey metaphors were often used which constructed the future as a destination, with autism as one of the potential roadblocks to progress… Participants spoke or wrote about academic qualifications and future careers as destinations they were focussed on working towards, or of skills they were working hard to learn. (p.188)
Jones et al. (2015)	‘Like I was in denial with this whole thing since freshman year. I started to agree during my junior year. I started to see all of the signs and was like yeah I have it.’(p.1496)	Kelly described that over time she was able to reflect on her process of making meaning of her diagnosis (p.1496)

Meaning-making: The stories of those around me

This third-order construct focuses on how an individual's identity construction may be influenced by other people's stories about them. Fourteen papers included references to interactions with other people. Stories of bullying and stigmatisation were present in seven papers (Berkovits et al., 2019; Chapman et al., 2022; Jones et al., 2015; Mesa & Hamilton, 2022; Morgan, 2023; Stevenson et al., 2016; Tesfaye et al., 2023), which aligns with previous findings, which find that the prevalence of bullying for autistic young people is higher than for their neurotypical peers (Maiano et al. 2016). Autistic young people shared being called names, including being seen as 'freaky' (Mesa & Hamilton) or the 'weird kid' (Berkovitz et al., 2019) and facing prejudice

> "*Ahh, mainly lots of people can misjudge me sometimes and I'm like "dude I'm a regular person" and a few people are like "you'll never get a girlfriend because you're autistic," and I'm like "wow, that's a little prejudice, there.*" (Tesfaye et al., 2023; p 1147).

Following bullying or seeing themselves as different to peers, as seen in the previous third order construct, many young people reported masking who they authentically were to fit in (Cage et al., 2016; Chapman et al., 2022; Hanai et al., 2021; Kofke, 2019; Mesa & Hamilton, 2022; Morgan, 2023).

Family stories also played a role in shaping how young people saw themselves (Chapman et al., 2022; Gaffney, 2017; King et al., 2019; Morgan, 2023; Riccio, 2021; Stevenson et al., 2016). Riccio (2012) found that parental perception and disclosure of diagnosis impacted how young people saw autism. Those who had not had their diagnosis voluntarily shared with them were more likely to have a negative perception of autism. Conversely, those who had it openly shared were less likely to perceive a stigma as openness discards the notion that there should be any form of secrecy or shame. Similarly, Gaffney

(2017) found that stories that had arisen from a problem context where young people were referred for a diagnosis following difficulties at school were more likely to have a negative story of themselves. Other participants spoke about supportive family members and family belonging, which helped them to feel supported and happy.

Participants highlighted occasions where they had felt dismissed by others due to being ‘othered’ or their emotions being dismissed as a part of their autism and not seen as valid (Hanai et al., 2021; Morgan, 2023; Tesfaye et al. 2023).

These studies highlight the challenges individuals with autism face and how other people’s perceptions play a role in the suppression or celebration of authentic identity.

Table 10 provides examples of first-order and second-order constructs used in the development of this third-order construct. Fourteen papers contributed overall to this construct, spanning a number of years (2015-2023). Key contributing studies were: Morgan (2023), which was considered high quality, and Chapman et al. (2022) and Hanai et al. (2021), which were considered moderate quality.

Table 10

Meaning-making: The stories of those around me – example first and second-order constructs

Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Tesfaye et al. (2023)	"Ahh, mainly lots of people can misjudge me sometimes and I'm like "dude I'm a regular person" and a few people are like "you'll never get a girlfriend because you're autistic," and I'm like "wow, that's a little prejudice, there." Probably. I don't know if, I don't know what they would call it when people don't like people under the spectrum" (p 1147)	It is of note that while the participants did appreciate the opportunity to engage with peers during school, experiences of bullying and stigmatization were commonly brought up as barriers at various stages of their school careers. (P1149)	Stories of stigma and bullying
Berkovits et al. (2019)	"The kids didn't understand me so that would cause them to pick on me. But everyone else I think kind of sees me as a weird, almost insane kid with awkward opinions. Like they just see me as the weird kid I am… I think they don't really understand how to react to me."	Other comments regarding social difficulties included experiences of being teased or bullied, feeling misunderstood by others due to their ASD diagnosis, or perceiving deficits in their social skills due to having ASD	
Stevenson et al. (2016)	My sister makes me feel happy, when I tell her she says the people who take the mickey are idiots and I shouldn't listen to them.		Stories of family
Morgan (2023)	"I don't feel that l belong in any group. I feel l am an outcast. I belong with my immediate family" (p190)	Belonging in family	
Mesa & Hamilton (2022)	(parent) "because he has held it together all day at school, when he is home,	Social camouflaging at school… these accounts suggest that young people	Masking and fitting in

	he is a total wreck”. (p 13)	often experience the home environment as a sanctuary, where the ‘mask’ worn at school, under social pressure to ‘fit in’, can be dropped. (p14)	
Hanai et al. (2021)	“I also wanted to think that I was an ordinary girl, I also wanted to be thought that by others too. Even though I knew I was different from others, but I do not want to go [psychiatry] because I usually think that it is good to be normal. So, why do I have to go [psychiatry]? [The doctor told me that] I got better, I was glad, but if I got better, do I need to come [to see the doctor], don’t I?”	Participants were keen to be accepted by others. They wanted to be normal, and to be considered normal by others	
Tesfaye et al. (2023)	(points to letters on an alphabet display board) I-H-A-T-E-D I-T B-E-C-A-U-S-E- T-H-E-Y- T-R-E-A-T-E-D- M-E L-I-K-E A-N I-D-I-O-T (p.1149)	School was the primary stressor for the majority of participants…Many described the school environment as unwelcoming, a detriment to their wellbeing, and a barrier to future aspirations.	Feeling dismissed
Hanai et al. (2021)	Because they (parents and teacher) only say, “you should try your best first,” or “let’s go as it is for a while.” So I didn’t talk to my mom about something even I had trouble with in school. Well, I thought it was worthless to talk to people, both the counselor and my family.	“On the other hand, more than half of the participants [sic] not to express their emotions but to work things out on their own.” (p.1671)	

Social connection and relationships

This third-order construct describes the importance of social connection and seeking relationships for autistic adolescents. It is a common misconception that autistic individuals do not seek out social connections or relationships with others. This construct demonstrates the importance of friendship and connection for autistic adolescents despite the difficulties they may have navigating within the complex social realm.

Group belonging was highlighted as an important factor in feeling accepted in ten papers (Cage et al., 2016; Chapman et al., 2022; Cridland et al., 2015; Hanai et al., 2021; Jones et al., 2015; King et al., 2019; Kofke 2019; Mesa & Hamilton, 2022; Morgan, 2023; Stevenson et al., 2016;). Participants built connections facilitated by an activity, interest, or shared characteristics.

> *‘I think of a lone jelly bean all by myself. No friends, until he realizes, I’m not alone; I’m not the only jelly bean. There are jelly beans just like me, I’m not alone.’* (Jones et al. 2016, p. 1499).

Five studies identified individuals seeking relationships with others (Cage et al., 2016, Hanai et al., 2021, Tesfaye et al. 2023). Four studies mentioned navigating social interaction and the difficulties they had (Cage et al, 2016; Chapman et al. 2022; Cridland et al. 2015 & Gaffney 2017).

Table 11 provides examples of the first-order and second-order constructs used in the development of this third-order construct. Twelve papers contributed to this third-order construct, spanning from 2015-2023. Cage et al. (2016) was a key contributing study, which was considered moderate quality.

Table 11

Social connection & relationship – example first and second-order constructs

Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Chapman et al. (2022)	And church… there's a few kids who have an autism diagnosis. I get on well with them… It's just this circle of complete and utter transparency and honesty, and it makes my life so much easier (p.9)	Most commonly, participants felt more authentic in their interactions with other autistic people, people they knew well, particularly close friends and family members, people who knew they were autistic and people who they shared interests with or felt similar to. (p.9)	Group belonging
Jones et al. (2015)	'I think of a lone jelly bean all by myself. No friends, until he realizes, I'm not alone; I'm not the only jelly bean. There are jelly beans just like me, I'm not alone.' (p.1499)	James' recognition of others who share similar experiences gave him a sense of belonging and group membership among others with ASD that appeared to change the meaning of his diagnosis in regard to his self-identity.	
Tesfaye et al. (2023)	"I'd rather have a few close friends rather than just more friends… More close friend, I guess it would just kind of give me another purpose in life, like something to care about beyond the usual" p1148	Seeking social connection on their own terms. Despite enjoying being alone sometimes, many participants expressed a need to connect more with other people. P1148	Seeking relationships
Cage et al., (2016)	You can rely on each other, you can cheer each other up, and there is just someone there to help you and be friends with you, someone who cares.	Friends gave them emotional support (page 17)	
Gaffney (2017)	… and eye contact, I'm awful at and talking to people, small talk I'm	Communication… Ellie talks about finding conversations difficult	Navigating social interactions

	awful at… It’s really odd but I’d rather do public speaking than… I find it a lot easier than just trying to hold a conversation with someone (p.65)		
Chapman et al. (2022)	“I’ve realised like why kids never used to like me, because my social skills weren’t good enough. But now that they’ve got better so hopefully no one will criticise me on them because I’ve had teachers at school criticise me on them. And I go to a special needs school, where they should really be encouraging me… I used to be told a lot to keep things inside my head. It’s been very hard for me.” (Participant 11)	Specific experiences were shared of times when teenager’s social differences were criticised by important people in their lives.	

Navigating autism in a ‘neurotypical’ world

This third-order construct describes how the immediate environment can have an impact on autistic adolescents. Five papers referenced support structures in school (Barber, 2020; Jones et al., 2015; Mesa & Hamilton, 2022; Morgan, 2023; Tesfaye et al., 2023). Support was felt to be needed to manage the expectations put on the young people and to manage bullying. Conversely, one participant highlighted how support may impact further on being ostracised by others, “[support would] probably ruin my already practically non-existent social standing even further” (Mesa & Hamilton, 2022, p10).

Five papers highlighted the impact of sensory differences in their daily lives, citing noise, overwhelming classes, and visual stimuli (Berkovits et al., 2019; Cage et al., 2016; Hanai et al., 2021; Kofke 2019; Tesfaye et al., 2023).

Four papers highlighted how the surrounding environment can be an enabler for young people to access what they liked to do or support who they wanted to be (Barber, 2020; Hanai et al., 2021; King et al., 2019; Tesfaye et al., 2023).

Table 12 provides examples of the first-order and second-order constructs used in the development of this third-order construct. Ten papers made up this third-order construct. While support structures were mentioned across the studies published between 2015 and 2023, this was more frequent in papers between 2019 and 2023, which may reflect a change in thinking from autism being considered an individual medical manifestation, to being seen as a social disability, which requires universal environmental change. Tesfaye et al. (2023) was a key contributing study, which was considered high quality.

Table 12

Navigating autism in a neurotypical world – example first and second-order constructs

Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Morgan (2023)	"It just makes me sad how I needed to go through years of struggles and tough times for then a diagnosis to suddenly change everything. It makes me think that I could've had these adjustments much sooner if school were more willing to see me as more than just a badly behaved girl." P185	This discursive construct was used in talk that constructed the self in terms of being a person with support needs. It constructed the self as being inhibited, disabled or constrained by a lack of access to the right supports (p185)	Access to support
Tesfaye et al. (2023)	"I had this one teacher in grade 4 who people said she was very caring and kind, like all the people who ever met her said. So and I walked up to her, told her I was being bullied and she literally straight up said she did not care. After that I lost a lot of trust and after that I really . . . got the sense that the world is a terrible place—that like you can never know what someone is actually thinking. They could be a liar . . . I just ended up being scared of the world . . . And after that it prompted me to go to homeschool because I never wanted to have that	Participants identified multiple stressors in their school environment, including a lack of positive rapport with teachers (p.1149)	

	experience again.”		
Cage et al. (2016)	“It is very distracting when the class is being a bit noisy. I really do not like that all”	Notable challenges related to school (p.17)	Sensory needs
Berkovits et al. (2019)	“Sometimes, if there’s something that distracts you, like a shiny object or like a big touch, or something gets like a little bit disturbing for autism. But I don’t have that kind of problem, but except for my eye problem. I don’t know why, every time when I see like some kind of corner… Like if for example, butts like out, like more out pointing, I get distracted. Like I start rubbing my eyes to just like get some kind of pressure off.”		
Hanai et al. (2021)		Almost half of the participants said they felt blessed with their environment and grateful to their families and the people around them. (p 1673)	Environment as an enabler
King et al (2019)	I’m sort of quite active and adventurous. I don’t like being inside, I’m always outside.	I am what I do. This sub-theme encapsulated how participants made sense of themselves in relation to everyday activity, or an activity that they particularly enjoyed or disliked (p.235)	

Societal narratives

This third-order construct is made up of wider societal discourses and how they are a part of young people's story of identity. The dominant medical model narrative of autism as a disability came up in five papers (Barber, 2020; Cridland et al, 2015; Jones et al., 2015; Morgan, 2023; Riccio, 2021). Across the five papers, there were mixed views on whether autism should be classed as a disability. "I mean, that depends how you identify a disability. Technically speaking, and generally how I identify myself, no. But some people view autism as a disability". For others who did see autism as a disability, they considered it positively (Cridland et al., 2015; Morgan, 2023): "*I actually really like having this disability because it actually makes me feel a bit special*" (Cridland et al, 2015 p.359). This fits with the second-order construct of 'autism makes me who I am' and is in line with the neurodiversity movement. There did not seem to be a pattern in older studies being more aligned with a disability narrative and newer studies being aligned with neurodiversity, as predicted might be the case before the literature search. In fact, neurodiversity was not quoted in any of the fifteen papers.

Other community narratives identified had themes of wanting to see a change in society regarding how autism is portrayed (Morgan, 2023) or viewed by others (Stevenson et al., 2016), and an acceptance between autistic and non-autistic people working both ways:

> *"I feel like if I need to accept them a bit, they need to accept me a bit… it's just come from this like sense that if I have to accept neurotypicals' way of thinking, then why can't they accept mine?"* (Chapman et al., 2022, p.8).

Table 13 provides examples of the first-order and second-order constructs used in the development of this third-order construct. Seven papers contributed to this third-order construct. Morgan (2023) was a key contributing study, which was considered high quality.

Table 13

Societal narratives of autism – example first and second-order constructs

Author	Example first order constructs (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Morgan (2023)	I hated it at first as what I had seen in the media portrayed autistic types as annoying, socially awkward men that had no chance of a normal life being used as a laugh. (p.190)		Community narratives
Chapman et al. (2022)	"I feel like if I got myself into a scenario in life where I have to completely redefine myself, just to fit the scene, I'm questioning if I want to be a part of that scene, because I feel like if I need to accept them a bit, they need to accept me a bit… it's just come from this like sense that if I have to accept neurotypicals' way of thinking, then why can't they accept mine? So like, if you want me to rein it in mostly, sure, that's perfectly fine. But if you want me to be a different person for like seven to eight hours of the day, then you're asking for something that I'm not in the mood to give you. In some ways autism makes me more capable than normal people" (p8)	Some shared strong convictions about acceptance between autistic and non-autistic people needing to work both ways and illustrated in their descriptions how a positive self-image and a positive narrative directly reduced or prevented the need for masking (p.8)	
Riccio (2021)	As a condition that makes it more difficult for people to understand certain things that other people say but brings their attention to other things that other people might not notice. It's just a different way of thinking. It shouldn't be called a disability or disorder. (p.386)		Disability narratives

Morgan (2023)	“Oh I would say that like autism is like a type of disability that some people have. And that’s like OK to have a disability p185 I don’t quite know how to feel about being autistic as it is perceived as being rather negative, a disability that can hold you back. (p188)	A diagnostic discourse enables access to rhetoric that legitimises the need of autistic people to have access to social and educational supports, through a social model of disability rhetoric (Oliver & Sapey, 1983). Three participants made use of the word “disability” to describe autism, and it was most often in a positive way. P185

Discussion

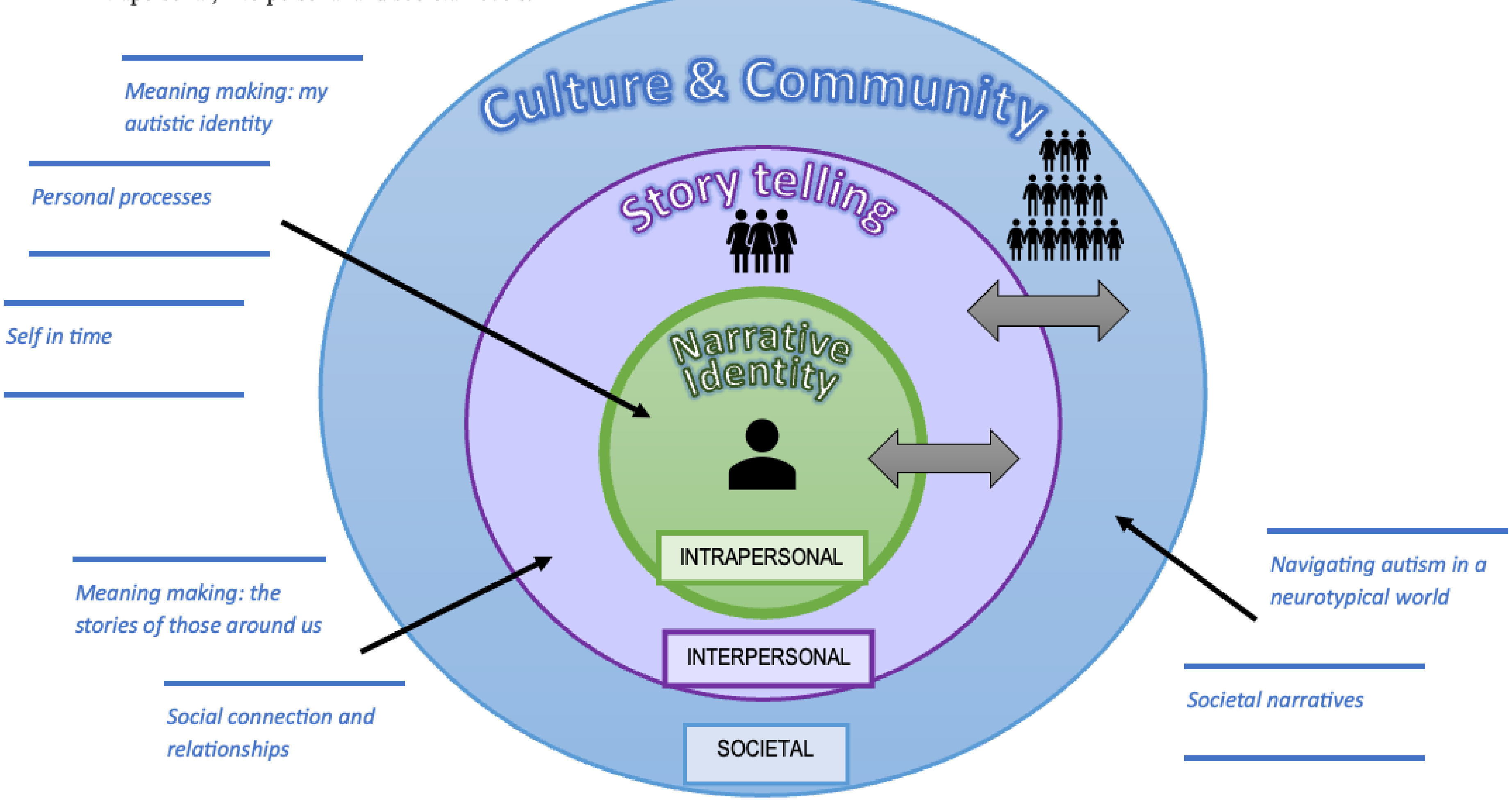
The aims of the review were threefold: to understand the stories of identity development in autistic adolescents, to understand the impact of the stories of others as identity is co-constructed, and to develop a theoretical framework of autistic identity formation. To do this, fifteen qualitative studies exploring autistic adolescents' stories of identity development were reviewed. A systematic literature search, critical appraisal, and meta-ethnographic synthesis were then conducted. Seven third-order constructs were developed from 25 underlying researcher-interpreted second-order constructs. These were: meaning-making: my autistic identity; personal processes; self in time; meaning making: stories of those around me; social connection and relationships; navigating autism in a 'neurotypical' world, and societal narratives. In each case, the themes were well supported by several high-quality studies. These constructs were integrated into a theoretical model of identity development (see Figure 2) based on McAdams's model of identity development (McAdams and McLean, 2013) and influenced by Granic's theoretical model of identity development in the digital age (Granic et al., 2020). Whilst aspects of the model also may be relevant for neurotypical adolescents, the focus of this review was specifically to integrate findings for young autistic people. This included particular contributions in terms of the influence of navigating autistic identity in a neurotypical world, social narratives of autism, social communication differences and relationships with others.

A theoretical model of identity development in autistic adolescents

There was a clear interaction between the three different levels of factors to affect narrative identity and identity development in general. The findings from the review indicated there is a clear difference in how autistic adolescents constructed their identity in comparison to their neurotypical peers due to the additional challenges they faced in a neurotypical world. The three levels are explored in the following sections.

Figure 2

Diagrammatical representation of how meta-ethnography findings integrate with the narrative identity model, with factors at the intrapersonal, interpersonal and societal levels.



Stories of identity development in autistic adolescents – intrapersonal factors

Of the third-order constructs in this review, meaning making: my autistic identity, personal processes and self in time composed the stories of identity development that young people told. Intrapersonal factors are processes that function within individuals and can lead them to infuse their narrative identity with purpose and consistency. Participants who understood autism and were able to reflect on their autistic strengths and differences positively were more likely to conceptualise their autistic identity in either a neutral or positive way. This corresponds with McAdams' idea of agency (McAdams and McLean, 2013) where adolescents can stop conforming to social expectations and begin to explore their own strengths, proposed as a key element for identity development, leading to self-mastery, empowerment and achievement. For these participants the diagnosis was more likely to be seen as a turning point, which allowed them to understand how they were different to their peers and how that difference could be positive. Those who did not understand the nuances of autism or saw autism as a difference from 'normal' via not meeting social norms were more likely to see an autism diagnosis as negative and reject the diagnosis. This had a direct relationship with the stories told by others at the interpersonal level of the theoretical model. Past research has shown that narrators who find redemption in their life stories have been found to have higher levels of mental health, wellbeing and maturity (McAdams & McClean, 2013). It could be that those who initially struggle with their autism diagnosis but come to accept it in time follow a similar redemption arc when they integrate the diagnosis into their personal narratives.

A temporally meaningful story of the evolution of self is considered a basic psychological need (Erikson, 1968). Narrative identity consists of a life story over time that incorporates past experiences and projection to the future self. This was evident in the stories of young people who brought up past significant memories that connected to their present selves and linked their present self and their autonomy to their hopes, dreams and worries for their future selves. A part of autistic adolescents' day-to-day lives was navigating personal cognitive and emotional processes. These were strongly linked to navigating autism in a neurotypical world and the stories of others. Participants described cognitive challenges related to autism and also how they used stimming to cope with cognitive overwhelm. Cognitive challenges could lead to emotional processes of feeling strong emotions. When these were constant and participants did not have constructive ways of coping with the emotions this could have a direct impact on their mental health (Chapman et al., 2022).

The impact of others in autistic adolescents' identity development – interpersonal factors

Interpersonal factors influence how narrative identity is shaped during social interactions. McAdams highlights the importance of storytelling and meaning-making in the identity development process to cultivate a stable and coherent sense of self. Communion, which is the need to be socially accepted and belong (McAdams & McLean, 2013), is indicated as important to identity development, with social partners influencing the extent to which narrative identities are attended to, elaborated on, reinforced and changed. The importance of forming social connections and relationships for autistic adolescents was highlighted in this review. Individuals experience collective identity based on their membership in a group (Tajfel and Turner, 1986). In this review, participants co-constructed their narratives with the significant people in their lives. When friendships developed based on shared interests, like gaming, or group characteristics, or being neurodiverse, a sense of belonging was achieved. This sense of belonging and other positive relationships led some individuals to feel they had a strongly defined sense of self and that they could be their authentic selves.

Conversely, when autistic individuals experienced bullying, rejection, and negative narratives of autism, this led to a sense of isolation and feeling the need to mask their authentic selves. This, in turn, could lead to negative emotional processes, mental health difficulties and distance from connecting with those around them. And is particularly prevalent in autistic females (Bernardin et al., 2021; Chapman et al., 2022; Hull et al. 2017).

The impact of others on autistic adolescents' – societal factors

Societal factors, including cultural and community narratives, determine the ease with which individuals can construct narrative identities that authentically integrate personal and societal values (Mankowski & Rappaport, 2000). This can include the presence of master narratives. As the majority of the studies reviewed were carried out in White Western cultures, the often-dominant narrative that prevails is one of the deficit-focused medical model. Alternative community and cultural narratives may provide individuals with a better fit to their personal values. Of the third-order constructs, navigating autism in a neurotypical world and societal narratives align with the culture and community narratives. One focuses on the stories society tells, and the other focuses on the direct environmental impact this can have on autistic young people. It was unsurprising that a master narrative of disability arose for the participants. In line with other research, there seemed to be a sense of confusion as to whether autism was a disability (e.g. Baron-Cohen, 2000; Grinker, 2020) and whether acknowledgement of a disability could result in more environmental support.

The review emphasises the significance of having support structures put in place in the environment to help autistic teenagers navigate life in a world that is set up for neurotypical people. Narratives are impacted by the environment we are in. McAdams and McLean (2013) state that individuals may adapt their narratives in response to environmental demands. Without appropriate support structures, autistic individuals may not be able to perform to the best of their ability. Some may externalise this struggle and realise it is due to the environment, but others may internalise this and see it as an individual failing, incorporating this into their life story.

Notably absent from the papers in the review were alternative cultural and community narratives of autism. There was no acknowledgement or highlighting of any cultural differences between participants and how that might play a role in how participants view both their autistic identity and wider identity. Intersectional factors of class and gender were highlighted in three papers, but other factors like faith and ethnicity were not, which may have been expected given previous research (e.g. Hussein et al., 2019; Liu et al. 2014; Marker et al., 2007).

Implications

It is important to reflect on the implications and application of the findings of this review. Narrative identity develops slowly over time, beginning in adolescence, as people tell stories about their experiences to others. Selves create stories, which in turn create selves (McLean et al., 2007). The storyteller develops a broader, more integrated narrative identity through interaction with others; stories about personal experiences are processed, edited, reinterpreted, retold and subjected to a range of discursive and societal influences. Developing narrative identity can be constrained by first learning how to share a story in accordance with particular social and cultural parameters with family, peers and other formal and informal societal contexts. Autistic individuals may experience this fundamentally differently from their neurotypical peers due to their social communication style, stigma from society, and additional daily challenges they face.

It is important for clinicians and other staff working with autistic adolescents to place particular emphasis on the storytelling of those around them in order to support positive experiences and enhance the meaning-making of an autistic identity. There may be an increased importance on family stories, where social circles are smaller. Where families themselves have a limited understanding of autism or different family rules on speaking about the self, this could have an impact on how young people come to understand their authentic selves. Where there may be limited opportunities for storytelling for autistic adolescents in informal spaces, it should be considered whether more formal spaces, such as therapy, could be helpful in processing some of these stories, as found in previous research into reducing distress using narrative therapy (Cashin et al., 2012; Monteiro, 2021). Clinical psychologists are recommended as part of autism assessment teams, and their understanding of systemic and narrative models can uniquely contribute to developing service pathways which provide space and consideration to individual and family narratives, considering their importance in adjustment and wellbeing. The development of psychological formulations in multi-disciplinary teams can seek to integrate an understanding of individual meaning with societal context. Emphasising an individual’s relationship with autism, identity, and their experiences is a vital part of mental health intervention. There is emerging evidence that Cognitive Behavioural Therapy (CBT) is limited in helpfulness and, in some cases, can be harmful to autistic individuals (Wilson & Gullon-Scott, 2023) This review indicates following narrative, and systemic approaches may be more helpful. Future research should focus on evaluation of these methods as an alternative to CBT.

If autistic young people are accessing therapy, clinicians may wish to explore having family members take part alongside them to help understand what their child may be experiencing after finding out they are autistic. Research indicated that parental and child adjustment may be closely linked (Boyer et al., 2000), therefore it will be important to consider how to support parents through the adjustment period as well. This raises the importance of post-diagnostic psychoeducation so young people and families can understand their diagnosis and the strengths and challenges this may come with. Additionally, the findings show that it may be helpful for more consideration of societal narratives in post-diagnosis and offering space to reflect on alternative viewpoints of autism. It also highlights the importance of schools and teachers creating environments which reduce bullying and increase peer understanding of autism. The significance of autistic adolescents finding belonging in a group, whether that is through shared interests or characteristics, should not be downplayed, and efforts to scaffold and support autistic individuals with this should be made. It also highlights the role for clinical psychologists and other specialist clinicians in supporting school in understanding and acceptance of autistic pupils and staff.

The review highlights the lack of research exploring narratives of autistic adolescents. Particularly of note is the absence of people of the global majority featured in the research. Munroe et al. (2016) found that cultural beliefs and the Western medical understanding of autism can create cognitive dissonance for mothers of autistic children. Societal narratives can be powerful in defining our personal stories, and further research into cultural narratives should be done.

The studies that were included in this review were often done at one point in time. Future research may wish to look at a longitudinal design to see the change in narratives and identity over time, alongside exploring the systemic and societal factors around the individual to investigate whether there is further evidence of a correlation. Additionally, further research could investigate the impact of family and school psychoeducational approaches on how young people feel about their autism diagnosis and general wellbeing outcomes.

Strengths and limitations of the review

This review has several strengths and limitations. This is the first synthesis to investigate first-person experiences of autism in adolescence, with much of the previous research focusing on parent and caregiver views. Additionally, providing a theoretical framework of identity is a helpful basis to guide formulations and future research. The papers included were considered reasonable to high quality, and therefore, first- and second-order constructs were considered reliable in laying the groundwork for building third-order constructs. Weaknesses in the papers included a lack of diversity in participants and reflexivity in the papers, which limits the generalisability of the studies.

The synthesis of qualitative methodology is subjective, and where meta-ethnography seeks new insights; this is especially the case. As the resulting constructs are interpretations of interpretations, this review aimed to retain the original language of the reviewed studies to mitigate this. However, given that the researcher operates from a social constructionist viewpoint and celebrates neurodiversity, this likely has shaped the findings.

Conclusions

Through a meta-ethnographic approach to qualitative synthesis, this review pulled together existing literature to develop an understanding of identity development in autistic individuals. The findings from the papers were integrated with the narrative identity model to understand how intrapersonal, interpersonal and societal factors all interweave and influence the stories we tell of ourselves to form our narrative identity. For autistic adolescents, central to their narrative identity was meaning making of their autistic identity, personal processes that they went through on a day-to-day basis and making sense of themselves in time. Their stories of identity were closely linked with the stories those around them told and the social connections and relationships they had made. This was influenced by having to navigate autism in a neurotypical world and the additional boundaries they face compared to their neurotypical peers, and wider societal narratives such as those of autism and other intersectional factors. There are implications for future research, school systems, family dynamics, and clinical work in the language used when disclosing diagnoses, support needed in the school environment, and post-diagnosis support.

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BETHANY COPPING BSc Hons MSc

EXPLORING STORIES OF AUTISTIC ADOLESCENTS

Section B: Stories of young people of the Global Majority and their families after receiving a diagnosis of Autism: exploring the interplay of culture, neurodiversity and other aspects of identity

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A thesis submitted in partial fulfilment of the requirements of
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Note on terminology

People of the Global Majority is a collective term that refers to people who are Black, Asian, Brown, dual-heritage, indigenous to the global south, and or have been racialised as 'ethnic minorities'. This was chosen over the terms ‘BAME’ and ‘people of colour’ as this perpetuates the idea that ‘whiteness’ is the default (Ahsan, 2020).

Autism spectrum disorder (ASD) is a clinical diagnosis defined as persistent difficulties with social communication and social interaction and restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013. For the purpose of this report, the terms ‘autism’ and ‘autistic’ will be used to reflect the identity-first language that the autism community advocates for and will not refer to autism as a ‘disorder’, which implies impairment rather than difference.

Abstract

The aim of this study was to understand the stories of young people of the global majority and their families after an autism diagnosis, exploring identity development, interactions with services and the presence of cultural narratives. Nine interviews were conducted, four with young people, and five with parents. Findings highlighted the unique stories people of the global majority tell after receiving an autism diagnosis. Personal narratives were influenced by family, community, and cultural narratives. Of particular note were barriers to services, cultural and faith narratives, increased bullying and stigma. Clinical implications are discussed for creating culturally sensitive services, increasing community presence and challenging dominant medical narratives of autism.

Key words: autism, identity development, people of the global majority, cultural narratives

Introduction

Constructing and telling stories is an important way for people to make sense of the world around them, express meaning to themselves and others and shape their identities (Fisher, 1984; Murray, 2003). Personal narratives tell the story of who we are, which informs our sense of self (Bruner, 1990; Polkinghorne, 1988). Narrative Identity theory (McAdams & McLean, 2013) suggests that an individual's personal narrative develops by integrating their past experiences with their expectation of their future, providing them with a sense of life purpose. Personal narratives are situated in the context of personal beliefs that are held as an individual, family member and as part of a society (Dallos & Draper, 2015). Rappaport proposed a three-tier narrative model encompassing individual, community, and societal/cultural perspectives to demonstrate how personal stories are shaped by our context (Mankowski & Rappaport, 2000). Community narratives are a shared story amongst a smaller group of people, formed through the telling and re-telling of knowledge and shared experiences, which communicate to members of the group important information about themselves. Dominant cultural narratives are stories repeatedly told in mainstream establishments like mass media and educational institutions, which influence the values, beliefs and identity of people living in that place. Dominant cultural narratives can be incorporated and internalised into personal narratives with positive and negative consequences.

Autism and ethnicity

In the United Kingdom, one percent people are estimated to be on the autism spectrum (Baird et al., 2006; Brugha et al., 2009) and this increases to 1.76 percent in children and young people (Roman-Urrestarazu et al., 2022). Additionally, Elsabbagh et al., (2012) estimate this to be one in 160 worldwide. Roman-Urrestarazu et al. (2022) investigated the prevalence rate of autism in People of the Global Majority (PoGM) in the

UK and found that there was a significant difference across ethnic groups and geographical areas.

Several studies indicate that PoGM do not have or are reluctant to access health and mental health services due to institutional racism and clinicians' unconscious bias (e.g. Sainsbury Centre for Mental Health, 2002). Experiences of contact with services can be further impacted by the diagnosis of autism. The National Autistic Society's (NAS) report (Slade, 2014) found that autistic children from PoGM experience discrimination in relation to ethnicity and disability. They discovered five key themes as to why autistic PoGM people were not receiving appropriate support or struggling to get a diagnosis: challenges in obtaining a diagnosis, barriers to accessing services, communication difficulties with professionals, limited understanding and awareness of autism within communities, and isolation and denial. Lindsay et al. (2012) established that the prevalence of autism diagnosed in students of Asian heritage was half of the prevalence in white British pupils. Additional research has found evidence of disparities due to ethnicity in the United States (Jo et al., 2015; Mandell et al., 2009), with PoGM less likely to have documented autism relative to their white peers or receive an autism diagnosis at a later date. However, Jang et al. (2014) found no significant difference between PoGM and white groups, regarding the age at which caregivers would first report concerns. Research proposes that culture influences families on many levels when looking after a child with a developmental disability; detecting and making sense of differences, communications with healthcare organisations, selecting treatment approaches, and future hopes (Ennis-Cole et al., 2013; Mandell & Novak, 2005; Norbury & Sparks, 2013; Ravindran & Myers, 2012).

Intersectionality posits that a person with several oppressed identities will have different experiences than someone with just one of the oppressed identities (Crenshaw, 1989). Intersectionality considers that identity can be mediated by cultural constructs implicated in power, privilege and oppression (Liasidou, 2013). Butler (2015) posits that the complexities of lived experiences are represented when we look at intersectionality. It is, therefore, important to consider the implication of intersectionality that occurs when an autistic individual is a Person of the Global Majority (PoGM). Parents can find the diagnostic process for autistic children complex to navigate (Boshoff et al., 2018), which is likely to be further impacted by intersectional factors.

Autism and narratives

Socially constructed accounts, which function to stigmatise and marginalise groups, can be modified or overturned by individuals' personal narratives (Saleebey, 1994). The dominant narrative of autism in the UK centres around a deficit-focused medical model. An increasing counter-cultural narrative is the concept of 'neurodiversity', which indicates that autistic individuals consider themselves neurologically 'different', rather than having a disorder in need of treatment (Ortega 2009). Additionally, many autistic people face stigma (Botha et al., 2022), which may influence their personal stories Goffman (1963).

Most research relating to autism has been conducted in Western cultures, involving predominantly white participants (Dyches et al., 2004). In a qualitative study with parents, Munroe et al. (2016) showed the complex interaction between adopting a Western medical model of autism and cultural narratives for parents of autistic children. It suggested the stance a family or community take about autism is influenced by their cultural background. In other studies, parents spoke of using spirituality and faith as a framework in understanding why their child was autistic (Luther et al., 2005; Phelps et al., 2009). The UK voice symposium found that cultural, ethnic and religious sensitivities were often ignored by white professionals (Kandeh et al., 2020). Hussain (2021) explored the lived experience of autistic young PoGM using an interpretive phenomenological analysis approach and found distinct experiences unique to their cultural and racial identity.

Present study

There is limited research which involves hearing from autistic young PoGM. This study sought to understand the stories of young PoGM and their families, explore their personal narratives, and understand how these are shaped by the diagnosis process of autism, as well as cultural, community, and dominant narratives. The author acknowledges the diversity within People of the Global Majority. The research does not seek to over-generalise findings but aims to give a voice to those who are not often included in autism research within the UK. Alongside the young people, it was felt to be important that families also told their story of diagnosis, as often seeking a diagnosis is initiated by the family rather than the young person. Alongside autism and ethnicity further intersectional factors may be present through the stories of the participants, such as education, geography, gender, faith, and sexuality.

Narrative approaches facilitate the identification of and interaction between individual, cultural and societal stories (Plummer, 1995) and also attend to the dynamics of the interviewer-interviewee relationship (Riessman, 1993). They are suited to understanding the experiences of silenced stories and marginalised groups to contribute to knowledge construction (Canagarajah, 1996; Creswell, 1998). Interpreting how young people of the global majority and their families take meaning from and position themselves in relation to dominant discourses when describing their autism journey and how these fit with their identity could provide contextually rich data which can be utilised to develop culturally sensitive policies, clinical services, and suggest further research. Sharing the research findings might allow underrepresented groups to voice their stories and challenge suppressive stereotypes.

Research aims

There were four main aims of the investigation, to find out:

1. What are the personal stories of young people of the global majority who have received an autism diagnosis?
2. What are the personal stories of their family members of their child, including autism assessment and diagnosis?
3. Are there shared narratives about autism between the young people and their families?
4. Do community and cultural narratives of autism feature in the personal stories?

Method

Theoretical framework

The study assumes a social constructionist approach where the concept of a multi-perspective view is favoured over an ‘objective truth’. Experience and meaning are co-constructed and constantly modified by language between individuals rooted within a cultural, historical, political, and social context (Burr, 1995). Social constructionism focuses on the cultural resources that are drawn on and meaning making inferred when talking about autism. The aim is to investigate people’s personal narratives and how they incorporate cultural and community narratives into their story to both constrain and provide ways of thinking about autism.

Design

A narrative enquiry approach was used in the study. Narrative interviewing aims to generate detailed accounts rather than brief answers to general statements. In narrative analysis, there are two active participants who jointly construct narrative and meaning (Mishler, 1995)., Whole interviews were taken to represent the participants’ narratives, which is consistent with the use of narrative analysis in psychology (Riessman, 2008). Narrative analysis places importance on personal meaning-making through the reconstruction of identity (Frank, 1993). It also allows for the recognition of multiple layers that make up a person's story (Frank, 2012), such as the replication of the voices of family members, professionals, or community and cultural discourses about autism. It explores how people position themselves in relation to the dominant cultural narratives. In having a focus on personal stories and their connection with societal discourses, narrative analysis was felt to be the most suitable methodology for the study.

Participants

One boy and four girls, aged 14 to 16, and one or more of their caregivers agreed to participate in the study. One young person withdrew from the interview; her father participated in the parent interview. A purposive sampling method was employed, which involved the intentional selection of participants. All young people were diagnosed with autism and from a Global Majority background. Inclusion and exclusion criteria are outlined in Table 1, and a breakdown of participant demographics is in Table 2. Participants were recruited through one NHS Trust (see Appendix E for letter of access), which was a second opinion autism assessment service, and two charities, the National Autistic Society and the Autistic Trust, using a recruitment poster (Appendix F). Ethnicity was recorded as participants identified and not limited to a prior framework. Narrative analysis does not claim generalisability. Pre-determined sample sizes within this methodology are not stipulated and are often based on opportunistic grounds (Squire et al., 2014).

Table 1

Inclusion and Exclusion Criteria

Inclusion criteria
Young person: - 13-19 years old, with - a diagnosis of autism at least 3 months ago (to allow processing of the diagnosis),

- of the Global Majority,
- willing to talk about their diagnosis
- communication level that will allow a discussion

Parents/carers of young people:

- willing to talk about diagnosis and autism journey

Exclusion criteria

- no autism diagnosis
- evidence of significant mental health concerns, self harm or suicidality and was considered that taking part in the research would exacerbate this
- if clinicians and/or parents feel that taking part in the research interview will be distressing to a potentially harmful extent.

Table 2

Participant demographics

Participants	Ethnicity of child	Age	Age diagnosed
Mother - daughter	Black Afro-Caribbean British born	16	14
Father - (daughter)	Black African	15	7
Mother, father – daughter	Pakistani/White Asian	14	13
Mother – son	Somali	15	14
Mother - daughter	British Filipino	15	4

* pseudonyms have not been linked to demographics to minimise chance of identification

Ethics

The Research Ethics Committee reviewed the study and granted approval (see Appendix D). Any information received by the participants was reviewed by an Autistic Expert by Experience and a consultant from a Global Majority ethnicity. The information and assent/consent forms for young people were modified so that they were more accessible. For participants under 16, assent was obtained, and consent from a caregiver was gained (see

Appendix G). Participants over 16 and parents gave consent to take part (see Appendix H. Participant information sheets (see Appendix I and J) were adjusted to make them easy to read, and time was given to answer questions at the beginning of the interview to ensure that participants understood what they were consenting to. To manage any potential distress, a distress protocol and a lead professional letter (see Appendix M and N respectively) were developed. Transcripts were obtained from recordings using transcription software and manually adjusted for any discrepancies. These were anonymised and saved using encryption before being archived when the analysis phase was completed.

Data Collection

Interview schedules were developed for young people and parents (see Appendix K and L). Participants were asked the question, "Tell me the story of your (child's) life, including your(their) Autism journey", after which they were encouraged to tell their story without interruption. Follow-up prompts were developed to be used if the participant needed. Additional visual methods were available to help young people tell their stories: A spider diagram of topics was sent out one week prior to the interview (as seen in the Participant Information Sheet), a cultural genogram could be used at the researcher's discretion if this was thought to be helpful and participants were given the opportunity to bring photos with them to the interview to help them tell their story. Participants completed demographic information prior to the commencement of interviews. They were also offered the opportunity to ask further questions about the study, and the recording was only started when the participants gave their verbal consent. Interviews were conducted online due to the wide geographical area of recruitment. The length of interviews ranged from 37 minutes to 1 hour 25 minutes.

Analytical approach

The term ‘narrative analysis’ represents a range of methods (Reissman, 2008). In the present study, the methodology combined various narrative analysis approaches: thematic (Reissman, 2008), dialogical/positional analysis (Murray 2000), and Rappaport’s three-tier model of narratives (Makowski & Rappaport, 2000) which considered the personal narratives, community narratives, and dominant cultural narratives in the participant interviews. Narrative thematic analysis focuses on the content of a story and keeps a story intact by theorising from the case rather than from component themes across cases. It does not attend to the co-constructed nature of the narratives. Dialogical or positional analysis (Murray, 2000) seeks to move beyond the content of stories to consider the purpose of it being communicated and to whom. Makowski & Rappaport (2000) look to identify the personal, community and cultural narratives present in the story to consider how they are integrated together to form a narrative identity. The analytical approach taken is presented in Table 3. While it is written linearly, the analysis was undertaken iteratively, and steps were revisited as the analysis progressed.

Table 3

Analytical procedure

Step 1	Interviews were listened to, and transcribed, and initial thoughts, feelings and reflections were noted.
Step 2	Each transcript was read, and the content was explored. Elements of personal narratives were identified, and the findings were recorded in the narrative summary sheet (see example in Appendix X). This involved looking at: - Where do the narratives begin? - Were there turning points in the narrative? - What is the tone of the story?

	- What metaphors were used? - What meaning has been made of their experiences?
Step 3	Each transcript was re-read and themes from each narrative were identified, and findings were recorded in the narrative summary sheet. A summary of the narrative was also produced to include: - Settings - People - Important moments highlighted in the narrative - Their understanding of autism - Hopes for the future
Step 4	Dialogical/position analysis was undertaken, informed by Murray (2000). This involved observing the following: - How was the narrative created? - What were the key narratives? - What was the function of the narrative for the participant? - What messages were particpants trying to convey? - Were there omissions or gaps in the narrative? - What aspects of peoples' identity may have impacted on the narrative?
Step 5	What were the community and cultural narratives evident in the interviews?
Step 6	What dominant or counter-cultural narratives of autism could be recognised within the story?
Step 7	Narratives were contrasted and compared to identify themes in young people's stories, and themes in parents' stories, and themes in both (see Appendix P and Appendix Q)
Step 8	Quotes were extracted to demonstrate the findings
Step 9	Participants were sent a summary of their narrative for respondent validation so they could give feedback on its validity

Reflexivity

The author, who is a white British female, conducted all nine of the interviews in the study. A reflexive journal was made throughout the process to examine the self and reflect on how the researcher’s values, personal characteristics, and circumstances may have influenced the research process (see extracts in Appendix C). A supervisor (white British female) and consultant (Black African female) conducted an audit of the analysis to improve the quality of the research further, and reflexive conversations were had throughout with a consultant of the Global Majority to advise and collaborate to assist the researcher understand their positioning within the study. As an introduction to the study, the author's photograph was put in the participant sheet so participants were aware there would be a difference in ethnicity between themselves and the researcher. Additionally, during the introductory part of the interview, the difference in ethnicity was named in the hope that this would not silence the discussion. It is likely the author’s identities and preconceptions came into play, given the disparity in geography, religion, class, race, and age. Narratives were therefore co-constructed given that the story was likely to be recipient designed for a particular listener, i.e. a white western woman without autism, associated with health services (Riessman, 2008) and may have had an impact on the questions asked by the researcher about certain parts of individual’s narratives. The author partook in the creation of narratives rather than ‘finding’ them in the interviews. As the researcher was white British and not autistic, this is the lens through which the analysis was conducted. The researcher notes that this may have limited the discovery of cultural and community narratives and nuances in the stories. The hope of including respondent validation was to aim to minimise this where possible.

Results

This section begins with a summary of the unique stories heard during the research (Table 4), which provides a context for the following analysis. Pseudonyms have been used throughout to maintain confidentiality. Subsequently, results are displayed thematically, addressing the research questions. This will start with themes exclusive to young people’s personal narratives, then their parents, then shared narratives between young people and their parents, and lastly, cultural and community narratives. While these are presented in separate sections, it is acknowledged that there will be interaction between them. Insights are offered from Rappaport's three-tier model and dialogical narrative analysis approach.

Table 4

Summary of narratives

Participant	Summary
Nathanial	Nathanial shared the story of his daughter's diagnosis. This started with teachers at school pointing out that something was different about Adina and that she should be observed to understand what was happening. The family GP was helpful in explaining this may be autism from behavioural descriptions and referring them for further assessment. The diagnosis was a surprise as Nathanial hadn't come across autism before. Initially, he thought autism was alien to the Black race but has come to understand that autism is present across all ethnicities. Nathanial has gone on a journey of understanding autism and has found connection with other parents going through the same thing. He is a strong advocate for change to support young people with autism; he has a role in educating others and participates in research to further understanding. His faith plays a big role in his life, and he prays for Adina to be able to get through her struggles. Before diagnosis, some of Nathanial's wider family thought Adina's difficulties may be related to being possessed by spirits, but the diagnosis was a turning point in realising this was a medical condition that Adina would need support for. Nathanial highlighted that Adina is kind, caring and very creative. She struggles with change and loud noises and sometimes isolates herself from others as she thinks they may find her weird. Nathanial described that Adina's communication and behaviour had been difficult in the past, but having an

	understanding of autism and giving her patience and empathy has been helpful, and as Adina has developed, these things have gotten better. Nathanial hopes that Adina will become a nurse when she is older, which fits with her caring nature
Aamiina	Aamiina told the story of Abadir's autism via an interpreter. Sometimes Aamiina and the interpreter would have a long conversation, and then the interpreter would share a short sentence back to the researcher. Therefore, this story is co-constructed between three parties and may have missed some information that Aamiina would have wanted to share. Aamiina's story talked of her son's difficulties with motor skills, communication barriers and emotional dysregulation. She shared his strengths in reading and business studies and often interpreting for the family. She shared that the school had been helpful support to Abadir and health care professionals were aware of autism and accessible to her through interpreters and Abadir translating appointment letters. She shared she was Muslim and that she and her family accepted autism as God had brought it to Abadir. Family was important, and Abadir would spend time at his aunt's house. She shared that communication could sometimes be difficult for Abadir, and he would spend much time alone on the computer or watching TV. Her hopes for Abadir were to become independent and help his family.
Abadir	Abadir told a story of his life which was co-constructed with the researcher. Important people included his family and his friendship group. He enjoyed travelling and shared significant memories of visiting Switzerland to see family. Autism was a concept he first came across when someone asked him if he was autistic. At the time, he mentioned this to his Mum, but as far as he knew, this didn't go any further. Abadir wasn't sure what autism was but could recall going to a post-diagnostic workshop, where they spoke about the special interests of famous autistic people, and he got to meet other young people with autism, which he found helpful. Abadir's strengths were watching and playing sports and being a good listener to his friends. He felt that he

	could be sensitive to what others said to him, which could result in anger that’s hard to control. He felt able to share his autism diagnosis with friends but wouldn’t share it with wider circles. Abadir received support at school, which he found helpful. He considered autism to be a disability and felt that to call it a ‘different ability’ was to minimise the struggles that autistic people face. He had hopes in the future to go to sixth form to study biology and economics and travel with family and friends.
Ellen	Ellen's story contained her dual identities as a working professional and advocate mother. She spoke of the difficulties her daughter experienced throughout her life, including allergies, dyslexia, and getting an ASC diagnosis at a later age. Ellen was an NHS employee and described the difficulty of waiting for an assessment and knowing the process, even when working within the system. She portrayed the long waiting lists and shared she had to write a letter to the Trust director to try and speed up the process. When they finally got an assessment, she shared that the high staff turnover meant there was no consistency, and they would have to start all over again. By the time they had their second assessment, Grace had identified for herself that she thought she was autistic and had used videos on social media to work out some adaptions for herself. Ellen shared that in the Afro-Caribbean community, people aren’t always aware of neurodevelopmental conditions and believe that their children will catch up with their peers. She felt that she hadn’t experienced direct discrimination when interacting with systems but reflected that as she is well-spoken, English is her first language, and she is an NHS professional; this meant she both knew what to ask for and may have meant people treated her better. She shared stories of racism when Grace was at primary school and seeing others be discriminated against by NHS and education professionals. She described a family history of masking difficulties and learning coping mechanisms to get through. This was particularly evident in the women of the family and she thinks that being female may have led Grace to getting a diagnosis

	later in life than her male counterparts. She feels that through the process of Grace's assessment she also wonders whether she and her eldest daughter are on the spectrum as well. Her hopes for Grace's future is that she isn't restricted and can build the future she would like for herself.
Grace	Grace's narrative was co-constructed with the researcher. She described herself as a lonely child who was avoided by others. School and college gave her a chance to find her genuine friends, some of whom are similar to her and to whom she finds belonging. Her autism diagnosis was a turning point that allowed her to understand herself and the people around her better. She discovered communication differences by others pointing it out to her, like limited eye contact or using repetitive phrasing. She sees autism as a difference in thinking, which can be a real strength but also leads to misunderstandings in communication. She rejected support at school as she didn't feel it was helpful and found it awkward to have a TA sit with her. She doesn't believe there is a link between ethnicity and autism but shared that family views are really important for how people might see themselves. She described that people with non-accepting families may be suffering in silence and she feels lucky to have a supportive family around her.
Natalie	Natalie's narrative communicated her passionate determination as a mother, with stories of the battles she faced to ensure her child reached her potential. She had to fight for a referral through the GP and was told Lizzie's behaviour wasn't bad enough. She knew this wasn't the case as a professional working in a school. She went back armed with a report of evidence and got a referral to and diagnosis through the paediatrician. She shared the impact of the obstacles she had faced along the journey and how she learnt the 'broken' system so that she could overcome it. When it appeared the county council wanted to put Lizzie in a mainstream school, she fought for her to be in a special school where she could access more support. Each year for school, she updates an information pack to help her teachers get to know Lizzie.

	Natalie felt that in the services she had encountered, she had not perceived racism or unconscious bias. Natalie spoke about the frustration of other people assuming her ethnicity rather than asking her. Culturally, she shared feeling British, so when others made assumptions that she wasn't, it would feel jarring. She found that moving out of London was quite a shock going from a multicultural population to a predominantly white one. She has encountered people in public who can be quite oblivious about how to talk to people of different ethnicities, who potentially mean well but come across as offensive. She has had conversations with Lizzie about how because they look different, they may encounter people being ignorant. She felt that awareness of autism in the UK was similar to that of her country of heritage. She also spoke about the importance of her daughter finding independence and learning emotional maturity. She shared her hope for Lizzie's future is that she is happy.
Lizzie	Lizzie told the story of her life co-constructed with the researcher. She described having a good childhood and being very close to her parents. She shared a memory of nursery where she'd been told she had bitten three children in primary school and was embarrassed about it. She explained maybe this happened because she was angry and competitive but doesn't see herself that way anymore. She shared that in a mainstream primary school, she was rejected by a friendship group, which impacted her self-esteem. She describes herself as friendly and enjoys spending time with her friends. Lots of her friends are neurodiverse and she feels lucky to be going to a special school where the staff are understanding. She shared that when she was first told by her Mum that she was autistic, she was upset, as in her mind, she had linked this with being angry and needing extra help in the provision. She says she is now okay with having autism. Lizzie was aware autism is a spectrum, and everyone is different. She said she hadn't felt discriminated against for having autism, but she is aware that this is something that may happen to other people and that often, there are stereotyped ideas of those on the spectrum held by other

	people. She has previously had discriminatory comments directed towards her by a peer at school due to her ethnicity. Lizzie saw autism and ethnicity as distinct factors that didn’t impact on each other. Outside of her school friends, she doesn’t often tell people that she’s autistic if it doesn’t come up in conversations. She doesn’t feel like she has to mask socially, but does often mask her emotions, and bottle up little things. She’s not sure why as she knows she can talk to her parents if she needs to. Lizzie shared that she loves to draw and hopes to be an animator one day.
Maryam and Bilal	Maryam and Bilal’s narrative began when their daughter was born, and they spoke of how unsettled she was with sleep and having other people in the house. They spoke of the increasing isolation as they had to adjust their lives. Maryam’s sister was the first to point out that she thought Fatima may have autism. They spoke about the battle to access diagnosis services and being passed back from CAMHS to the paediatrician multiple times before they were seen. The whole process left them feeling unheard and it was incredibly time consuming to keep chasing up. When Fatima was diagnosed, they described it as a relief to have an answer for the struggles Fatima faces. Fatima’s brother also has autism, but he was diagnosed earlier as he was a ‘textbook’ presentation. They spoke about the conflict of having clashing noise sensitivities with both siblings, so sharing a space is difficult. They shared how difficult it was to watch their daughter experience friendship difficulties and severe bullying at school. They also spoke about the challenges that Fatima faces associated with autism, like increased anxiety, emotional dysregulation, and fixations on certain things. Through the process, they have wondered whether Bilal has undiagnosed autism and spoke about how things can appear normal to one person that aren't normal to others. Bilal described this as 'if somebody thinks it's that positive negative and I think no that's negative positive then it's just the way they and I think'. Ethnicity didn’t feature in their story of Fatima’s autism journey. They shared that they didn’t feel like their faith had an impact in how they saw

	autism. Their narrative did not look to the future, which may be represent their overwhelm with dealing with the present difficulties and frustrations.
Fatima	Fatima told a story of her life co-constructed with the researcher. She felt like her childhood was good but remembers taking a lot of time for appointments when she was younger. She shared that she didn’t really care about getting an autism diagnosis because she didn’t really feel any different and felt like it wasn’t that new. She describes autism as when your brain is wired differently and gives her strengths in socialising and her special interest of reading. She does not identify with others with autism and states this is because of her increased social motivation. She describes ongoing anxiety, which she receives support for through mental health services. She sees her anxiety and autism as separate and describes her anxiety as related to when she doesn’t know what’s happening and unpredictability, which means she asks lots of questions about what is going on. Fatima hasn’t told many of her friends about receiving a diagnosis, and those that she has told she shared that they “don’t really care. They’re like oh, you’re still the same person”. She doesn’t like to tell people who don’t know her as she is worried they will see her for her autism and not who she really is. Her cultural identity was important to her, telling stories of family friends, cultural celebrations, duel citizenship, and time spent with her mother’s extended family in that country. She felt like ethnicity could play a part in the way she is parented compared to her peers. She didn’t think that ethnicity and autism were related. Fatima hopes that in the future she can move into an apartment with friends and be a teacher or psychologist as she would like to work with children.

Research question 1: what are the personal stories of young people of the global majority who have received an autism diagnosis?

All four of the young people found it challenging to answer the narrative enquiry questions of “Tell me about your life, including your autism journey” with an un-prompted narrative, so the follow-up prompts were utilised, creating a co-constructed narrative with the researcher. It is, therefore, not possible to comment on the sequence of the narrative. Some of the young people commented that the questions were something they had not thought about before. The themes exclusive to the young people’s stories were the meaning-making of autism, the importance of people, and the awareness of self in time.

Meaning making of autism

This theme encompasses how the young people made sense of and identified with their autism diagnosis. All of the young people had parents who sought out diagnoses on their behalf, as opposed to being sought out by the young people themselves (see Table 5 for examples). None of them have distinct memories of the process, but they recall going to appointments. Fatima shared that it had been disruptive going to so many doctors’ appointments at a young age. Grace and Abadir felt like having a diagnosis helped them better understand themselves. Lizzie initially rejected having autism, and she reflected that this may be linked to stereotypes she had of what autism was and the stigma attached that autistic people were ‘*annoying’*. She still recognises that those stigmas can impact how she sees herself but has come to accept that having autism is a good thing. Fatima found it important that she was seen as herself first and emphasised that it didn’t change anything to have a diagnosis. She rejected that she had social difficulties and saw this as one of her strengths. Generally, she felt like having the label of ‘anxiety’ better explained the challenges she faced. Later on in the interview, she shared that she has repetitive interests, showing that there may be some conflicted feelings about having autism, where she does not associate with having social difficulties but does associate with having repetitive interests. All four of the young people understood autism as a difference in thinking or the brain being '*wired differently'* from peers.

All of the young people had stories of other people pointing out their autistic traits, which is how they first came to realise they were different. Through understanding what autism is, they began to gain insight into how other people may perceive them. Grace reflected that sometimes how she spoke to people may have been considered rude, and her Mum pointed out to her that she wouldn't make eye contact with others.

Table 5

Example Quotes Demonstrating Meaning Making of Autism

Example quote	Participant
And what was it like last year when you got that autism diagnosis? Umm, it wasn't really that new. Like I didn't care too much. Because yeah, I just didn't really feel any different. **Is it something you'd heard of before?** I don't think so, but like I didn't really matter about it.	Fatima
How do you feel that having an autism diagnosis has has, like, what impact do you think it's made? I feel like. I feel like it made me understand myself and people the people around me more. **Mm hmm. What impact do you think it had on how you saw yourself?** Uh. I don't really think you had that much of an impact and how I saw myself. I just feel like it gave me more understanding as to why I am a certain way or something.	Grace
Umm well yeah, I know, because I like hyperfixate. Well, like get obsessions with certain things. Not really anymore. But when I was a kid and I do notice that, like, this isn't all the time, but sometimes, like I I'm not good at socialising. Like you know,	Lizzie

sometimes well, so social anxiety a little bit.
I mean, personally, I do remember the first time my mom I had autism, and I think I freaked out because, you know, I really saw it as like, a bad thing.
Umm, I don't know. I think I have healed a little bit from then like, but you know there's some part of me that's like doesn't want to accept it for some reason because, you know, I think it's cause I go to like an autistic school and tons of the kids like, you know, really roudy. And like annoying and stuff and I don't really. I feel like, you know, being autistic does not mean like you're annoying and tons of autistic people are annoying. But I'm telling myself you're annoying and stuff like that. It’s like, no, I'm not. I’m autistic. That's fine. It's good. Doesn't mean you're annoying. It's just, you know, it's different for every person.
Mm hmm.
But yeah, there's nothing wrong with autism. Yeah, it's good. [thumbs up]

Important people

Important people were a theme that arose in all the young people’s narratives. Stories of family and friends reoccurred throughout the interviews, with an emphasis on how they acted as a source of support (see Table 6 for examples). The interviewees consistently underscored the importance of having a family to turn to who made efforts to understand their situation better over time and look for ways to accommodate their struggles. It became clear that all the young people felt they had at least one member of their family they could turn to who offered understanding and compassion. Grace highlighted that if people don’t have a supportive family, they may “*suffer in silence*”.

Friendship also played a key role. Generally, interviewees felt heard, supported, and understood by their friendship group, and their friends accepted them for who they were. For

Fatima, it was important for her that her diagnosis had not changed anything, and her friends saw her as Fatima first.

Table 6

Example Quotes Demonstrating Important People

Example quote	Participant
I've a friend group at school. I usually hang out with. Yeah, I I'd say at least like 8, possibly 9, let's say. **Mmm hmm.** Friend wise and umm. My mum and dad. They're my main support thing or I guess I usually talk to my dad about like emotions and stuff.	Lizzie
So if you were to have questions about what autism is, who do you think you would go to, or would you? Umm, no one apart from my relatives and my mum. **OK. So Mum's a big support?** Mm Hmm.	Abadir

Awareness of self over time

All the young people could identify and talk about their strengths, interests and challenges that they face in the present and think about how this would look in time (see Table 7). Fatima and Abadir linked how they saw their 'repetitive interests' as strengths. When they spoke about their hopes and dreams for their future, these often involved utilising their strengths in a career. In addition, three of the young people had thought about living independently from their parents, with friends or siblings. Lizzie shared that she hoped to live independently but expected that she would need ongoing emotional support.

Table 7

Example Quotes Demonstrating Awareness of Self Over Time

Example quote	Participant
And what do you think of the strength associated with autism, if any? Hmm.I feel like if when you have a different perspective, you are able to figure out things in different ways that others don't think of. **Mm-hmm. Do you have any examples of when that's happened?** Umm. No. But I feel like everyone's always asking me for help for things. **OK.** Just like, oh, my goodness, she's smart. Just like I don't think so. [laughs]	Grace
And what are you hoping to do in the future? Do you have any ideas? Oh, I think I wanna be an animator. Like make cartoons and stuff. And if not that something art related. … And where I'll live I'm hoping, well, I've actually thought about it much because, well, I do wanna move out of my parents house. Like at least before I'm 30 or something, but I haven't really thought of it much. I think I'd get like an apartment, or at least like a bungalow or something, or I'd share a house with people.	Lizzie

Research question 2: What are the personal stories of the family members of their child, including their assessment and autism diagnosis?

Four of the parent interviews were narratives that needed minimal prompting. Their stories started at the birth of their child before moving on sequentially to the differences or struggles they noticed in their children and their process of getting a diagnosis for their young person. The interview involving the interpreter included a lot of prompting from the researcher, and sometimes the answer that was provided did not seem to fit the question, which may indicate that the narrative was altered from the one the mother wanted to share. The themes in this section were identifying autism, battles and barriers, emotional coping, professional roles and hopes and dreams for their young people.

Identifying autism

This theme encompasses how parents first identified autistic differences in their child. For some of the parents, it was others who first pointed out that their child might need more support or a referral to services (see Table 8). Two of the mothers spoke about their sisters, indicating differences with their children compared to their peers. One parent spoke about the school identifying that their child might need more support and encouraged them to go to their GP. There was a consistent theme that diagnoses were sought following difficulties and problems at home, such as sleeping difficulties, emotional dysregulation, or not responding to their name. The parents described identifying young people’s difficulties with friendships, such as intensity or social isolation from peers. Identifying differences led them to seek an assessment.

Table 8

Example Quotes Demonstrating Identifying Autism

Example quote	Participant
I had absolutely no clue, so it just when he was literally was about a year and a half, we were away on holiday. My sisters, the doctor. So she just, whatever the symptoms were, then things were.I just thought this is how the children are. **Mmm.** This is how it is because I had no exposure to any other child, so she said to me he was quite young that, you know, I don't want to worry you and anything. But I think you should ask your GP to refer him to paeditrician,	Maryam

because I think there's some traits of autism and I didn't know what autism was she explained and everything.	
So Grace would kind of pass milestones with her in certain terms, like she was always physically bigger and she was always chatting and stuff and touching. And just I thought she was like, hyperactive. She would just always into everything and. I can remember my sister saying I should go and get her hearing checked because every time she calls her sometimes and she's watching the TV or she's playing a game and she she wouldn't turn. She would be so focused	Ellen

Battles and barriers to services

All parents spoke of the significant challenges they faced in getting a diagnosis for their child (see Table 9 for examples). This included waiting lists, being passed between services, not feeling listened to by professionals and needing to have someone else validate the claim to keep fighting for a referral. The process was described as a battle that was very time-consuming. Natalie described: *"The system is broken. I mean the system is broken anyway within the NHS, it's all broken and I think unless I'm fighting for her, she doesn't stand a chance at all."* Three of the families had accessed a second-opinion autism assessment service, so they would have had to wait for their first opinion and again for a second opinion. Parents described the validation they felt and experienced in getting a diagnosis for their child. However, they described this as short-lived when they then had to then battle for financial support (Maryam and Bilal) and access to educational support (Nathanial and Natalie) following the diagnosis. Most of the parents who participated in the study talked about the onus for them to be proactive and advocate for their child. To do this, they described having to know the system in order to 'beat it' and spoke about how time-consuming everything is. Parents mentioned that access to diagnosis and, therefore, support earlier would have been helpful for their children. After getting a diagnosis, parents reported that the battles were not over and follow-up with other services, such as education, were needed.

A further barrier could be interpreters. The family using an interpreter in this study said they had been able to access NHS appointments by using interpreters and their son translating appointment letters when they arrived. During the interview, the interpreter and interviewee would often have long conversations before a short answer was given back to the researcher, and the answers did not always fit the question, which may indicate a silencing of the mother's story.

Table 9

Example Quotes Demonstrating Battles and barriers

Example quote	Participant
I think the thing with people passed on at least on 3 occasions, to CAMHS. So even when she was little as well, so pediatricians would say no, this is the case that CAMHS should deal with, we would refer to CAMHS. It would take weeks and months for the appointment to come. We'll go then they'll assess and things and do something and they say ohh no, she's at this age of whatever. This is the paediatrician should do it. But we'll go back to paediatrician again. Appointment. So, so much of times being wasted even in that as well going back and forth and they just couldn't decide who should be looking after her case and or what.	Maryam
And I went to, I said to the GP, I need a referral. Please, because you know she has challenging behaviours. She finds things difficult. She's not understanding. She's not listening. And the GP wasn't very good. Now the GP's do not know anything about autism, or special needs or anything like that, and I'd had experience in working in a school, but by then I was working with teenagers and the GP just said Ohh no, her behaviour has to be really bad for and it's got nothing to do with behaviour.	Natalie

So anyway, six months later I tried again with another cause I thought no, I've I've really got. I really want to get her help and we've got to get this sorted because I know that there is something not right. I just knew as a mum, you know your child really well and. So when we saw the paediatrician, she just said to me, I produced this before I went to the paediatrician. I produced this report from when she was born to up until then, which was when she was three of the of all the challenges and the difficulties she faced and her needs and everything. And I asked the paediatrician to read it first before we got talking. And she said that was, she said to me that is absolutely brilliant that you've done this. That's you've got evidence here, **Mmm.** she said that definitely helps her job a lot and. She she just said. Why didn't you come to us sooner? And I said, well, I tried, but the GP wouldn't refer me.	

Emotional dysregulation

Parents' stories all featured stories of their young people having to manage strong emotions and the impact this can have both on the young person and their family (see Table 10 for examples). For some, this was dealing with anxiety; others shared that the young people were quick to get angry, which could lead to behaviours directed at family members. One family spoke about the additional impact this could have on their neighbours when screaming occurred.

Table 10

Example Quotes Demonstrating Emotional Regulation

Example quote	Participant
We actually had the complaint from a neighbours. And because it was like night time, she will cry and scream and think it's we're just too loud. Uh had another complaint and one of the neighbours, and she was studying for exams or something and she couldn't really study.	Maryam

We had people come once a couple of doors away, they said. There's child in distress. That sound is coming, I think from your garden. And I said yes, it's my daughter. She just having her moment. We just couldn't do anything.	
…so then it came back that she had depression and anxiety, which she did. She was really struggling with the friendship group with the learning, with everything with hormones, with everything was up in the air…	Ellen

Professional roles

Where parent's professional roles were in a related field such as healthcare or education, this was evident in their narratives both dialogically and thematically (see Table 11 for examples). Three of the mothers interviewed spoke about their professions and how they were relevant in helping them learn about autism and better understand the system, which they could use to help them access diagnostic or educational services. Dialogically, it felt like these three participants were positioning themselves both as educating the researcher from a position of being a mother and positioning themselves at times as a peer, alluding to inside knowledge of the health and education systems.

Three of the parents went on to speak about using their knowledge and experience of the system to help and support others in the community around them who were trying to navigate services for their own children. Nathanial also spoke about educating others in the community about autism to dispel myths and foster community with other SEN parents.

Table 11

Example Quotes Demonstrating Professional Roles

Example quote	Participant
But I'm lucky I had the initiative to do it. I know I I've actually helped out quite a few parents because I had strangers approaching me and saying we've heard that you've got a lot of knowledge about autism.	Natalie

We don't know where to start and they were like a rabbit in headlights and they asked for my help so I started helping some parents and guiding because I knew the process I'd worked in a school.	
….But she didn't even get seen for another two years or something. **Yeah**. And it was at the Trust that I actually worked at. **OK. Gosh.** And I just, I just ended up writing to the chief exec cause this is ridiculous…	Ellen

Hope and dreams for their young people

Four of the parents spoke about their hopes for the future for their young people (see Table 12 for examples). These were around having independence, an unrestricted future that would be whatever the young person chose, and for them to be happy.

Table 12

Example Quotes Demonstrating Hopes and Dreams

Example quote	Participant
The mother said that when he grows up in the future, she wants him to be independent and help his family.	Aamiina
I just want Lizzie to have umm. The you know and the easy life as best as she can and a happy one. I want her to be happy. Whatever she decides to do and she can decide to do whatever she likes and I just want her to be happy. **Mmm.** So that's my main thing for Lizzie. Just happiness above everything else. You know, even more important than getting academic qualifications, or I'd rather her be happy in her life and you know, it doesn't mean that she I'm trying to encourage her with those social skills and always trying to because. That's a skill that I think is really key, and I say not just for people with autism.	Natalie

Well, I want her to be a nurse because she's quite because of the empathy she has found around the whole family setting. She's, she feels she's so caring	Nathanial

Research question 3: Are there shared narratives about autism between young people and their families?

Some narrative themes were shared by young people and their parents. The themes identified were post-diagnosis support, school support, and autism in the family.

Post-diagnosis support

Post-diagnosis support was named as key for young people and families coming to understand autism better (see Table 13 for examples). This gave young people and parents space to think about strengths and challenges and time to process the diagnosis.

Table 13

Example Quotes Demonstrating Post-diagnosis support

Example quote	Participant
What's helped? A thing is that we we had so much courses now … we we had the one in [place name] as well. Yeah. Yeah, we had [place name] went to the ASD group where they had the parents, ones who really wants in the. So we had like a lot of things that my son was said he was like probably four or five years, so about 2010.	Maryam and Bilal
what do you remember of going to [service] and meeting people? What was it like? Uh, great. **It was good?** Uh-huh. Yeah it's just like about special interests. People have like special interests and stuff. **Mmm hmm, so they paid attention to those?**	Abadir

Yeah, like the, the creative Pokémon had, like like an special interest in like collecting bugs. Which was as inspiration for the Pokémon game.	

School support

Support from schools was mentioned by all participants, with some differentiating between support offered at different schools. There were stories of finding the school supportive and helpful (Ellen, Natalie, Nathanial, Abadir, Aamiina), and stories of not feeling heard or fully supported by their school (Maryam & Bilal, Ellen, Natalie). Grace also spoke about being offered support but rejecting it. Lizzie said she felt lucky to be as supported as she was in her school. Abadir had found school support helpful, which his mother also confirmed. Ellen spoke about the report following the autism diagnosis being the catalyst for change in the school, following which they were helpful in making changes.

Table 14

Example Quotes Demonstrating School Support

Example quote	Participant
I did get support, but they're just like I didn't really use it so. **OK. Oh, is that a school?** Yeah. **Mm hmm. What kind of thing did they try to do?** They'd have like someone who'd sit with me in class. Who I can ask a questions. I didn't really. They were just sitting there and I never really talked to them.	Grace
I was finding out all about the [EHCP] process of that myself and the school would say yes, yes, we will do that, but we need to gather evidence for six months and I would say OK, that's fine. After six months, I would say OK, have you you've gathered your evidence now?	Natalie

Well, we need some more evidence and long story short, because I won't bore you with all of it. Erm but you know, they they weren't going to do it.	

Autism in the family

Two parents (Ellen and Bilal) spoke about how, through the diagnosis process for the child, they have wondered whether they are also on the spectrum or have noticed traits of autism in themselves (see Table 15). Lizzie wondered whether her parents had autistic traits but wasn't sure if they had noticed. One family had another child with an autism diagnosis but commented on how different their two children were and thought it may have delayed getting their second child diagnosed.

Table 15

Example Quotes Demonstrating Autism in the family

Example quote	Participant
I think my parents, they never got a diagnosis for autism and they were wondering, well, you know, if you're autistic and maybe we might be too. Personally, I think, yeah, my parents are autistic traits and I just don't think they realize it or like sometimes they don't really. Think about it	Lizzie
During our journey with autism, with both the children, we actually realize that hubby, we realized that he's autistic as well he's just never diagnosed. **Mmm.**	Maryam

Going through these old parenting groups and everything and he I think he actually found out that he has all those traits and things as well.

Mmm.

So I know it can be heredity as well. But yeah, so he had a self discovery during this journey for him, yeah.

Research question four: Do community and cultural narratives of autism feature in the personal stories?

Cultural and community narratives were identified in participants' stories; these were cultural narratives of autism, faith narratives, stigma, and intersectionality, which was further broken down into discrimination, gender, and bullying.

Cultural narratives of autism

Dominant cultural narratives were present in participants' personal narratives (16), including whether autism is considered a disability, which shaped their stories. Lizzie was aware of the word neurodiversity and used it to refer to people at her school. Abadir was in a mainstream school and felt it was important that autism was recognised as a disability rather than a different ability because that label more appropriately acknowledges his own personal struggles.

Nathanial shared the clash between his family's cultural understanding of the behaviours his daughter was displaying and finding relief in a medical diagnosis. Initially, he thought autism was 'alien' to the black race but has now come to understand that prevalence can happen across all ethnicities. Nathanial spoke about how he goes into the community to educate people about autism, to dispel myths and stigma.

Table 16

Example Quotes Demonstrating Cultural Narratives

Example quote	Participant
[Autism is] a neurological like condition or I guess disability because I mean I think it qualifies as disabled, Umm… Yeah, I don't know. I think that's like, you know where your brain works differently	Lizzie
Some people say that it’s a different ability, not disability. Which, and it’s kind of divided, at least because everyone says it’s not disabilities, just a different ability, which I kind of disagree on really… It’s a disability because, that’s like struggles, like basic things, like that sensitivity	Abadir
when I really spoke with my most extended relatives about what we were really facing about Adina, behaviours towards communication, it sounds so strange, and, and more like she was being possessed by some spirits which made her really think, made people really think she was abnormal. And I, I at some point, I was almost beginning to believe the same thing. Not until when I had some discussions with my GP and I had the understanding of the whole medical condition related with my daughter and, and what, what she needed was support and uhm, sort of ways of helping her navigate through these challenges because she wasn’t really finding it so easy for herself, was a whole strange thing for everyone	Nathanial

Faith narratives

Stories of faith were mentioned by one young person (Grace) and parents (Aamiina, Nathanial, Ellen) and featured prominently in how people made sense of their personal stories. Participants were from Christian, Catholic, and Muslim faith groups. Grace said her faith changed her perspective on autism, changing her perception of the role it plays (see Table 17). Similarly, Aamina shared that her family were able to accept her son’s autism diagnosis as God had brought it to them. Nathanial shared that he prays for his daughter to get through the things she struggles with and for her to live a happy life.

Table 17

Example Quotes Demonstrating Faith Narratives

Example quote	Participant
What does her family think of the autism diagnosis? She said that the family knows about his situation, about his the autism. **Mm-hmm.** And then they accept, because the that God has bring for him, the autism.	Aamiina
“I just feel religion made me see things with more purpose, just like it’s not there for no reason, and people struggle with things more, like, because God knows they can handle it”.	Grace

Stigma

All four young people stated that they would tell their friends that they have autism, but they do not feel comfortable sharing this more widely (see Table 18). Abadir said he was glad he got his autism diagnosis when he was a teenager as he felt that if he had a diagnosis at a younger age, other children would have seen him as weird, but his peers are now more accepting. Lizzie thinks stigma comes from people having stereotypes of autistic people and admitted that she had this as well, which made it hard to accept her diagnosis initially. All of the participants had told a few close friends that they had autism, but none of them felt comfortable sharing this more widely, which indicated fear of judgement and stigma they might encounter from others. This led to them feeling they had to hide and mask their autism outside of their family and friendship groups.

Table 18

Example Quotes Demonstrating Stigma

Example quote	Participant
"I don't really know how they'll react. But then people that I know, it's like they already know who I am and so I don't think that they would care that much because it's not really changing anything".	Fatima
OK. And do you feel like you have to try and hide your autism? Umm… yeah. **Can you tell me a bit more about that?** To me, to me, it's like personal, to me it's personal. I don't wanna like tell like if I get I don't like that you just wanna tell everyone because even like, even through some random people I don't wanna tell them because otherwise they're, they're just gonna say that they're just gonna say, they're just gonna tell it to other people and then, like, people just gonna spread rumors like this. Blah, I don't want that to happen, cause I'll tell it to my friends, but I wouldn't tell it to like random people.	Abadir

Intersectionality

Seven of the participants spoke about the effects of multiple forms of discrimination they or their child had faced.

Gender All but one of the young people who took part in the study were female. Of these families, three of them felt like girls were more likely to camouflage and try and fit in and, therefore, were delayed in getting a diagnosis. Nathanial was aware of the male-to-female ratio but felt like it hadn't impacted his daughter in getting a diagnosis.

Table 19

Example Quotes Demonstrating Gender

I think it's quite bad with the whole process. I know girls more difficult so than boys, but to be negated when they've got video evidence and everything else and people trying to buy off the system.	Bilal

And unfortunately, that's just say it is that they're saying at almost she looks normal to me. That's fine.	
I've noticed that and I think it's just a, you know, more proven like I think the reason that girls get diagnosed less of autism is because they tend to mask or like umm. They tend to have less symptoms. They tend to mask and I think that's because you know, especially in younger boys when they have autism, you can really tell which is where that whole. I I don't know which is.	Lizzie

Discrimination Nathanial shared that their ethnicity delayed getting a diagnosis as he felt healthcare professionals found it strange that his daughter was autistic, as this was something that was not associated with the Black race. Ellen also felt that there may be factors such as accent, ethnicity and education that may impact how people have access to services.

Table 20

Example Quotes Demonstrating Discrimination

I do think that because I am Umm… Let's just say I went to Catholic school. If you speak to me on the phone, you wouldn't know necessarily what race I was. I'm well spoken, I'm reasonably well educated. I'm in the NHS. I'm like, I'm in my trakkie now, but I'm normally you know…So I think that because I present in a professional kind of manner with my entirety. Because I'm well-spoken and my English is pure. Because if something's wrong, I would say excuse me. I don't understand.. what was this? This is not correct. Whatever, I just think. I'm treated better to a certain extent.	Ellen
Umm, initially I think I'm not the only one who have had that misconception about autism, I think most of the healthcare professionals have been able to meet really felt it quite strange for my daughter to actually be, be autistic on when when her symptoms kept on kept on display in and kept on getting worse and worse. It was really a concern for me because we really needed to have a diagnosis before we	Nathanial

could really get the support and and the diagnosis took a whole lot of time and that was that was really that really caught my mind and made me to understand that a lot of people think it's couldn't or it's not been associated with the black race. It seems so a little percentage, or if not so infinitesimal. You get so it poses it a whole challenge in getting a diagnosis.	

Bullying Three of the young people had faced bullying and ostracism at school. Two of these stories were related to their ethnicity and facing racism (Grace and Lizzie), and it was not known in the third situation, but parents hypothesised that it could have been because their daughter misread social communication, and the situation escalated. Neither Grace nor Fatima brought these stories up themselves, and it was told to the researcher by their parents.

Table 21

Example Quotes Demonstrating Bullying

I think I just might be one time in like high school. When this girl was like, you know, you started COVID or something. And even then, I don't know if she was trying to be racist. I generally think she was just trying to be mean and not being racist, even though it's a coincidence I'm Asian cause apparently she was mean to a lot of people.	Lizzie
So I think for her she she did doesn't realize it's just because she's a bit vulnerable. She doesn't understand many things. She gets picked on and get bullied as well. **Mmm**. So I think it's it's much better than school understands as whether this child has needs, but they can understand that, you know, she has needs. And so it because of that it just came to a point that she was beaten up.	Maryam and Bilal
…primary school she had there was some bullying that was just nonsense and yeah, I was a governor, and I don't mess around with her so. And you know, I start sending those emails and stuff like.. What? What is going? What? What's what's going on? **Mmm**. You know, there was just blatant, there was a bit of racism in school…	Ellen

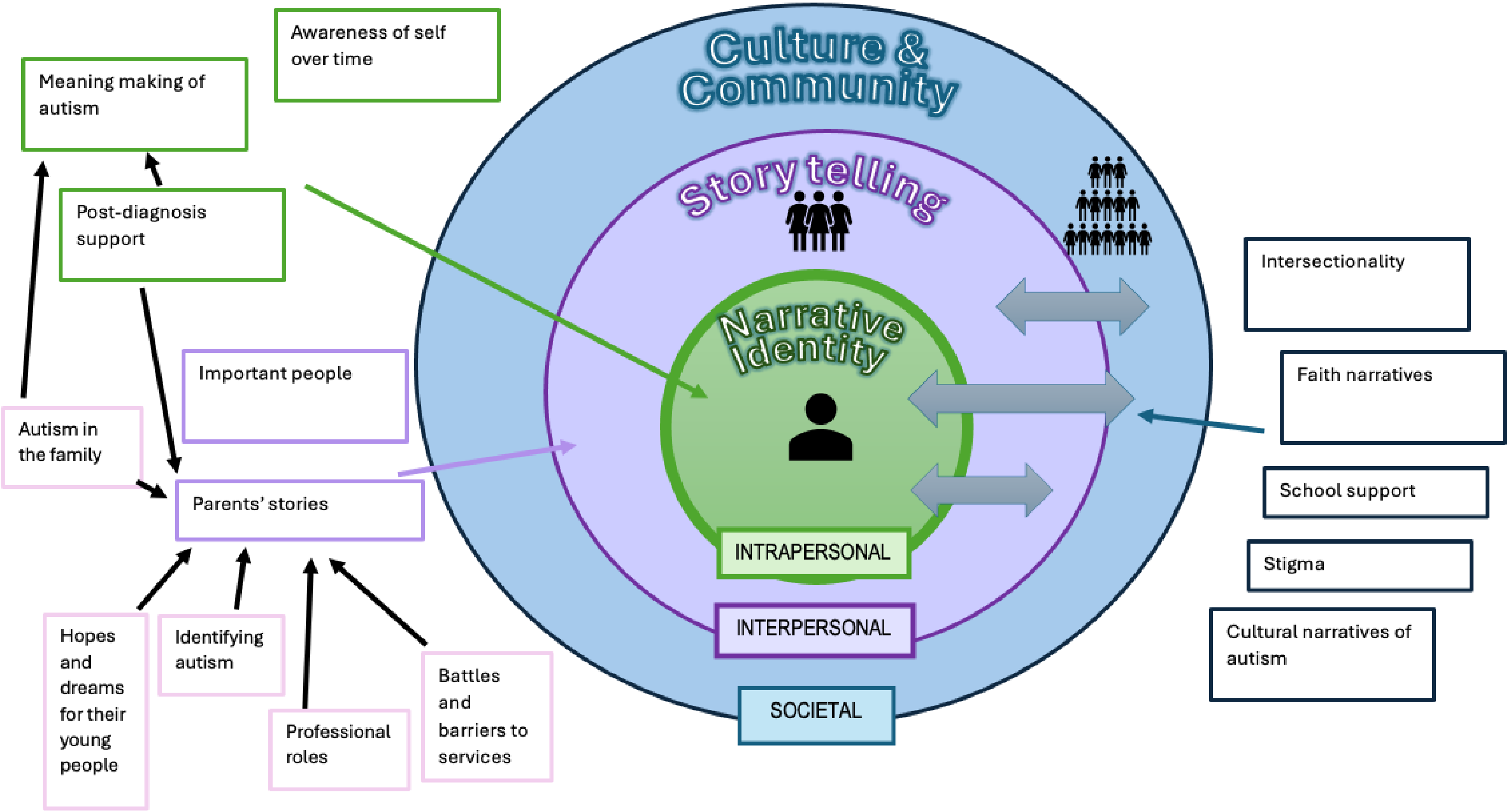
Discussion

This study aimed to explore the stories of young people and their families from a global majority heritage to understand their autism journey and how they integrate cultural, community and dominant narratives into their personal narratives and narrative identity. An interpretation of the findings will be discussed in relation to the existing literature. The study's limitations, clinical implications, and considerations for future research are presented below.

Figure 1 displays a conceptual model of young people’s narrative identity (McAdams & McLean, 2013), representing how the narrative themes from this research integrate with Rappaport’s three-tier model (Mankowski & Rappaport, 2000). Previous research has shown the impact parents’ stories can have on how young people see autism (Riccio et al., 2021). The diagram highlights how cultural and community narratives and storytelling can shape young people’s personal stories and narrative identities, and in return, individual narratives can shape the family, cultural, and community narratives around them. For this review, the model is applied specifically to the stories of autistic young PoGM, but it could also be applied conceptually to general narrative identity development and to those from white cultures. Many of the themes will not be unique to just families of the global majority navigating, and many others may recognise similarities in their own journeys.

Figure 1

Research findings integrated with the narrative identity model, with factors at the intrapersonal, interpersonal, and societal levels.



What were the personal stories of young people of the global majority who have received an autism diagnosis, and do community and cultural narratives feature?

Six areas emerged from the young peoples’ narratives in relation to their personal stories; these were meaning-making of autism, important people, awareness of self over time, post-diagnosis support, school support, and autism in the family. These were shaped by family, community and cultural narratives. All of the young people shared stories of making sense of their autism by first understanding what autism was, either through theoretical knowledge they learnt from post-diagnosis support or other people pointing it out to them, and then integrating this with how they saw themselves. These were closely linked to the community narratives around them. For example, Lizzie went to a special needs school and heard the term neurodiversity used at school, and she felt lucky for the support she received. Conversely, Grace had been in a mainstream school, had rejected support and didn’t like to tell people at school that she had autism. Hornby (2011) suggested that children in special needs schools are more likely to develop a sense of belonging than those in mainstream schools because they are comfortable around peers with similar needs. Fatima had accepted that she had repetitive interests as she saw this as a strength but rejected that she had social communication difficulties and saw her communication as a strength. It may be that those diagnosed with autism in mainstream school find it harder to accept having autism to ‘fit in’ with their peers.

Stories of stigma, racism, and bullying were raised in narratives. Research has previously found higher rates of bullying in adolescents of the global majority (Sapouna et al., 2023) and autistic adolescents (Humphrey & Hebron, 2015). For two young people, their parents told the stories of bullying, and they did not bring it up themselves. This could be linked to shame or feeling uncomfortable telling someone they had just met. In line with the NAS report, (Slade, 2014), young people from PoGM communities experience discrimination in relation to their autism and their ethnicity. Individuals may manage stigma by attempting to ‘pass’ (Goffman, 1963) or camouflaging. One of the participants reflected that she may be treated better as her race is masked over the phone with how she talks. While ethnicity is a seen difference that participants cannot mask, this may increase attempts to mask autism, which could be considered invisible and unvoiced (Burnham, 2012). School support to provide an inclusive classroom environment for young people can combat stigmatisation from other pupils (Underhill et al., 2019).

Noticeably absent from three of the young people’s narratives was a discussion about the neurodiversity movement, which aims to celebrate autism as an inseparable part of identity (Kapp et al.. 2013). However, two did cite differences in thinking or their brain being wired differently, and one rejected autism as a difference and saw it as a disability. This could demonstrate that the concept of neurodiversity has been spoken about, but they have chosen not to adopt it, or that it has not been explicitly named.

What are the personal stories of the family members of their child, including their assessment and autism diagnosis, and do community and cultural narratives feature?

Eight areas emerged in the parents’ narratives; these were identifying autism, battle and barriers to services, emotional dysregulation, professional roles, hopes and dreams for their young person, post-diagnosis support, school support, and autism in the family.

In keeping with previous findings, themes of struggling to navigate services saturated personal narratives. Given that some of the participants were recruited through a Tier 4 NHS service, which meant they had already had one autism assessment through a local service that was deemed inconclusive or had been disputed by parents or professionals who knew the young person, this journey may have been even more complex. Participants shared stories of difficulties and delays in getting a diagnosis for their child. This had an impact on the services they could then access for support, education, and funding. This highlights the power dynamics between services and parents where clinicians hold the expert knowledge (Avdi et al., 2000) and act as gatekeepers to specialist services or diagnoses. Nathanial felt that professionals took longer to recognise that his daughter was autistic due to their ethnicity. Three parents spoke about the need to be proactive in persisting with services when they weren't listened to and advocating for their children. While these parents have now achieved having their young people seen for a diagnosis, this likely indicates other parents who do not have the time, capacity, or understanding to access services are missing out. Additionally, those with English as a second language have an additional barrier to accessing services and, when they do, having their voices heard. In some languages, for example, Somali, there is no word for 'autism' (Hussain et al., 2019) and therefore, direct translation is not always possible. In line with previous findings (Gould, 2017), parents and young people spoke about the delay in recognising autism in girls due to the social masking that may happen and clinicians dismissing autism if there was a discrepancy with school. Increased awareness of the presentation of girls with autism is still needed in schools and clinicians such as GPs and paediatricians who gatekeep referrals to specialist services.

Parental stories of emotional dysregulation were prevalent among all the parents in this study, and they spoke about the impact that this could have on the young person and family home. This is in line with the finding that emotional dysregulation is commonly experienced by autistic individuals (Cai et al., 2018), and anxiety and depression occur at higher rates (Hollocks et al., 2019). This indicates the importance of family intervention and parenting groups in setting up an environment that caters for autistic people, alongside early intervention from schools and services to help autistic young people manage their emotions.

Strengths and Limitations

Common in narrative research is the limitation of its generalisability (Riessman, 1993). The small number of families who took part, the range of geographical locations and the diversity of cultural groups and ethnicities mean the findings should not be considered universal, but the concepts may be transferable to families in similar situations. The research aimed to give a voice to families who are often missed in research and to understand whether there were common experiences in their stories. The findings can have implications for autism services and may shape clinical interventions for those in similar situations.

The parents who took part all mentioned being proactive about seeking an autism diagnosis and fighting battles with the system. It is important to bear this in mind when reading the findings as it is likely that this proactiveness also meant they are more likely to sign up for research opportunities. Therefore, other families who struggle to access services, or do not have the time to take part in research may have other experiences.

The young people in this study struggled with the narrative enquiry approach. They found the question broad and unstructured. When prompted, they could share their strengths, challenges and where they would like to be in the future. This could indicate that autistic individuals find sharing stories about themselves easier when it is co-constructed with others. It was unclear when the researchers designed the study whether this approach had been used with autistic young people before. Additional visual prompts were designed, and verbal prompts were included to go alongside the initial question. Recommendations for further research using narrative approaches with autistic people may wish to consider using semi-structured interviews or pre-approved prompts to help facilitate the sharing of narratives,

Clinical Implications and Future Research

For policymakers, educators, and clinicians, a number of considerations emerge from the research. The narratives demonstrate the clinical importance of exploring alternative narratives of autism both at assessment and in post-diagnostic support to help young people and their families integrate potentially conflicting narratives into their own understanding. This is especially important for faith and cultural narratives, moving away from the clinician as the expert role and towards helping service users make their own meaning and tell their own stories. Post-diagnosis support workshops were highlighted as helpful in understanding autism and meeting others with autism, but this is not always available or accessible to young people and families and may cover different content according to who is running it. As highlighted in the study, the stories of those around young people are important in shaping their narratives, and assessment services should be aware of the stories they are telling those young people at a pivotal moment in their lives. Consideration should be taken as to whether workshops facilitate autistic young people meeting each other and which societal narratives are drawn upon when designing groups. Post-diagnosis support is sometimes used synonymously with psychoeducation, however, this study shows that the meaning made of autism is important in integrating this with identity and the impact in can have on masking to avoid stigma. Post-diagnosis support can play a role in beginning these conversations and equip young people and their parents with navigating this within their communities.

The research highlights the importance of having supportive local communities and the power of parents as advocates in supporting and educating the community around them. Kandeh et al. (2020) found that there can be a lack of recognition and acceptance of autistic people in some communities, which can lead to social isolation, loneliness and ostracism. Community psychology initiatives focusing on engaging local communities and co-creating resources and workshops should be considered. By services working in parallel with parent advocates, this in turn could be helpful in increasing awareness of autism in some communities and dismantling barriers to accessing services, as well as making clinical resources more culturally appropriate. Consideration should also be made for assessment teams to have information available in other languages.

Autistic adolescents of the global majority are at risk of higher rates of stigma, racism, ostracisation, and bullying that can occur when someone has multiple oppressed identities. The findings from this review indicated young people had been bullied for their ethnicity and for being autistic. Additionally, autistic individuals are more likely to be gender and/or sexually diverse and report greater adverse stress when they have multiple oppressed identities (Soto et al., 2014). The study indicated that when young people have these negative experiences and stories spoken over them, they are more likely to reject their diagnosis. Chapman et al. (2022) found that increased masking of autism can lead to worse mental health outcomes. Clinicians working with young people should be aware of this at assessment to consider whether further referrals are needed for mental health support or help at school, and when considering the most appropriate therapy when a need is indicated. Given the additional challenges autistic young PoGM face, systemic factors should be included in the psychological formulation and drawn upon when offering intervention. Discussion and consideration of autistic differences, adaptations needed for therapy, cultural sensitivity and curiosity of individual and family narratives should be incorporated throughout any support offered.

The paper highlighted the journey of self-discovery of autism that some parents may go through when their child accesses services. This can have clinical implications for assessment services, who should be aware that parents could also be going through their own reflection or require help with accessing adult diagnosis services. Future research should be done to further understand the rates at which this can occur.

The study highlighted further avenues to be explored in future research. Barriers to accessing services arose in parental narratives. There is still more work to be done in understanding why rates of autism are different across different ethnic groups in the UK and in different areas (Roman-Urrestarazu et al., 2021) and whether this is related to the barriers mentioned in this study, such as clinician awareness of autism across different cultures. Further research should focus on how to enable cultural and community narratives of autism to be integrated within therapeutic work. It could explore different models of individual and family therapy, alongside community psychology, in order to do this.

It is hoped that the conceptual model suggested in this study can be used in wider research to understand the development of narrative identity, with an emphasis on community and cultural narratives and the role they can play. Further research should focus on specific communities to further understand personal and cultural narratives, particularly for autistic individuals.

Conclusions

Through a narrative analytic approach, this study offers the first step in understanding stories from young people and their parents of the Global Majority. It aimed to investigate what aspects of identity featured in participants' personal and family narratives and explore how they made meaning of autism, how cultural and community narratives can shape personal narratives and hear participants' experiences of an autism assessment. The study found themes at the interpersonal, intrapersonal, and societal levels, which interacted with each other to begin to form a narrative identity. In young people's narratives, their stories included making sense of autism and what it meant for them, the role of important people in their lives, their awareness of themselves in time, the helpfulness of post-diagnosis support, and family members having autism. In narratives from family members, themes arose around hopes and dreams for their young people, the process of identifying their child might be autistic, battles and barriers to accessing services, and their own professional roles. Community and cultural narratives included the tole of stigma in society, school support, faith narratives, intersectionality and cultural narratives of autism. In summarising the participants’ stories, the study offered a model conceptualising how narrative identity is influenced in autistic adolescents and how this comes with unique challenges for PoGM. While many of the narrative themes found will translate to all autistic adolescents, PoGM faced increased challenges in accessing services due to clinician bias, racism and discrimination at school, and a lack of curiosity and awareness into their faith and cultural narratives when accessing services. Several clinical implications were raised, including how assessment and therapeutic services can be adapted to be more inclusive and personalised to PoGM and increasing clinicians’ understanding of the additional barriers and challenges they may face both in wider society and in accessing services. Further research is needed to understand the barriers PoGM face accessing services, and what clinicians and wider society can do to reduce stigma.

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Appendices

Appendix A: CASP Checklist for Qualitative Research

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Appendix B: Full data extraction tables

Meaning making of autistic identity – My story – first and second-order constructs			
Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Tesfaye et al. (2023)	I wouldn’t change the fact that I have autism because it’s who I am. And I think if I really did change that it would be really bad because I’d be changing a part of me. So I’d say make it easier that I can have friends (p.1147)	Although they identified many challenges linked to autism traits or perceived autism traits, they recognized that being autistic was part of their identity. Youth indicated that rather than changing who they are as autistic individuals, they would prefer barriers in their environment, or specific behaviors with which they struggle, to change. Hence, youth conveyed that they were “OK” with their autism diagnosis, but they wanted being autistic to be easier…. Participants also identified positive aspects of being autistic. Similar to the challenges, some advantages were directly linked to clinical autism features (e.g. developing knowledge and skills by focusing on specific interests), while other advantages were related to cognitive abilities (e.g. having a good memory, being “smarter,” and seeing situations uniquely or creatively). P1147	Autism makes me who I am
Chapman et al (2022)	“because I feel like autism in my case is better than being normal… I wouldn’t want to be normal. I wouldn’t be as smart and want to do as much learning as I am. I wouldn’t have my amazing memory” (page 8)	Some participants also spoke about valuing their personal strengths, which related to being autistic; teenagers expressed pride in their intelligence, specific skills or abilities, self-awareness, creativity and ability to be a good friend.(p8)	Autism makes me who I am

Kofke (2019)	Well. The brain, when my brain, you know there's the left side of the brain, the right side of the, brain the hemispheres?...Left side of the brain's all about work and logical things…Right side of the brain's all about creativity and stuff…In my brain my autism makes it so that my right side of the brain is always dominated over the left side...So, I'm more prone to using the right side of my brain rather than the left side of my brain (p. 94)	Maia understood her creativity as a manifestation of her autistic neurology. She articulated her understanding of how her brain was more creative	Autism makes me who I am
Jones et al.	'I almost slipped and said no big deal, but it is a big deal. It's actually something I like about myself because I can do things normal people can't. Like I can be in my own world or this world.' (p.1498)	Gary also described a sense of pride in his unique abilities. When asked what he thought of when he heard the word autism, Gary stated:	Autism makes me who I am
Stevenson et al (2016)	I wouldn't want to change it, I'm perfect the way I am. I don't want to change who I am.' (p.225)	…the theme of accepting autism also came up for many students (p.225)	Autism makes me who I am
Stevenson et al (2016)	Having autism can be good though, like I feel I look at the world in a differ-ent way...a bit like what an artist would look at it, or a film director, and it's a really interesting way like, to see it from my eyes	Alongside the desire to understand the medical diagnosis, the students also thought about their own personal meanings of autism, and this often moved away from the 'difficulties' of autism to the strengths or uniqueness that autism gave (p219)	Autism makes me who I am
Cridland et al. (2015)	It's okay that I have AS, otherwise I wouldn't be who I am… It doesn't really affect me… You are born with AS so I have always had it and have never had a problem with it… I mean it's a brain thing so that is going to make you different, but I don't know what ways"		Autism makes me who I am

	"I don't really know what AS does [to me]… It's not a good thing or a bad thing, it's just a thing!" (p.359)		
Cridland et al. (2015)		Some participants also spoke about valuing their personal strengths, which related to being autistic: teenagers expressed pride in their intelligence, specific skills or abilities, self awareness, creativity and ability to be a good friend (page 8)	Autism makes me who I am
Berkovits et al (2019)	Sometimes I think in a completely different way from others and I end up getting a cool result (p.838)	Nearly half of the adolescents with ASD (44.6%) described cognitive benefits of having ASD. (p.837)	I am differet
Tesfaye et al. (2023)	Ahm, like a lot of times, autistic people's brains work differently . . . Like, if you look at it, a neuro-typical brain and an autistic brain you won't find anything different by individually looking at them. It's just the paths of how things transmit in a neuro-typical brain and an autistic brain are different. It's kind of like how people, it's kind of like Canadian and American people write back and forth and Chinese [people] write up and down. (Participant 12, Female, 13 years old) (p.5)	"Autistic Identity. Youth described autism in complex and nuanced ways. There was no overwhelming preference for describing being autistic as either negative or positive. Many of the participants described the diagnosis as a human variation stemming from differences in brain function" (p.1147)	I am different
Morgan (2023)	"I was glad that I finally had answers as to why I was very clearly different to most people in school" (p184)	Through this construct autism becomes a kind of lens through which participants (and others) are now able to make sense of themselves and their lived experiences, and through which they can reframe the self … A diagnostic discourse presented	I am different

		participants with the discursive resources to construct their self-concept in relation to “being autistic”. This supports what other researchers have found, with autistic adolescents claiming autism as a core part of self (p 184)	
Mesa & Hamilton (2022)	“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 lables are a bad thing… I like being labelled autistic, I don’t know why…because it’s the reason I am why I am.” P.9	‘an autism diagnosis had been exonerating in explaining the basis of their perceived difference and they have positively integrated the idea of ‘being autistic’ into their personal identity’ (p.9)	I am different
King et al. (2015)	One thing about me is that I know loads of facts and really obscure facts about that no one does, and I know loads about films, and I know loads of old films that my parents know but no one else knows.	Self in relation to others: I am different. Participants shared an understanding of themselves as different from other people through making social comparisons. (p.237)	I am different
Hanai	I could not act as I liked, I could not act freely in a regular class, I did not have any kind of cooperation, so I’m going to feel, oh, I’m different from others. [Researcher: Did someone say so to you?] Not that what I really mean… I started thinking about myself and felt I was different on my own after all.	Some participants came to wonder why they were in a special support class or why they were different from other children, which caused them to start thinking about themselves.	I’m different
Morgan	When I was diagnosed, I felt different to everyone around me and it wasn’t until being in a specialized school for autism and being around other girls in similar situations that I felt like I wasn’t alone. (p190)	Most participants construct the self as different from their neurotypical peer groups and convey a sense of not belonging with them.	I am different

Stevenson et al (2016)	‘You may seems a bit different, and I know sometimes it can be hard, youknow, and sometimes you may look at people and think ‘they’re normal, Iwish I was them.’‘I would say to myself I can’t take it anymore, I want to change, to be normal.’ ‘I realise that I was different to everyone else, like ask me anything about Dr Who and I know the answer.’	Often within the interviews and group discussions, the students spoke about how they had realised that they were in some way ‘different’ from others… For some students, this feeling of difference was often linked to a desire to be ‘normal’:, however, with continued discussion, there was a wider questioning of what it meant to be different that seemed to help the students construct a more positive perception.	I am different
Kofke (2019)		Each student discussed their relationships with her autism or neurodiversity label both within their school and then related it back to herself. They understood they were set apart from the other students as different. At times they were explicit and stated this understanding within the construct normal or not normal. For some of the students it was a point of pride that it was difficult to tell if they were autistic, for other students they deeply felt and understood their autism as setting them apart from the rest of the school population.(p.69)	I am different
Gaffney (2017)	… I kinda knew, I kinda knew, that there was something different.. I knew it was probably nothing and that. But like in Year 4 they started this club; it was a very nice club and I get why they did it and everyone who was autistic, disability, and they all put us, every Thursday we would have breakfast and we would talk and that, it was, it was, like a, a nice time and	She hadn’t heard of autism although she had realised that she was ‘different’ in primary school because she was put in a club for children with ‘problems’	I am different

	we would miss French so we were quite happy with that, laughs . . . And in Year 4 I was like, okay, so I'm a little bit different and that's why they've done this and I think (p.60)		
Jones et al. (2015)	When asked whether there were any other ways he learned about autism, Chris said: 'Studies and therapy, and a whole bunch of suspicion of why the heck am I doing this sort of stuff. Plus, my curiosity at why I have such a hard time at school.'	Chris expressed that he knew so much about autism because of his lived experience and interest in understanding his unique behaviors and need for supports.	Understanding autism
Kofke (2019)		Marking autistic identity. We discussed several markers that highlight understanding of autism as it related to identifying as an autistic person. These markers traversed their history of being autistic, which included conversations about going through the diagnostic procedures to be given the official autism label, identity first language, how autism impacted their daily lives, and where they were learning about autism (e.g. online, reading books). Additionally, some of the students took to the practice of discerning autistic traits in fictionalized characters, which demonstrated their ability to recognize autism in others, based on their previous experiences and research about autism.	Understanding autism
Gaffney	I never fully understood it, even now I still sometimes struggle with it, erm but I know, if I'm right, then it affected my social life, because that's what it does affect. (p63)	What is autism? Participants found it difficult to explain autism	Understanding autism

Stevenson et al (2016)	'I don't get it. So now I'm thinking my brain is not developed properly. Does it mean my brain? The wires in my brain are not connected? That's what, I'm confused now.''So now it's a lot different but it's still new. No-one knows exactly how autism is affected, no-one knows how it affects you and no-one knows why it's given to you.''Lots of kids like me who have got it, don't know what it is, they tell you you've got it, but you don't know what it is. (p.220)	Quite often in the interviews (especially when discussing causes of autism) there was a sense of confusion for the students	Understanding autism
Morgan	Overall, my diagnosis has allowed me to understand myself 10 times better. I always wondered why I had meltdowns, I knew it wasn't normal. I wondered why school was the most stressful, overwhelming and anxiety-provoking experience. Autism answered a lot of questions and for that I'm very grateful. I was the one to ask to go through the diagnosis process for Autism. . .Through the entire process most of the adults I told . . . said that they didn't believe that I was autistic. P184	Some participants referred to others not believing their experiences or self-knowledge, even though they themselves knew they were "different"; diagnosis represented external validation which others must now accept… For many the struggle for being believed was now over, and the diagnosis provided the answers people had been looking for p184	Understanding autism
Tesfaye et al. 2023		youth distinguished between their personal experience of autism and the experiences of other autistic youth. Their observations of multiple autistic profiles were also highlighted when defining what autism meant to them.	Understanding autism
Stevenson et al (2016)	…you went to get diagnosed with autism, how did your mum cope? Well I'll be honest with you, my mum was really shocked cos she	[Diagnosis] was often accompanied by expression of shock, upset or blame…. Within these accounts, the emphasis on	Understanding autism

	didn't know what autism was and she had to do some research on the internet. But then she got to understand me more.	love and acceptance and researching to understand came out strongly as ways to cope with the initial diagnosis, and this also leads to wider themes of constructing a positive identity (p.217)	
Berkovits et al (2019)	It's terribly sad when I have to go through this, cause no one wants to have Asperger's (p.837)	42.1% of adolescents described a variety of perceived burdens related to having a diagnosis of ASD.	Rejection of diagnosis
Riccio (2021)	"Autism . . . means like you can't it basically stops you from doing normal human tasks, you're going to be walking like this (walks around tripping over foot and banging into things) . . . it stops you from doing the normal things, you get frustrated that you can't do the things you would normally do. And you start complaining every minute, I can't do this why can't I do this, and you go on mental breakdowns every minute and it can be really annoying for other people to have autism around . . . autism is bad and I don't think anyone should have it . . . I am not autistic." (p.386)	Adolescents who were told they were autistic by a parent involuntarily or not told at all were more likely to include challenges in their definition of autism (p.378)	Rejection of diagnosis
Gaffney (2017)	. . . I wish that sort of, I wish, that I don't have it and don't want to know, I don't like saying that I have it, cause for me it don't feel comfortable saying it, it feels something not right. When I speak with people who don't have anything wrong with them it feels awkward and all that for me.	Kerry has always had a negative response towards her diagnsosis… she does not want autism in her life	Rejection of diagnosis
Jones et al. (2016)	I would change my auuu [stutters], I would try to get rid of, I would change, I would try to get rid of my autism. It can be a burden. Ehh, but that's what makes up half of my	Chris highlighted this incongruity; when asked whether there was anything he would change about himself, he replied (p.1498)	Rejection of diagnosis

	intelligence, it is what makes up most of my intelligence.		
Mesa & Hamilton	"I want to be treated like normal. I don't want to be treated like there is something, like I have Asperger's". (p10)	Despite differing responses to diagnosis, a commonality was the desire to be treated as 'mainstream', like everyone else. Jenny (p10)	Rejection of diagnosis
Chapman	I remember trying to act calm or normal in a posh, rich area… so like imagine this everyday person, you know, you see them on the street. Now imagine them in a restaurant. A rich one. Just like being awkward. With the handkerchief on his lap (p.10) '	Teenagers also alluded to ways in which being autistic intersected with other aspects of their identity in specific contexts' (p.10)	Intersectional identities
Barber	Well, from things I have researched on my own through online things, it seems like people with autism and people who are a bit more neurodiverse usually are more likely to have gender dysphoria, from what I read at least. Not sure if it's actually true or not, but I definitely think since I have autism, it might make a bit more likely for me to identify as transgender (p.90)	When asked what how they thought autism influenced their gender identity, participants shared that they viewed their gender identity as being separate from their autism identity or diagnosis.	Intersectional identities
Kofke (2019)	Well. I've heard that autistic women, like myself, tend to be kind of shy. You know. Or they might be a bit irritable…Kind of like me…considering the fact that I don't really understand, like the difference between autistic women and autistic men quite yet. Like I guess ah. Not sure. I just, I just know. I'm not an expert, you know. I'm just going based off of what I've seen. You know…But you know, I think. I don't think these things are exclusive to women though. I think	There was an intersectional component to these student's social lives at school and how that impacted their school experience …. This theme focused on the impact of their understandings of their gender as a female, girl, or young woman and any intersections with autism. Each student conceptualized identifying with their gender differently. They felt autism or neurodivergent traits, which affected each person differently, regardless of gender. (p.70).	Intersectional identities

	ah, I think autistic guys might be shy or antisocial, or they might be really irritable, like me. (p.135)		

Self in time – first and second-order constructs			
Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
King et al.	I remember this day and it was really, really funny. We were driving to school and it was really icy, this road that was a bit of a shortcut, and we [Dad and I] call it cat road because we see lots of cats and it was actually quite scary because it was really icy and dad accidentally crashed into the back of this van. (p.237)	Self-extended in time For some participants, reflecting on the past contributed to self-understanding. Rory recalled a series of specific events including a birthday celebration, a difficult situation that lead to the development of a close friendship, a "funny story" relating to a family friend and a "scary" car crash. (p.237)	Past selves
Hanai	Because I've been working hard until now, I have confidence, I guess I'm getting stuck, I have experiences, so I can do something with it this way, already my experiences has been utilized well in my life. (P/18, m)	Participants considered overcoming past painful experiences as connected to their present selves. . (p 1673)	Past selves
Chapman	"I don't really like talking about what they [my social skills] were like at the time because it's really embarrassing because. Because I used to board and partly why I left boarding is	Participants spoke about feeling ashamed of their past social skills, behaviour or expression of distress.	Past selves

	because the care team kept talking to me about what I used to be like. And, I kept saying, please could you stop talking about what I used to be like? I'm really ashamed of the person I used to be… Like because I'm not the idiot I was then. Like I never thought about anything'		
Morgan	"I also realised that I'm going to have this my whole life and I began to stress about the future - will I be able to cope in a job?" (p.189)	A majority of participants talked about their future self, the ways they were trying to improve themselves, or fears about the future as an autistic person… Participants spoke or wrote about academic qualifications and future careers as destinations they were focussed on working towards, or of skills they were working hard to learn… However, a further challenge for autistic adolescents is how to manage the potential dissonance between constructing the self as a person with support needs alongside a future self who will have a job, career and independent life beyond the immediate family, as is so often the normative ideal in western cultures. (p.188)	Future selves
Gaffney		Despite her depressed feelings, Kerry retains the motivation to do well at school and wants to go to university,	Future selves

Hanai	Wow I have a strong desire to become ordinary, so I was trying to go to university, but now I think it is not necessary to be ordinary is it? Because I was not ordinary there are a world that seems to be visible. There's not much different whatever I choose. What do I think of life, … life, and after all, I don't want to make that boring life, I don't want to make it into boring high school life, I want to make something better. It's in a better direction, and even if I am not aiming for the best, I say, aiming for the better. (p1673)	Intentionality and self-transformation Some participants felt that they has changed in terms of ways of thinking, behaviour and personality and others felt their perception of their own characteristics and disabilities had changed (p1672)	Future selves
King et al. 2015	If I don't do it [music practice] I'm going to be stuck and then there's no point in me carrying on is there? Not if you've got nothing to show what you've done and if [I do] by year 11 or maybe year 10 I would be able to teach people how to play the trumpet.	Holding in mind a future possible self appeared to help participants make important decisions and provided motivation. Having established his identity as a musician, Henry hoped to attend a prestigious music school and pursue a career as a music teacher. Holding this future in mind reinforced his commitment to current musical endeavours.	Future selves

Berkovitz	Alejandro (Male, Age 15, IQ 86): “I don’t know if I’ll be able to marry anyone, because who wants to marry a guy who has Asperger’s? And if I marry someone I’m going to have to tell them I have Asperger’s… I can never really have a child because there could be the fear of, you know, having, putting another person with Asperger’s in the world. (p836)	When discussing this perceived stigma, many adolescents also referenced ways in which they predicted ASD could negatively affect their futures	Future selves
Tesfaye	“Ok, and for what reason would you like to have a girlfriend?” “So that way I could start a family that doesn’t have to be fully autistic. But they need to understand me and I can understand them back. I mean it would be cool if the whole family was autistic.” (p 1149)	Some youth indicated that they would like to establish romantic relationships later in life (p1148)	Future selves
Stevenson et al. (2016)	“One day I would like to have my own flat, have my own family, and be happy…” (p.22)		Future selves
Tesfaye et al 2023	. . . well a house I do want but after I learned a lot about responsibilities to a house, I think I’d rather stick to an apartment. (p1148)	In the initial ordering activity, the future was the second most frequently identified worry among participants. Most participants, both minimally speaking and speaking, were	Future selves

		able to identify attributes they both wanted and did not want in their future. Youth both looked forward to the future and identified the theme as a major stressor. Two participants declined to discuss the future as this made them feel uncomfortable or sad. P1147	
Tesfaye et al. (2023)	Interviewer: Who will make the important decisions [in your life]? Participant: Probably my parents [. . .] I'd go to more places, like maybe instead of making my parents go do the groceries, I would probably go do it. (p.1149)	Seeking autonomy. It was clear that many youth wanted to gain autonomy, particularly in the sense of being able to make independent decisions about matters that affect them.	Autonomy
Morgan (2023)	If I could, I'd be as independent as I possibly could be, you know, um, but I wanted to just seem like a normal child.	Fears around remaining dependent on others are set against expectations to become independent and self-sufficient, with many explicitly stating that they understood they were not on the same time trajectory (towards independence) as their peers	Autonomy
Hanai	I had some pets, they were mine, so I had to take care of them. My parents told me it was about time for	Participants imagined what they wanted to be, such as being on their own and independent from their parents.	Autonomy

	you to work. Well, I hate to be told so, … and I did my best [to find a job]. (D/24, f)		
Stevenson et al. (2016)	I've always wanted to go to the cinema on my own. Or I want to go to the shops and be able to confidently buy stuff.	The students continued to talk about their hopes for independence… (p.22)	Autonomy
Mesa and Hamilton (2022)	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%".	Changing understanding 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. P 11	Acceptance of autism over time
Morgan (2023)	I feel that l have learnt to accept myself and will continue to learn to be my best self . . .but l don't think the world is ready to be understanding and supportive.(p.188)	A discourse of individualism is used in participants' constructions of the self in the process of "becoming" a hoped-for future self. A majority of participants talked about their future self, the ways they were trying to improve themselves, or fears about the future as an autistic person. Journey metaphors were often used which constructed the future as a destination, with autism as one of the potential roadblocks to progress… Participants spoke or wrote about academic qualifications and future careers as	Acceptance of autism over time

		destinations they were focussed on working towards, or of skills they were working hard to learn. (p.188)	
Stevenson (2016)	‘I used to say I wish I didn’t have autism, I don’t say it any more, I’m starting to accept it. (p.225)		Acceptance of autism over time
Jones et al. (2015)	‘Like I was in denial with this whole thing since freshman year. I started to agree during my junior year. I started to see all of the signs and was like yeah I have it.’(p.1496)	Kelly described that over time she was able to reflect on her process of making meaning of her diagnosis (p.1496)	Acceptance of autism over time

Personal process –first and second-order constructs			
Cridland et al (2015)	He gets very fixed on an idea. It can be very frustrating at times but it can be good at other times…If he has an idea on something…he will stick to that even if you tell him it is wrong… (Brother, Family 2) [He] thinks he is right all of the time and that is his downfall…sort of contradicts everything you say. He’s a real challenger; he will challenge you on everything. (Father, Family 6)	The majority of family members (n = 15/19) discussed the adolescents’ tendency to have rigid thought processing styles rather than developing flexible processing. Common areas of rigidity included retaining an opinion despite conflicting evidence, following rules without exception, difficulty accommodating change, and perfectionism (p.359)	Cognitive challenges

Berkovits	"I take things over literal and it just makes the conversation harder. But I'm starting to learn how to not to take things over literal but I'm still really bad at that. So like, we'll be talking about something and I'll just take it over literal and get the situation all wrong."	Many adolescents (42.1%) also noted having cognitive challenges they perceived to be related to their ASD. These included feeling they had lowered intellectual capacity, struggles with school, or had a different way of thinking (with a negative connotation) due to having ASD.	Cognitive challenges
Kofke (2019)	She described that she would "want to do it with a passion" and then she found she "can't bring myself to do it at all."	Ernie discussed what she termed issues with "executive dysfunction" where she either could not start a school project, despite thinking about and had desire to start the project. … Alternatively, she had a hard time stopping her work on a project that she was intently focused on and did not want to complete it. In these examples, Ernie was describing what it was like to have autistic inertia, a common phenomenon among autistic people. (p.155)	Cognitive challenges
Cage et al. (2016)	"I do not like people leaving and then coming. It kind of confuses me. I just like it being all the same people, the same always"	Coping with the unpredictability of everyday life (page 17)	Routine and unpredictability
Chapman et al. (2022)	"If it's something where I'm going every day, school particularly, it gets easier. So lessons are better. I don't have to worry about that kind of stuff at school. Occasionally it comes	Many participants described unfamiliar situations as a trigger for masking, and often related this to higher levels of anxiety and lower self-confidence associated with these unknown contexts. Teenagers	Routine and unpredictability

	back though usually if I'm talking about something new. If it's something rehearsed like public speaking it's actually not that bad because it's rehearsed. That's why because I've done drama before and I don't really have a problem with projection because it's a rehearsed idea" (p.9)	felt that they were able to unmask and feel more authentic in familiar situations where they were more relaxed and comfortable (p.9)	
Tesfaye	"I want to go to [name of his school] March 1st."	after being suspended for running away, one participant repeatedly stated, "I want to go to [name of his school] March 1st." His father confirmed he was fixated on returning to school and resuming his regular routine, as its disruption was a source of anxiety. 1150	Routine and unpredictability
Hanai et al.	When I became a high school student, my relationships also changed anew, and I worried about getting involved with people in a new environment. How do I get used to the environment? I had to look at myself as necessary. (p1671)	In many cases, when participants experienced environmental changes, they became to think about themselves.	Routine and unpredictability
Chapman	Everything in my brain just vanishes for a second, and I feel like I'm able to just process	When these participants were able to express themselves freely, particularly though stimming, they described an	Stimming

	everything and all I think about really is the running. I don’t care what happened. I just want to run run run run run… it all just vanishes, it all just melts away suddenly. Because all I really want in life is to be free.	immense emotional, sensory and cognitive release	
Berkovits	I sometimes talk to myself and make weird sounds. I sometimes repeat things other people say. And it just, it naturally makes me feel good.”	N/A	Stimming
Tesfaye	Interviewer: When you are feeling sad, how do you usually deal with that emotion? Participant: I ignore it. Interviewer: That’s OK. OK. So when you are feeling nervous, how do you usually deal with that emotion? Participant: I go to bed. P1150	Experiences of stress and anxiety Throughout the interviews, experiences related to anxiety and stress were consistently raised by participants. As mentioned earlier, both school and the future were identified as primary stressors; however, manifestations of anxiety and stress arose across all of the subjects discussed. In a minority of cases, participants described depression and helplessness…. In addition, many youth expressed that they did not have strategies for coping with anxiety or stress, stating they often “endure” these periods or ignore them: 1149	Emotional process
Hanai	I think I’m working my brain harder than anyone else.	Many participants felt pressure to do things that they could not do well, and	Emotional processes

	Sometimes others tell me that you should have your brain to rest, but if I will take a little rest and feel relieved, soon it will lead to mistakes, yeah, I know, so until I go to bed, I cannot but do my best (p.1672)	they constantly struggled with academic achievement and relationships with classmates and teachers, which caused daily anxiety and tension. (p.1672)	
Berkovits	"Sometimes I'll be just all happy and when I'm not, then I'll just be sad." "Maybe I might get stressed out at certain things. Like errors on a computer."	Other areas of related challenges discussed included attention difficulties or impulsivity, mood and anxiety symptoms, or other emotion regulation difficulties (p.837)	Emotional processes
Stevenson et al (2016)	My main struggles were in my teenage years. My emotions popped up and all these strange feelings popped up. So these were obviously quite hard to deal with, but I got through them with support (p.23)		Emotional processes
Chapman	"For some people, it will be easier to not exist rather than to exist. There have been countless times in my life where I have felt that and it has taken me great courage to keep on existing" (p.13)	One participant spoke about how the exhaustion and impact of masking took a profound toll on their mental health and how at times this led to suicidal thoughts and feelings	Emotional processes
Cridland et al., (2015)	I get angry easy…A lot of things [make me angry],	Management of emotions was considered a challenge for adolescents by all family members who discussed	Emotional processes

	probably people saying stuff about me…like, "Aw look at that retarded kid"…I usually just swear at them and sometimes hit them…I know it's bad. (Adolescent, Family 6) His anger is a big part of his challenges…He waits until he gets home, like into a safe environment where he knows he can "go-off"…[He has] trouble controlling his emotions and what's going on for him inside…He'll get violent if any of us is in his way or trying to help and he doesn't want it… (Sister, Family 4)	this issue. These participants indicated the most challenging emotion to be managed was anger. More specifically, it was identified that the adolescents struggled with controlling their emotions, and sometimes expressed their emotions in a socially inappropriate way (p.360)	

The stories of others – first and second-order constructs			
Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Tesfaye et al. (2023)	Ahh, mainly lots of people can misjudge me sometimes and I'm like "dude I'm a regular person" and a few people are like "you'll never get a girlfriend because you're autistic," and I'm like "wow, that's a little prejudice, there." Probably. I don't know if, I don't know what	many challenges they identified were not directly linked to autism traits but rather to other co-occurring conditions (attention difficulties, impulsivity, anxiety) and experiences of mistreatment or stigma. (p.1147)	Stories of stigma and bullying

	they would call it when people don’t like people under the spectrum . . . (p 1147)	It is of note that while the participants did appreciate the opportunity to engage with peers during school, experiences of bullying and stigmatization were commonly brought up as barriers at various stages of their school careers. P1149	
Mesa & Hamilton (2022)	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.”	Neurotypical peers were described as viewing autism unfavourably. Sometimes awareness of the diagnosis, or that the young person accessed support, resulted in bullying.	Stories of stigma and bullying
Berkovits	“The kids didn’t understand me so that would cause them to pick on me.” But everyone else I think kind of sees me as a weird, almost insane kid with awkward opinions. Like they just see me as the weird kid I am… I think they don’t really understand how to react to me.	Other comments regarding social difficulties included experiences of being teased or bullied, feeling misunderstood by others due to their ASD diagnosis, or perceiving deficits in their social skills due to having ASD.	Stories of stigma and bullying
Chapman et al. (2022)	I remember when I was in year seven, I used to get bullied a lot. I was pretty nervous when I first joined [Saturday club]. I was worried in case like people would make fun of my autism. I didn’t even tell anyone I had autism… I never told anyone about my autism there. (p.6)	How others treat me	Stories of stigma and bullying
Jones et al. (2015)	Umm, I kind of just feel, I feel like I am just marked. Like people just have, some people just kind of treat me different, and I don’t want to be treated different, I just wanted	Throughout the interviews, many adolescents referred to the social stigma of ASD. Nearly all adolescents in the sample described struggling with how they and	Stories of stigma and bullying

	to be treated how I was [before receiving a diagnosis]. And I just, ehh, I don’t really like talking about it. (p.1498)	others with ASD are viewed in light of their diagnoses.	
Stevenson et al. (2016)	It’s like when people judge me when I’m out. I think they take the mickey out of me sometimes. It’s really upsetting for me. It makes me feel like I’m ashamed to go out on my own.	Whilst for some students, being treated differently could be very hard to manage and lead to withdrawal (p.223)	Stories of stigma and bullying
Stevenson et al (2016)	‘Well, when I went to mainstream secondary school I got bullied and I was very different compared to the other children.” “When I think the children in mainstream school hear about autism they think-ing ‘a bit crazy, a bit loud, doesn’t really, can’t really read, can’t really write.’‘Sometimes in life, sometimes people ain’t always going to accept peoplewith autism. Sometimes they will accept you, sometimes they won’t. But sometimes I find it unfair.’‘You’re in the street and you see a group a kids come and say loner” (p.222)	Often in the discussions and interviews students talked of experiences in main-stream settings, such as school or in the community, as negative. Often this was linked to feeling different or not being accepted	Stories of stigma and bullying
Morgan	When I did finally get diagnosed, I became more cautions of how I acted in public, especially in school, mainly because I didn’t want to be the centre of all the autism jokes I had heard . . .	Hiding from a hostile world: feeling safe enough to be my authentic self	Stories of stigma and bullying
Cridland et al. (2015)	…he was getting bullied by this one guy… [who] was saying to him, “give me $10 and I’ll give you an iPhone” and my brother believed it and would gibe him the money and wouldn’t get anything from it… he just does’t understand that they are ling… I think it makes him feel vulnerable (p 358)	At least one participant from each family described experiences where their family member with ASD had been bullied as an adolescent.	Stories of stigma and bullying
Jones et al. (2016)	I would say people with autism are not different due to their brains, they are different because YOU think that they can’t do anything right, but they can. I mean look at YouTube, man. There	Chris also described struggling with the social stigma of ASD and feeling misunderstood	Stories of stigma and bullying

	are a lot of people on there who are pretty famous. I can name two examples of them, Temple Grandin and Jessie Saperstein.	by others. He expressed his desire for others to be more educated about ASD so that they would understand his unique behaviors and characteristics. When asked what he thought of when he heard the word autism, he said: ‘Hope. People will learn why I do these sorts of things; probably learn to accept me.’ James also expressed his frustration with the social stigma of ASD.	
Stevenson et al. (2016)	My sister makes me feel happy, when I tell her she says the people who take the mickey are idiots and I shouldn’t listen to them.		Stories of family
Morgan (2023)	“I don’t feel that l belong in any group. I feel l am an outcast. I belong with my immediate family” (p190)	Belonging in family	Stories of family
King et al.	I get it from my dad and I think cos he’s quite silly and he’s quite funny	Self in relation to others, I am like my parents	Stories of family
Riccio (2021)	(Teen who didn’t know they had autism) “Autism… means like you can’t it basically stops you form doing normal human tasks, you’re foing to be walking like this (walks around tripping over foot and banging into things)… it stops you from doing normal things, you get frustrated that you can’t do the things you would normally do….” Parent who hadn’t disclosed “Deficit in social thinking and skills. Impaired communication”.	Adolescents whose parents disclosed their child’s autism diagnosis to their child would be better able to define autism and more likely to describe autism in terms of strengths than their counterparts… Adolescents eho were told they were autistic involuntarily or not told at all were more likely to include challenges in their definition of autism.	Stories of family
Gaffney	. . . . he is sort of scared and all that, . . . mum tried to encourage him to go to work but he doesn’t want to go to work in case he meets horrible people and all that. And he acts like, like he has no hope and all that as well. (p.66)	Siblings with autism… Kerry’s has seen her older brother struggling with adult life. For Kerry, this re-enforces the idea that autism is associated with problems. Kerry worries about her younger brother, recognising that	Stories of family

		although he is happy “he might struggle sort of thing,” in future). She does not consider autism to be a good thing for him.(p.67)	
Gaffney		For the participants in my research study, the diagnostic process was triggered by ‘problematic’ behaviour when they were children or young adults, for example, not fitting in with peers, learning difficulties, sensory issues, and shyness.	Stories of family
Chapman	“A lot of people in my life do specify that it’s okay to be me. [brother] is very supportive of me and he doesn’t really falter in his faith in me. So like he’s very confident in my own abilities and sometimes more so than I am of my own”.		Stories of family
Berkovits	I’m pretty obsessed with stuff… my dad doesn’t like me being obsessed with things		Stories of family
Chapman et al. (2022)	“I had spent the last 2, 3 years of my life being stared at, being assessed, being looked like a guinea pig, not poked and prodded at, but like. Everyone writing on clipboards, asking me questions, asking my mum questions as if I was this alien from outer space… And as I said, although it was a relief [to receive the diagnosis], I was just like, OK, so now I definitely know that I’m not normal. Let’s try and hide that.”	Teenagers described developing masking as a gradual response to multiple criticisms and discouragements from others over time…For one participant the experience of being made to feel ‘alien’ during the autism assessment process played a role in the development of masking.	Masking and fitting in
Morgan (2023)	Um. I like to think I have like two sides. Um. The side where I’m open and I’m trusting people and the side where I haven’t yet trusted people. Um I can be really like, loud and happy and um excited but other times I’m just kinda mellow and quiet and keep to myself. Um I think it’s	As found in the research around camouflaging and compensatory behaviours (Bargiela et al., 2016; L. A. Livingston & Happé, 2017), participants recall attempts to blend in to their	Masking and fitting in

	‘cause I’m more open with people I know more because they know my quirks. And they don’t. I, I think I started doing that because I remember someone I was trying to become friends with. Um I have a habit of picking at my nails. Um and I remember doing that and they told me it was gross. Um. And then I started like not doing it in front of people. (p191)	environments, by using strategies to enable them to fit in, such as when one participant explains that her behaviour at home is better since she has learned to “compartmentalise” her autism and to act “normal” with others, and likewise another recalls finding strategies to “fit-in” with peers at school. This	
Mesa and Hamilton (2022)	“I want to be treated like normal. I don’t want to be treated like there is something, like I have Asperger’s”. (p10)	Despite differing responses to diagnosis, a commonality was the desire to be treated as 'mainstream', like everyone else. (p10)	Masking and fitting in
Kofke (2019)		In my exploration of the findings from this inquiry I found that the students experienced being “othered” while they were at school. This led to masking their autistic traits and mannerisms to pass and conform to be more like the other students who were not autistic. (p193)	Masking and fitting in
Mesa & Hamilton (2022)	(parent) “because he has held it together all day at school, when he is home, he is a total wreck”. (p 13)	Social camouflaging at school… 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. (p14)	Masking and fitting in
Cage et al. (2016)		Changing behaviour to make other like them	Masking and fitting in
Chapman		Participants indicated that their masks developed as a response to the narrative that a neurotypical style of communication was superior and most desirable. (page 8)	Masking and fitting in

Hanai	I also wanted to think that I was an ordinary girl, I also wanted to be thought that by others too. Even though I knew I was different from others, but I do not want to go [psychiatry] because I usually think that it is good to be normal. So, why do I have to go [psychiatry]? [The doctor told me that] I got better, I was glad, but if I got better, do I need to come [to see the doctor], don't I? (I/18, f)	Participants were keen to be accepted by others. They wanted to be normal, and to be considered normal by others	Masking and fitting in
Tesfaye	(points to letters on an alphabet display board) I-H-A-T-E-D I-T B-E-C-A-U-S-E- T-H-E-Y- T-R-E-A-T-E-D- M-E L-I-K-E A-N I-D-I-O-T (p.1149)	School was the primary stressor for the majority of participants…Many described the school environment as unwelcoming, a detriment to their wellbeing, and a barrier to future aspirations	Feeling dismissed
Hanai	Because they (parents and teacher) only say, "you should try your best first," or "let's go as it is for a while." So I didn't talk to my mom about something even I had trouble with in school. Well, I thought it was worthless to talk to people, both the counselor and my family.	On the other hand, more than half of the participants not to express their emotions but to work things out on their own. (p.1671)	Feeling dismissed
Morgan 2023	In my case I feel like although I may be different in certain ways, it doesn't mean I am not a human. My friends appreciate this but sometimes I'll be upset about something that is genuinely upsetting and I guess they just kind of pass it off as having a meltdown. Sometimes I feel like it's almost as if I can't express how I feel to teachers because they'll just throw me in a room somewhere to 'calm down'.	participants construct the self as separate to their autism, and communicate experiences of having their experiences "othered" as autistic, rather than part of a wider human experience	Feeling dismissed

Connection & relationship –first and second-order constructs			
Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Morgan	“I formed another friend group and again it was most of the people who didn’t fit in. I think I was kind of like drawn to them.” (p190)	a normativity discourse enables constructions of belonging with others who transgress normativity (p.190)	Group belonging
Chapman et al. (2022)	And church… there’s a few kids who have an autism diagnosis. I get on well with them… It’s just this circle of complete and utter transparency and honesty, and it makes my life so much easier (p.9)	Most commonly, participants felt more authentic in their interactions with other autistic people, people they knew well, particularly close friends and family members, people who knew they were autistic and people who they shared interests with or felt similar to. (p.9)	Group belonging
Jones et al. (2015)	‘I think of a lone jelly bean all by myself. No friends, until he realizes, I’m not alone; I’m not the only jelly bean. There are jelly beans just like me, I’m not alone.’ (p.1499)	James’ recognition of others who share similar experiences gave him a sense of belonging and group membership among others with ASD that appeared to change the meaning of his diagnosis in regard to his self-identity.	Group belonging
Kofke (2019)	I like to talk about what they like. They like to talk about Dungeons and Dragons. Not Raven. She’s more of the quiet, shy, type. But then Trent, and Kevin, and Lincoln, they’re all Dungeons and Dragons folk. They like to talk about Dungeons and Dragons and Pathfinder. They’re big gamers…Yea, they’re technically the card and board game type. (p.80)		Group belonging
King et al.,	I get it from my dad and I think cos he’s quite silly and he’s quite funny.	He described a close relationship with his father characterised by shared beliefs “me and	Group belonging

		my dad always think that" and sometimes emotions "my dad was a bit upset for me as well". He also commented on characteristics he shared with his mother who had died five years earlier. He spoke of preferences of his mother's that he did not share but still wanted to represent in his photographs, indicating that he perceived his mother as a part of who he is.	
Mesa and Hamilton	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 (p.9)	In describing their experiences of difference, some young people drew on an autistic group identity. Lee used phrases "the autism people" and and "people like me". Identification with other autistic young people helped hem make sense of their difference favourably, at least to some extent.	Group belonging
King et al. (2019)	When we first met I had brought some lego with me so I brought like an old batman set containing Batman, The Joker, batwing and Joker's helicopter and that. And Robert the new guy then Robert came up to me then and introduced himself and told me that he was the new guy and then he asked if he could play and I allowed him… it was great fun. (p. 235)	I am what I do with other people. This sub-theme captured participants' understanding of particular activities as an important means of establishing and maintaining relationships.	Group belonging
Cage et al (2016)	"I did try to look up more about games because my friends were always making funny references to games, so I tried to look up and find references to make as well"	Some reported that they had attempted to learn more about a particular topic (page 15)	Group belonging
Cridland et al (2015)	At school I generally hang around with my mates… We always joke around…		Group belonging

	[we] play occur on the field and sometimes talk (p. 357)		
Stevenson et al., (2016)	I can be myself, if that makes sense, because when I come here, I can see that I' not different, there's other people who I can talk to, who have autism and people wh understand me… I don't feel alone" (p.17)	Special schools were for the students generally seen as a place of acceptance (p.17)	Group belonging
Hanai et al (2021)	I felt like it was in line with everyone's actions, and because everyone was thinking this, I decided to do something about reading the air, I decided to do something about it… various topics, hobbies, etc. I'm starting to do everything, whether it's all spread, even I hate or I'm not interested in. (p1673)	Participants strongly felt the need to consider the feelings of others involved, and they made efforts to observe the reaction of others carefully and to respond appropriately	Group belonging
Hanai et al (2021)	It is not disgusting…I would like to talk. Even if I can't take steps with people, there are so many things I want to talk about, such things too. It's going to be a machinegun talk, but I want to talk. (N/18, m)	They sought to be with people, to be involved, to convey their feelings, and to be understood by others	Seeking relationships
Tesfaye et al. (2023)	"I'd rather have a few close friends rather than just more friends… More close friend, I guess it would just kind of give me another purpose in life, like something to care about beyond the usual" p1148	Seeking social connection on their own terms. Despite enjoying being alone sometimes, many participants expressed a need to connect more with other people. P1148	Seeking relationships
Hanai et al (2021)		Most participants felt a sense of security through stable relationships with their friends, classmates, teachers and family members.	Seeking relationship
Gaffney (2017)		Although they did not always find socialising easy, they all had a degree of social motivation. They generally described being passive within the	Seeking relationship

		classroom. They had developed compensatory strategies such as reading or working hard in class. They all had one or few close friendships.	
Kofke (2019)		The friendships Ernie made at school were valuable to her and she felt that the democratic model of the school promoted her ability to make friends when she was new to the school last year. She had about 4-5 close friends, who were not autistic, and she saw them regularly outside of school.	Seeking relationship
Cage et al., (2016)	You can rely on each other, you can cheer each other up, and there is just someone there to help you and be friends with you, someone who cares.	Friends gave them emotional support (page 17)	Seeking relationships
Cridland et al. (2015)	I don't mind [having ASD] but I just wish I was more social…[It would feel] nice for someone to at least comprehend the problems I go through every day. (Adolescent, Family 2)	Negative aspects of having ASD included feeling different and/or misunderstood, and having social difficulties (p.359)	Navigating social interactions
Gaffney (2017)	… and eye contact, I'm awful at and talking to people, small talk I'm awful at… It's really odd but I'd rather do public speaking than… I find it a lot easier than just trying to hold a conversation with someone (p.65)	Communication… Ellie talks about finding conversations difficult	Navigating social interactions
Cage et al. (2016)	"Someone [will] be all like, 'Oh this guy said this, and this guy said that, and then apparently "that is really rude, you swore at me" or something like that, and that's not really what I want. It is not exactly what I am interested in, it just confuses me."	If they had too many friends, difficulties could arise (page 17)	Navigating social interactions

Cage et al. (2016)	"A lot of things on there [on the internet] I can relate to, like struggling with things socially – having to act like you understand something when you do not"	The majority of adolescents identified social challenges they had faced… One adolescent described how he had used the internet to find others who had faced similar challenges to himself (page 17)	Navigating social interactions
Chapman et al. (2022)	"I've realised like why kids never used to like me, because my social skills weren't good enough. But now that they've got better so hopefully no one will criticise me on them because I've had teachers at school criticise me on them. And I go to a special needs school, where they should really be encouraging me… I used to be told a lot to keep things inside my head. It's been very hard for me." (Participant 11)	Specific experiences were shared of times when teenager's social differences were criticised by important people in their lives:	Navigating social interactions

Navigating autism in a neurotypical world – first and second-order constructs			
Author	Example first-order construct (illustrative quotes)	Example second-order construct (researcher interpretations)	Second-order theme
Barber	"Pretty sure all the schools have got to have an anti-bullying policy—I think every school has an anti-bullying policy, if I think about it. I don't think any tolerate bullying." (p.57)	School structures of support Anti-bullying policy… If there are no formal structures in place, school staff members do not have any formal structures	Access to support

		to call upon to issue consequences with. However, even participants who stated that their schools have anti-bullying policies that include such protections, it is the implementation of and adherence to policies that appear to influence feelings of safety.(p.58).	
Morgan (2023)	It just makes me sad how I needed to go through years of struggles and tough times for then a diagnosis to suddenly change everything. It makes me think that I could’ve had these adjustments much sooner if school were more willing to see me as more than just a badly behaved girl. P185	This discursive construct was used in talk that constructed the self in terms of being a person with support needs. It constructed the self as being inhibited, disabled or constrained by a lack of access to the right supports p185	Access to support
Mesa and Hamilton	“[support would] probably ruin my already practically non-existent social standing even further”. p 10	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.	Access to Support
Mesa & Hamilton (2022)	(teacher) 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.”	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	Access to support
Tesfaye	I had this one teacher in grade 4 who people said she was very caring and kind, like all the people who ever met her said. So	Participants identified multiple stressors in their school environment, including a lack of positive rapport with teachers 1149	Access to support

	and I walked up to her, told her I was being bullied and she literally straight up said she did not care. After that I lost a lot of trust and after that I really . . . got the sense that the world is a terrible place—that like you can never know what someone is actually thinking. They could be a liar . . . I just ended up being scared of the world . . . And after that it prompted me to go to homeschool because I never wanted to have that experience again.		
Jones et al. 2015	my mentor, Ms. Jenkins, at my school told me and I have to take speech class, and communication skills class cause I had really bad communication skills.' (p.1496)	Kelly described knowing she had Asperger's initially because someone told her. However, she then related her diagnosis to the extra supports that she receives at school. Kelly's disability narrative transitioned from an acknowledgment of the Asperger's label given to her by others to recognition of the unique meaning Asperger's has for her (e.g. supports for her communication skills) (p.1496)	Access to support
Cage et al. (2016)	"It is very distracting when the class is being a bit noisy. I really do not like that all"	Notable challenges related to school (page 17)	Sensory needs
Tesfaye et al., (2023)	N/A	Participants identified multiple stressors…overwhelming sensory surrounding (e.g. class size, transitions between classes, peers disrupting class, and feeling "drowned out" by their workload and academic evaluations). 1149	Sensory needs

Hanai (2021)	As I thought, [the sun shine] is too bright. When the weather is fine, it's painful for me, it's like can't stand it anymore (p. 1672)	Some [participants] described difficulties with sensory sensitivity	Sensory needs
Kofke (2019)		Their daily life at school was impacted by being autistic and intersected with many of the themes already described. Each student discussed her issues dealing with sensory stimulations that occurred at school and the school's response to their sensory needs. (p.68)	Sensory needs
Berkovits	"Sometimes, if there's something that distracts you, like a shiny object or like a big touch, or something gets like a little bit disturbing for autism. But I don't have that kind of problem, but except for my eye problem. I don't know why, every time when I see like some kind of corner… Like if for example, butts like out, like more out pointing, I get distracted. Like I start rubbing my eyes to just like get some kind of pressure off."		Sensory needs
Chapman et al., (2022)	"I always have everything I've ever done or said, what's going on right now, everything that's going in my head, I'm thinking at the same time I'm talking to you… All this stuff is because of my brain and because of my emotions and my reactions and everything that makes my head hurt… [Masking] does add to it. I	Several participants described overwhelming experiences of sensory sensitivities and cognitive overload, particularly when coping with the demands of the environments described in theme three. They described how masking could be highly physically uncomfortable and an additional mental and sensory demand. Specific aspects of masking, for	Sensory needs

	mean, I already have a dozen things to think about, I don't need like one to two more"	instance forcing oneself to make eye contact, were described as physically painful, and became harder when participants were already dealing with sensory and cognitive demands	
Barber (2020)	"Once my school changed my dead name to my preferred name, I definitely felt a lot better going into class because a lot of time I wouldn't go to class because I didn't like being called she, and I didn't like being called my dead name. So once they changed it, that's when I started going to my classes a bit more because I felt a lot better about doing so." (p55)	Brittany also appreciated the simple process of changing her name and gender in the school file system. A change at this level ameliorates potential issues with substitute teachers misgendering or misnaming transgender or gender diverse students, allowing them to feel safe, seen, and supported even when their primary teachers are absent.	Environment as an enabler
Hanai et al. (2021)		Almost half of the participants said they felt blessed with their environment and grateful to their families and the people around them. (p 1673)	Environment as an enabler
Tesfaye et al (2023)		Youth highlighted that school was enjoyable because they could meet and spend time with their peers. For the majority of youth, school was the only environment where they made friends and interacted with peers of the same age	Environment as an enabler
King et al (2019)	I'm sort of quite active and adventurous. I don't like being inside, I'm always outside.	I am what I do. This sub-theme encapsulated how participants made sense of themselves in relation to everyday activity, or an activity that they particularly enjoyed or disliked (p.235)	Environment as an enabler

Societal narratives of autism – first and second-order constructs			
Stevenson et al (2016)	People who have autism, I just want them to realise you haven’t got a disease, there’s nothing really like, it’s not the end of the world you know		Community narratives
Morgan (2023)	I hated it at first as what I had seen in the media portrayed autistic types as annoying, socially awkward men that had no chance of a normal life being used as a laugh. (p.190)		Community narratives
Chapman et al. 2022	“I feel like if I got myself into a scenario in life where I have to completely redefine myself, just to fit the scene, I’m questioning if I want to be a part of that scene, because I feel like if I need to accept them a bit, they need to accept me a bit… it’s just come from this like sense that if I have to accept neurotypicals’ way of thinking, then why can’t they accept mine? So like, if you want me to rein it in mostly, sure, that’s perfectly fine. But if you want me to be a different person for like seven to eight hours of the day, then you’re asking for something that I’m not in the mood to give you. In some ways autism makes me more capable than normal people” (p8)	Some shared strong convictions about acceptance between autistic and non-autistic people needing to work both ways and illustrated in their descriptions how a positive self-image and a positive narrative directly reduced or prevented the need for masking (page 8)	Community narratives
Barber (2020)	“I mean, that depends how you identify a disability. Technically speaking, and generally how I identify myself, no. But some people view autism as a disability” p 87	Disability identity and autism When asked if asked they identify as having a disability, nearly all of the participants said they did not identify that way. However, most of the participants followed up with response that indicated that there was a possible difference	Disability narratives

		between identifying as disabled and identifying as being Autistic or having autism p86	
Jones et al. (2015)	No I don’t think I, I would [see ASD as a disability]. I kind of see it as a, like somebody is really good at something that they don’t even think about it. I kind of see it as a gift sort of, but then again I could kind of see it as a disability because there is one subject they might not be good at. But I mostly see it as a gift. (p.1499)	Confusion regarding whether ASD is a disability… Most adolescence in this sample did not identify with the disability label or community and were uncertain as to whether or not autism or Asperger’s disorder were considered a disability. (p.1499)	Disability narratives
Riccio (2021)	As a condition that makes it more difficult for people to understand certain things that other people say but brings their attention to other things that other people might not notice. It’s just a different way of thinking. It shouldn’t be called a disability or disorder. (p.386)		Disability narratives
Morgan (2023)	“Oh I would say that like autism is like a type of disability that some people have. And that’s like OK to have a disability p185 I don’t quite know how to feel about being autistic as it is perceived as being rather negative, a disability that can hold you back. (p188)	A diagnostic discourse enables access to rhetoric that legitimises the need of autistic people to have access to social and educational supports, through a social model of disability rhetoric (Oliver & Sapey, 1983). Three participants made use of the word “disability” to describe autism, and it was most often in a positive way. P185	Disability narratives
Cridland et al. (2015)	I actually really like having this disability because it actually makes me feel a bit special (p.359)		Disability narratives

Appendix C: Reflexive journal example extracts

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Appendix D: REC/HRA Approval

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Appendix E: Letter of access from NHS Trust

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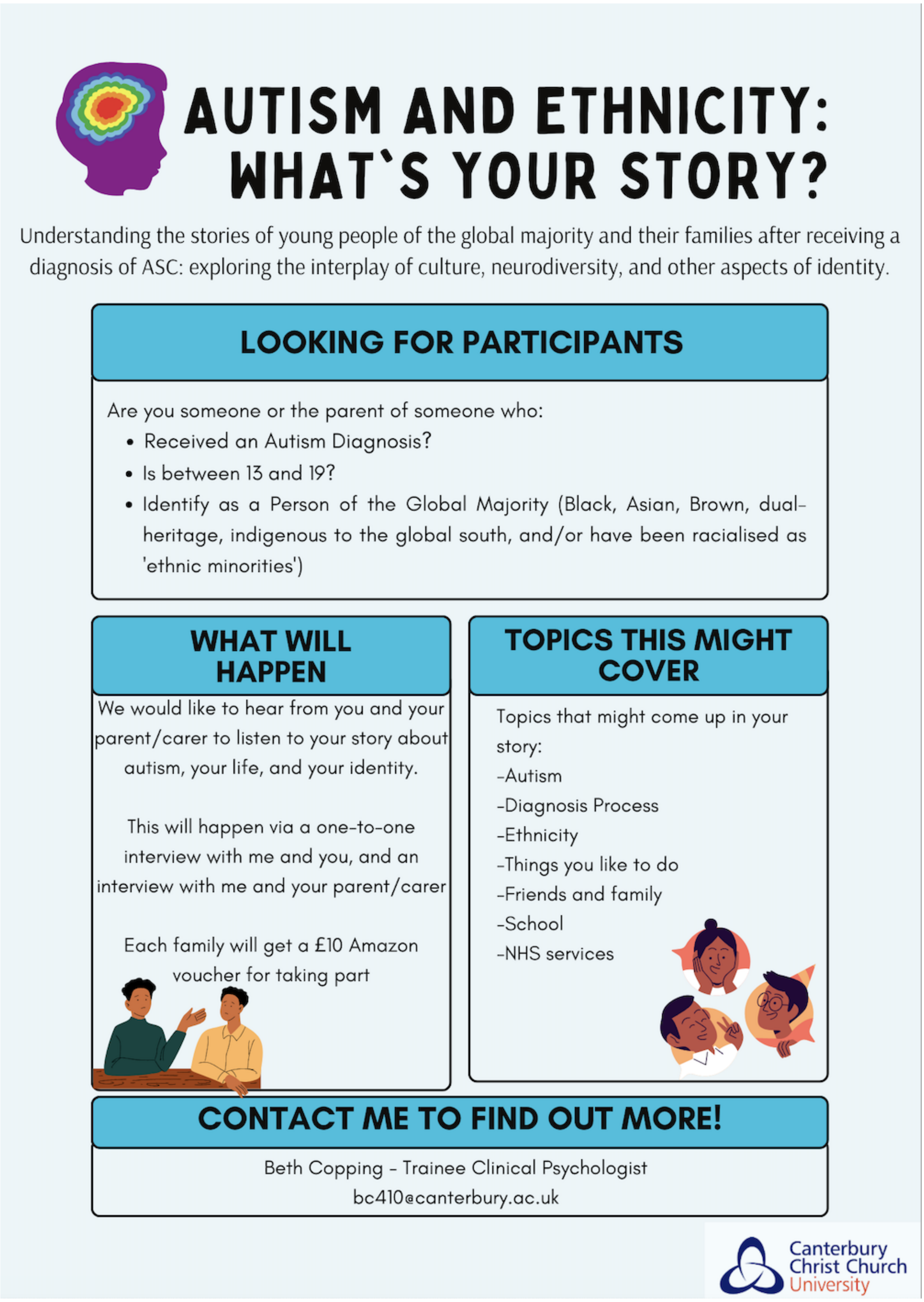
Appendix F: Poster



AUTISM AND ETHNICITY: WHAT`S YOUR STORY?

Understanding the stories of young people of the global majority and their families after receiving a diagnosis of ASC: exploring the interplay of culture, neurodiversity, and other aspects of identity.

LOOKING FOR PARTICIPANTS

Are you someone or the parent of someone who:

- Received an Autism Diagnosis?
- Is between 13 and 19?
- Identify as a Person of the Global Majority (Black, Asian, Brown, dual-heritage, indigenous to the global south, and/or have been racialised as 'ethnic minorities')

WHAT WILL HAPPEN

We would like to hear from you and your parent/carer to listen to your story about autism, your life, and your identity.

This will happen via a one-to-one interview with me and you, and an interview with me and your parent/carer

Each family will get a £10 Amazon voucher for taking part

TOPICS THIS MIGHT COVER

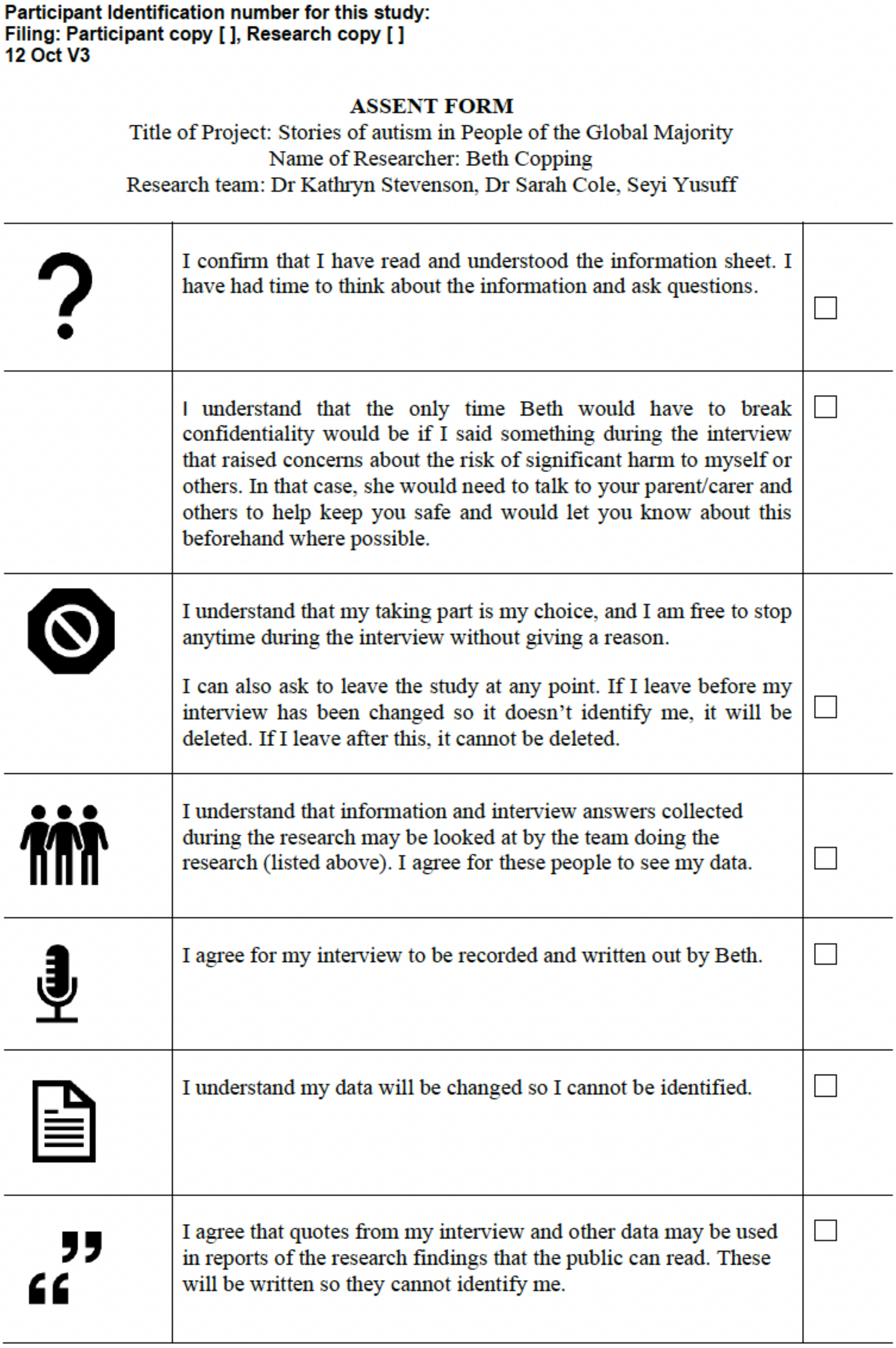
Topics that might come up in your story:
-Autism
-Diagnosis Process
-Ethnicity
-Things you like to do
-Friends and family
-School
-NHS services

CONTACT ME TO FIND OUT MORE!

Beth Copping - Trainee Clinical Psychologist
bc410@canterbury.ac.uk

Canterbury
Christ Church
University

Appendix G: Assent and Consent forms for young people



Participant Identification number for this study:
Filing: Participant copy [ ], Research copy [ ]
12 Oct V3

ASSENT FORM
Title of Project: Stories of autism in People of the Global Majority
Name of Researcher: Beth Copping
Research team: Dr Kathryn Stevenson, Dr Sarah Cole, Seyi Yusuff

?	I confirm that I have read and understood the information sheet. I have had time to think about the information and ask questions.	☐
	I understand that the only time Beth would have to break confidentiality would be if I said something during the interview that raised concerns about the risk of significant harm to myself or others. In that case, she would need to talk to your parent/carer and others to help keep you safe and would let you know about this beforehand where possible.	☐
🛇	I understand that my taking part is my choice, and I am free to stop anytime during the interview without giving a reason. I can also ask to leave the study at any point. If I leave before my interview has been changed so it doesn't identify me, it will be deleted. If I leave after this, it cannot be deleted.	☐
👥	I understand that information and interview answers collected during the research may be looked at by the team doing the research (listed above). I agree for these people to see my data.	☐
🎙	I agree for my interview to be recorded and written out by Beth.	☐
📄	I understand my data will be changed so I cannot be identified.	☐
” “	I agree that quotes from my interview and other data may be used in reports of the research findings that the public can read. These will be written so they cannot identify me.	☐

Participant Identification number for this study:
Filing: Participant copy [ ], Research copy [ ]
12 Oct V3

	Once my data has been changed, I agree it can be used in further studies. This will not require me to do anything.	☐
👍	I agree to take part in the study.	☐

I would like to receive a copy of my written interview and data analysis to provide feedback	YES NO
I would like to receive a copy of the completed research	YES NO

Name:	Signature:	Date:
Name of person taking assent:	Signature:	Date:

Participant Identification number for this study:
Filing: Participant copy [ ], Research copy [ ]
12 Oct V3

CONSENT FORM

Title of Project: Narratives of autism in People of the Global Majority
Name of Researcher: Beth Copping
Research team: Dr Kathryn Stevenson, Dr Sarah Cole, Seyi Yusuff

I confirm that me and my child have read and understood the information sheet for the above study. We have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	☐
I understand that if my child raises information that raises concerns about the risk of significant harm to myself, my child, or others, the researchers would be obliged to break confidentiality.	☐
I understand that my child's participation is voluntary, and they are free to withdraw at any time without giving any reason. I understand that before their data has been anonymised, they will be able to withdraw it from the research. After anonymisation, the data can no longer be deleted.	☐
I understand that data collected during the study may be looked at by the research team (named above). I give permission for these individuals to have access to my child's data.	☐
I agree for my child's interview to be recorded and transcribed by the researcher.	☐
I understand my child's data will be changed so they cannot be identified.	☐
I understand that this data may be used in future research. This will not require me to do anything.	☐
I agree that anonymous quotes from my child's interview and other anonymous data may be used in published reports of the study findings.	☐
I agree for my child to take part in the above study.	☐

Participant Identification number for this study:
Filing: Participant copy [ ], Research copy [ ]
12 Oct V3

Name:	Signature:	Date:
Name of person taking consent:	Signature:	Date:

Appendix H: Consent forms

Participant Identification number for this study:
Filing: Participant copy [ ], Research copy [ ]
12 Oct V3

CONSENT FORM

Title of Project: Stories of autism in People of the Global Majority
Name of Researcher: Beth Copping
Research team: Dr Kathryn Stevenson, Dr Sarah Cole, Seyi Yusuff

?	I confirm that I have read and understood the information sheet. I have had time to think about the information and ask questions.	☐
	I understand that the only time Beth would have to break confidentiality would be if I said something during the interview that raised concerns about the risk of significant harm to myself or others. In that case, she would need to talk to your parent/carer and others to help keep you safe and would let you know about this beforehand where possible.	☐
🛇	I understand that my taking part is my choice, and I am free to stop anytime during the interview without giving a reason. I can also ask to leave the study at any point. If I leave before my interview has been changed so it doesn't identify me, it will be deleted. If I leave after this, it cannot be deleted.	☐
👥	I understand that information and interview answers collected during the research may be looked at by the team doing the research (listed above). I agree for these people to see my data.	☐
🎙	I agree for my interview to be recorded and written out by Beth.	☐
📄	I understand my data will be changed so I cannot be identified.	☐
” “	I agree that quotes from my interview and other data may be used in reports of the research findings that can be read by the public. These will be written so they cannot identify me.	☐

Participant Identification number for this study:
Filing: Participant copy [ ], Research copy [ ]
12 Oct V3

	I understand that data from this study may be used in future research. This will not require me to do anything.	☐
👍	I agree to take part in the study.	☐

I would like to receive a copy of my written interview and data analysis to provide feedback	YES NO
I would like to receive a copy of the completed research	YES NO

Name:	Signature:	Date:
Name of person taking assent:	Signature:	Date:

Participant Identification number for this study:
Filing: Participant copy [ ], Research copy [ ]

CONSENT FORM

Title of Project: Narratives of autism in People of the Global Majority
Name of Researcher: Beth Copping
Research team: Dr Kathryn Stevenson, Dr Sarah Cole, Seyi Yusuff

I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	☐
I understand that if information that raises concerns about the risk of significant harm to myself, my child, or others, the researchers would be obliged to break confidentiality.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I understand that if I leave before my interview has been anonymised, it will be deleted. If I leave after this, it cannot be deleted.	☐
I understand that data collected during the study may be looked at by the research team (named above). I give permission for these individuals to have access to my data.	☐
I agree for my interview to be recorded and transcribed by the researcher.	☐
I understand my data will be changed so I cannot be identified.	☐
I understand that this data may be used in future research. This will not require me to do anything.	☐
I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings.	☐
I agree to take part in the above study.	☐
I would like to receive a copy of my transcript and data analysis to provide feedback	YES/NO

Participant Identification number for this study:
Filing: Participant copy [ ], Research copy [ ]

I would like to receive a copy of the completed research			YES/NO
Name:	Signature:	Date:	
Name of person taking consent:	Signature:	Date:	

Appendix I: Information sheet for parents

Title of Project: Understanding the stories of young people of the global majority and their families after receiving a diagnosis of Autism Spectrum Condition (ASC): exploring the interplay of culture, neurodiversity, and other aspects of identity.

Information sheet for parents

Lead researcher: Beth Copping – b.copping410@canterbury.ac.uk
Principle Supervisor: Dr Kathryn Stevenson
Secondary supervisor: Dr Sarah Cole
Consultant: Seyi Yusuff

My name is Beth, and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you. Talk to others about the study before deciding if you wish. Please ask if anything is unclear or if you would like more information.

What is the purpose of the study?

The research aims to explore your story of your child's autism diagnosis and how this has been influenced by the services you have accessed, your child, what autism means to you and your family, and your personal and cultural identity. This study is for People of the Global Majority, which refers to people who are Black, Asian, Brown, dual-heritage, indigenous to the global south, and/or have been defined as an 'ethnic minority'. These groups currently represent approximately 80% of the world's population.

Why have I been invited?

You have been invited to participate because your child has received a diagnosis of autism. You have valuable experience to offer and shape the services if you would like to. There will be at least 6 families taking part in this research.

Do I have to take part?

Taking part in the study is voluntary. If you agree to participate, I will ask you to sign a consent form. If your child is 16 or under, I will also ask you to sign a consent form on their behalf. You and/or your child are free to withdraw, without giving a reason, at any time until data transcription begins.

What will be expected of me if I take part?

You will be asked to take part in an interview with me in which I will ask questions relating to your experience of the above topics. This will take up to 90 minutes, depending on the amount you wish to share. You can also take breaks whenever you wish. The interview can take place online, using Microsoft Teams, or in person, whichever you prefer. The interview will be audio recorded. If you and another parent or carer of your child would also like to take part, you can choose whether you would like to be interviewed together or separately. Another interview will happen with your child and me either online or in person, which will take up to 90 minutes. If you'd like, you and/or your child can bring a picture from your life or something you feel represents your story to help you speak about it.

We will only need to meet once per interview unless you request to finish the interview at a later time. I will offer a verbal debrief with you immediately following the interview. This is to check in with you about how you feel having shared your story with me and think about your wellbeing if anything difficult was shared. I can also contact you one week after the interview for an additional debrief follow-up if you would like.

I will analyse the interview discussion using a method that explores and interprets the structure and themes of people's stories. If you like, I can summarise your interview and the research findings for you when your interview has been analysed, and you can give feedback on this to me. I can also share the write-up with you when the study is finished.

Expenses and payments
I can give your child a £10 Amazon voucher for taking part.

What are the possible disadvantages and risks of taking part?
You and/or your child might experience some distress during or after the interview if discussions have stirred up any difficult feelings. I will check in with you to see how you are and if you need a break. You can also raise concerns with me (or stop) at any point during the interview. Additionally, I will share sources of support with you.

What are the possible benefits of taking part?
It is possible that you will benefit from having space to share and reflect on your experiences in an open and non-judgemental space. You may find that this provides an opportunity to gain some personal insight. Whilst I cannot promise the study will help you, your contribution may help to improve the service and help clinicians and the wider population understand the experience of living with autism and the process of diagnosis while also being a Person of Global Majority.

What will happen if I do not want to carry on with the study?
You can withdraw your data from the study at any time until data transcription begins by telling me in person or via phone or email. This includes withdrawing your participation during the interview. You do not have to give a reason for your withdrawal. Once data analysis begins, data from all participants is anonymised and analysed together, making it difficult to remove your contribution specifically at that stage.

Will information from or about me be kept confidential?
We will only collect the information that we need for the research study. This information includes yours and your child's name, age, gender, ethnicity, the languages you speak, whether you are part of a faith group and when your child received their autism diagnosis. All information collected from or about you and your child during the research will be kept safe and secure. We will ensure no-one can work out who you are from the reports we write (including quotes). The information you share during the study will be recorded using an audio recorder, which will then be written up. Your data will be given a code number, so your name will not be connected with the interview outside of the research team. Any information that might mean people would know it is you, like where you live, will be changed so you can't be identified. Only members of the research team will listen to the recordings and once your interview has been written up, the audio recording will be deleted. The recording of your interview will be written out by me or someone who will keep your data private. We will keep all information about you safe and secure and will not share what is said with anyone else unless absolutely necessary.

Once we have finished the study, we will keep some of the data so we can check the results. Some of the data may be used for future research. This means some of the results from the study might be used by other research in future, but you won't need to do anything else in this situation. We will make sure no-one can work out who you are from the reports we write.

The only time I would have to break confidentiality would be if you said something during the interview that raised concerns about the risk of significant harm to yourself or others. In that case, I would need to talk to others to help keep you and your child safe and would let you know about this beforehand where possible. You have the right to check the correctness of the data held about you and correct any mistakes. If you wish to do this, you can contact me to ask for access to your information.

All data will be stored electronically and be protected with a password. Sometimes people will use this information to do research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. This information will be kept for 10 years and then will be disposed of securely after this time. Printed data will be destroyed immediately after use.

You can find out more about how we use your information:

· by asking one of the research team
· by contacting the Head of Data Protection at Canterbury Christ Church University. Their contact details are below:
Myriam Tavernier
Head of Data Protection
myriam.tavernier@canterbury.ac.uk
01227 925405

Concerns and complaints
If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me (Beth Copping) and I will get back to you as soon as possible. If you remain dissatisfied or wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology: fergal.jones@canterbury.ac.uk

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Who is sponsoring and funding the research?
Canterbury Christ Church University is sponsoring the research.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Health and Social Care B Research Ethics Committee.

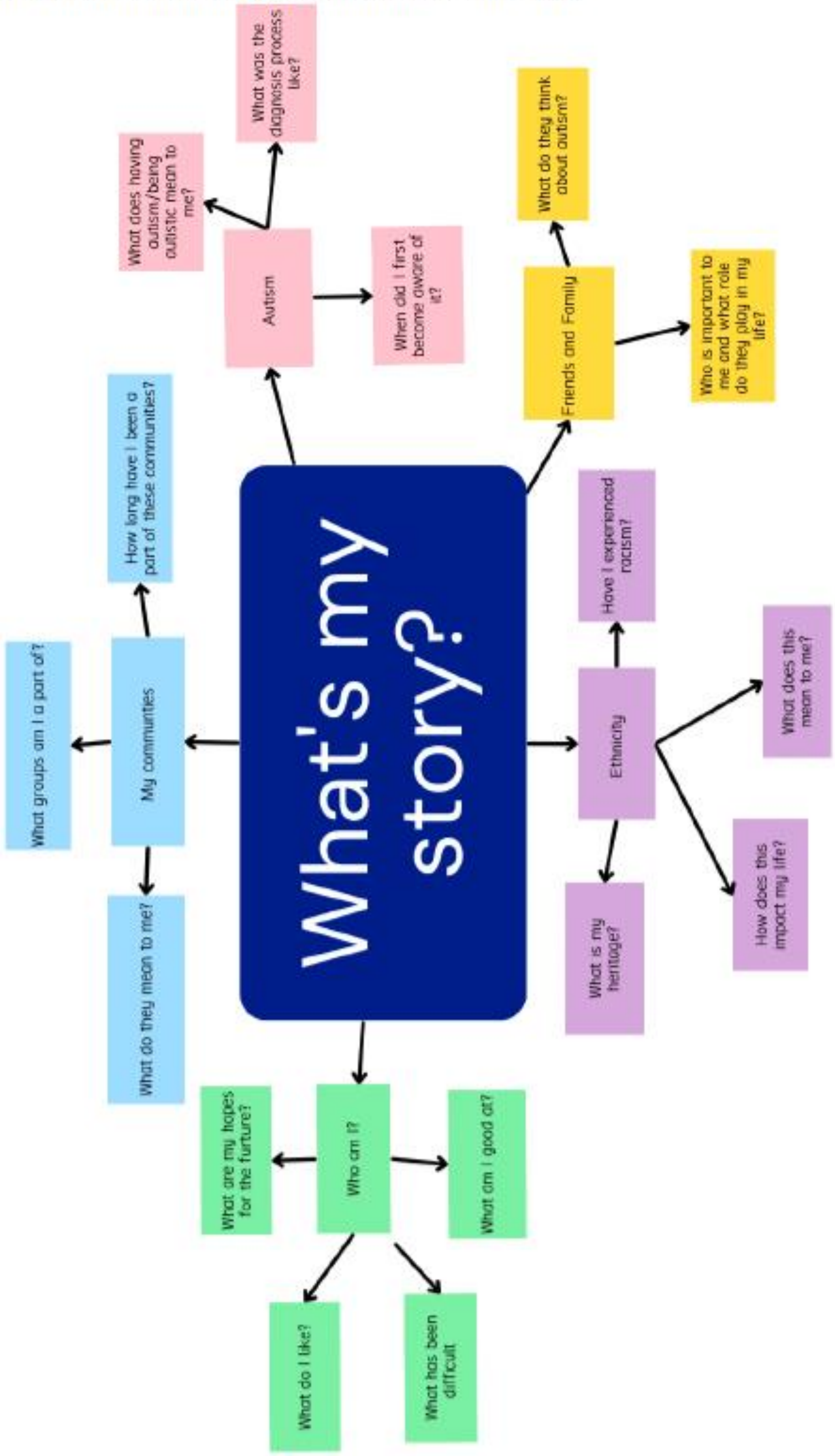
If you wish to contact me, or any of the research team, for further questions or discussion, you can do so using the contact details at the top of this information sheet.

THANK YOU

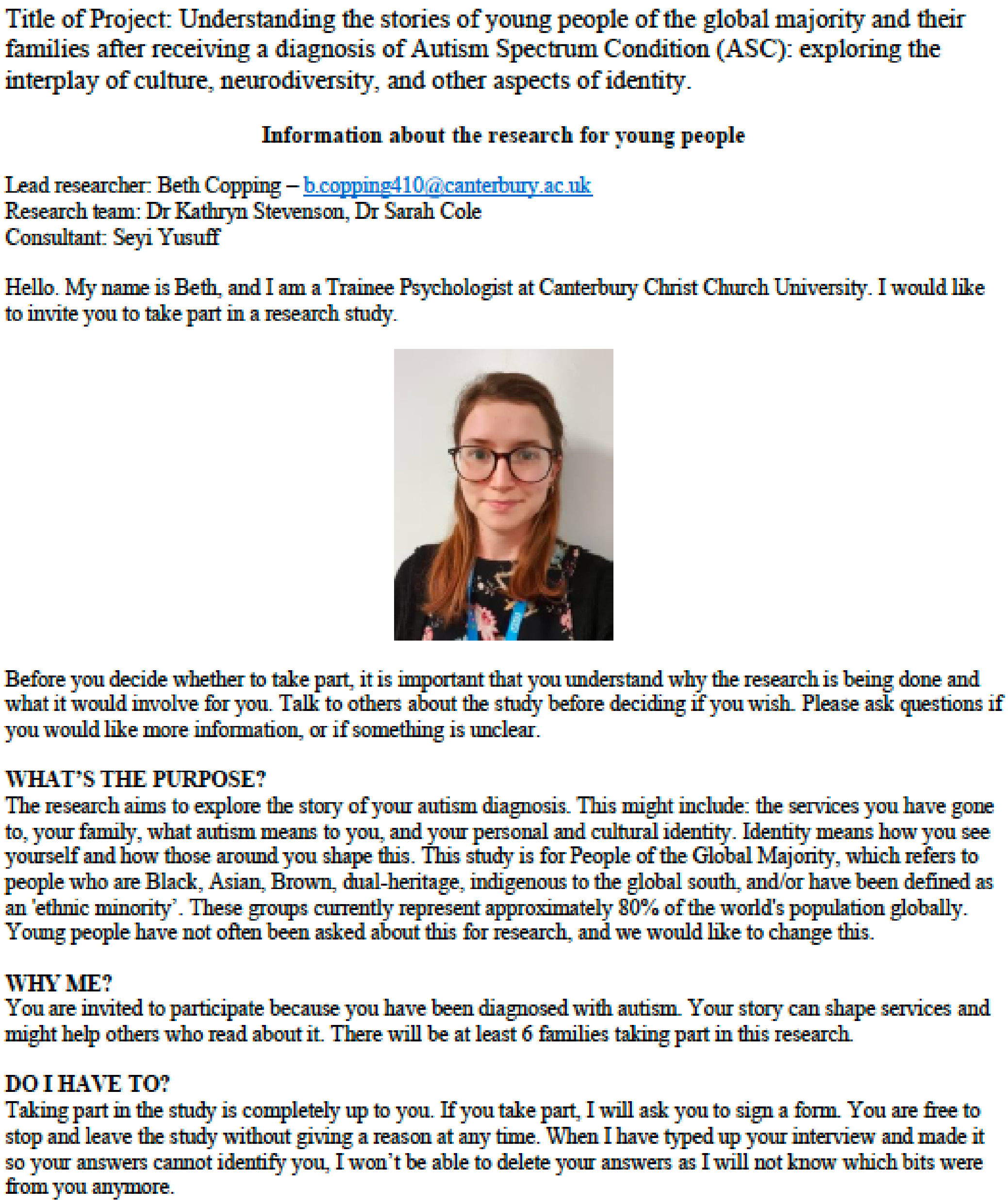
Sources of support

YOUNGMINDS	**Young Minds** The UK's leading charity committed to improving emotional wellbeing and mental health of children and young people
Beat Eating disorders	**Beat** A Website dedicated to information on eating disorders
ChildLine 0800 1111	**Childline** The NSPCC provides a counselling service for children and young people up to their 19th birthday in the UK.
NHS	**GP** Your GP can help you and refer you to local services.
SAMARITANS	**Samaritans** A registered charity aimed at providing emotional support to anyone in emotional distress or struggling to cope
National Autistic Society	**National Autistic Society** The leading UK charity for autistic people and their families

Ideas for topics that may come up in your child's story



Appendix J: Participants information sheet for young people



Title of Project: Understanding the stories of young people of the global majority and their families after receiving a diagnosis of Autism Spectrum Condition (ASC): exploring the interplay of culture, neurodiversity, and other aspects of identity.

Information about the research for young people

Lead researcher: Beth Copping – b.copping410@canterbury.ac.uk
Research team: Dr Kathryn Stevenson, Dr Sarah Cole
Consultant: Seyi Yusuff

Hello. My name is Beth, and I am a Trainee Psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study.

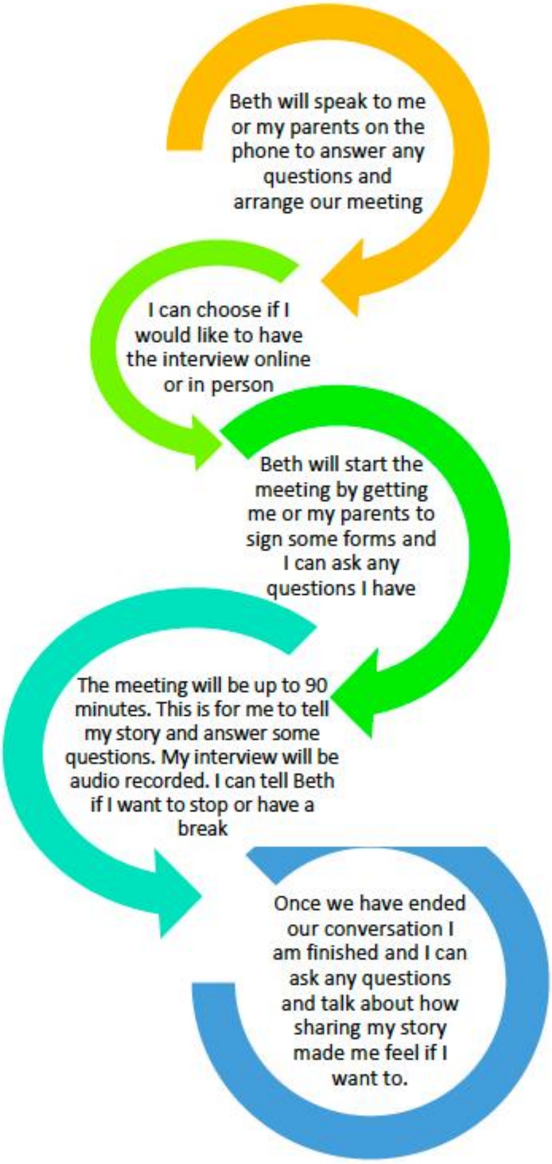
Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you. Talk to others about the study before deciding if you wish. Please ask questions if you would like more information, or if something is unclear.

WHAT'S THE PURPOSE?
The research aims to explore the story of your autism diagnosis. This might include: the services you have gone to, your family, what autism means to you, and your personal and cultural identity. Identity means how you see yourself and how those around you shape this. This study is for People of the Global Majority, which refers to people who are Black, Asian, Brown, dual-heritage, indigenous to the global south, and/or have been defined as an 'ethnic minority'. These groups currently represent approximately 80% of the world's population globally. Young people have not often been asked about this for research, and we would like to change this.

WHY ME?
You are invited to participate because you have been diagnosed with autism. Your story can shape services and might help others who read about it. There will be at least 6 families taking part in this research.

DO I HAVE TO?
Taking part in the study is completely up to you. If you take part, I will ask you to sign a form. You are free to stop and leave the study without giving a reason at any time. When I have typed up your interview and made it so your answers cannot identify you, I won't be able to delete your answers as I will not know which bits were from you anymore.

WHAT WILL HAPPEN?



Beth will speak to me or my parents on the phone to answer any questions and arrange our meeting

I can choose if I would like to have the interview online or in person

Beth will start the meeting by getting me or my parents to sign some forms and I can ask any questions I have

The meeting will be up to 90 minutes. This is for me to tell my story and answer some questions. My interview will be audio recorded. I can tell Beth if I want to stop or have a break

Once we have ended our conversation I am finished and I can ask any questions and talk about how sharing my story made me feel if I want to.

You will be asked to take part in a chat with me in which I will ask you about your story of getting an autism diagnosis and how you see yourself. I have included a spider diagram at the end, which suggests some topics that might come up as you tell your story. If you'd like, you can bring in a picture from your life or something you feel represents your story to help you talk about it.

Another interview will happen with your parent/carer too. I will only share information with your parents if I am worried about your or anyone else's safety. I will not share other information with your parent/career.

I will look at our discussion using a method that explores the meaning of people's stories. If you like, I can summarise your interview and the research findings for you when your interview has been analysed, and you can give feedback on this to me. I can also share the write-up with you when the study is finished.

PAYMENT
You will get a £10 Amazon voucher for taking part.

WHAT IS GOOD ABOUT TAKING PART?
You might like having space to share and think about your experiences in an open, non-judgemental space. I cannot promise that the study will help you, but your story may help to improve the service and help others understand what living with autism is like, and the process of diagnosis, while also being a Person of the Global Majority. This is not a therapy session but a chance for you to tell your life story and how your autism and ethnicity play a role in that.

COULD ANYTHING BAD HAPPEN?
If discussions stir up anything difficult, you might experience painful or sad feelings during or after the interview. I will check in with you to see how you are and if you need a break. You can also raise any worries you have with me or stop at any point during the interview.

WHAT IF I WANT TO STOP?
You can withdraw from the study at any time until your interview starts being written up as a script by telling me in person, via phone, or by email. You can also stop during the interview. You do not have to give a reason for stopping or asking for your interview answers not to be used. After this, your answers will be made so they cannot identify you, so it will be too difficult to remove your answers from the study.

WILL MY INFORMATION BE PRIVATE?
We will only collect the information that we need for the research study. This information includes your name, age, gender, ethnicity, the languages you speak, whether you are part of a faith group and when you got your autism diagnosis. All information collected from or about you during the research will be kept safe and secure. We will make sure no-one can work out who you are from the reports we write (including quotes). The information you share during the study will be recorded using an audio recorder, which will then be written up. Your data will be given a code number, so your name will not be connected with the interview outside of the research team. Any information that might mean people would know it is you, like where you live, will be changed so you can't be identified. Only members of the research team will listen to the recordings and once your interview has been written up, the audio recording will be deleted. The recording of your interview will be written out by me or someone who will keep your data private. We will keep all information about you safe and secure and will not share what is said with anyone else unless absolutely necessary.

Once we have finished the study, we will keep some of the data so we can check the results. Some of the data may be used for future research. This means some of the results from the study might be used by other research in future, but you won't need to do anything else in this situation. We will make sure no-one can work out who you are from the reports we write.

The only time I would have to break confidentiality would be if you said something during the interview that raised concerns about the risk of significant harm to yourself or others. In that case, I would need to talk to your parent/carer and others to help keep you safe and would let you know about this beforehand where possible. You have the right to check the correctness of the data held about you and correct any mistakes. If you wish to do this, you can contact me to ask for access to your information.

All data will be stored electronically and be protected with a password. Sometimes people will use this information to do research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. This information will be kept for 10 years and then will be disposed of securely after this time. Printed data will be destroyed immediately after use.
You can find out more about how we use your information:
· by asking one of the research team

· by contacting the Head of Data Protection at Canterbury Christ Church University. Their contact details are below:
Myriam Tavernier
Head of Data Protection
myriam.tavernier@canterbury.ac.uk
01227 925405

WORRIES AND COMPLAINTS

If you have a worry about any part of this study, you should ask to speak to your parent or carer or me, and I will do my best to talk to you about your worries. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me (Beth Copping) and I will get back to you as soon as possible. If you remain unhappy or wish to complain officially, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology: fergal.jones@canterbury.ac.uk

Who is sponsoring and funding the research?

Canterbury Christ Church University is sponsoring the research.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Health and Social Care B Research Ethics Committee.

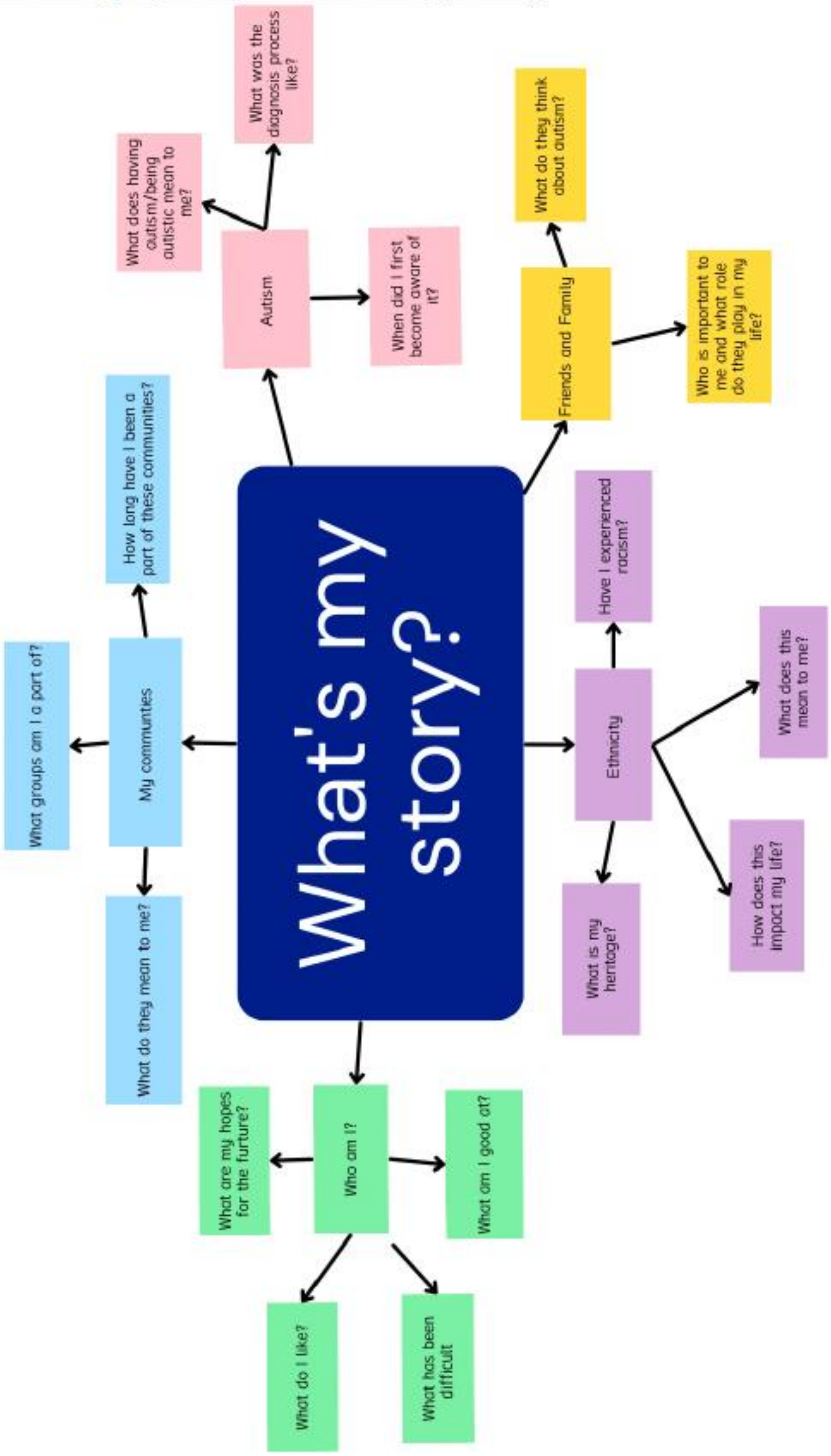
If you wish to contact me or any of the research team for further questions or discussion, you can use the contact details at the top of this information sheet.

THANK YOU

Sources of support

YOUNGMINDS	**Young Minds** The UK's leading charity committed to improving emotional wellbeing and mental health of children and young people
Beat Eating disorders	**Beat** A Website dedicated to information on eating disorders
ChildLine 0800 1111	**Childline** The NSPCC provides a counselling service for children and young people up to their 19th birthday in the UK.
NHS	**GP** Your GP can help you and refer you to local services.
SAMARITANS	**Samaritans** A registered charity aimed at providing emotional support to anyone in emotional distress or struggling to cope
National Autistic Society	**National Autistic Society** The leading UK charity for autistic people and their families

Ideas for topics you may want to cover in your story



Appendix K: Interview protocol for parents

Interview Schedule for parents

Demographic questionnaire:
Name:
Age:
Gender:
Ethnicity:
First language:
Faith group:
When did your child access the service?
First Autism diagnosis yes/no

Opening explanation
Start with an explanation of the project, including researching autism identity, autism journey through services and how this affected by the community around you. Acknowledge that ethnicity can play a factor in people's experience and that we may be from different ethnicities and communities, but I'd like to invite any comments relating to that if they feel able to do so. There is no right and wrong answers, I am just curious about your experiences.

What words do you when talking about autism? ASD? Autistic? Has Autism?

Narrative interview:
Narrative interview with open questions exploring their story of ASC/identity

Follow up question asked if needed exploring stories of autism identity, diagnosis pathway, culture

Draft narrative interview schedule for parents:
Tell me the story of your child's life, including their autism journey.

Visual prompts:

Draw a cultural genogram together that includes anyone/services/communities they feel are important.

Option for the young person to bring in a photo about their story (photos will be described in the work rather than copied, participants will take the photo away with them again, so there will be no identifying information)

Spider diagram they were sent with the information sheet to be available during the interview as well.

Verbal prompts:
Individual story
What was your child's childhood like?
Looking back at life, were there any early 'signs' of autism that you didn't realise before diagnosis?
How has your child's autism diagnosis/having autism influenced the story of their life and your life? [Rephrase in the way they prefer]
What is your understanding of autism?
Do you think there are strengths associated with being on the spectrum?
Do you think your child's autism has impacted their mental health? Positive, negative
Have they been supported for any mental health difficulties before they were diagnosed or currently? Elaborate…
What hopes do you have for the future?

Diagnosis story
What made you seek a diagnosis?
What was the diagnosis process like for you?

What impact has the diagnosis had?
What do you think would have been different, if anything, if your child received the diagnosis earlier?
[Do you think they have to mask/hide your autism?] Could you tell me about a time, if any, they have had to change their behaviour in order to fit in?
Are you aware of any support services for anyone with autism? What's your view of the support available to people with autism?
Do you think generic mental health services have an understanding of autism?

Community story
What is your wider network/family's ideas of autism and are they different to your own?
Do you think your culture/community has impacted how you see autism?
Is there anything else about you and your communities that you thinks impacts how you see your diagnosis?
Can you tell me about your relationships with friends and family and how this is impacted by their understanding of your child?
Do you come into contact with others with autism?
What has been your experience of healthcare professionals and their understanding of autism?

Intersectional factors
What does ethnicity mean to you?
Have there been times you've experienced discrimination?
Do you think their gender has impacted their autism?
Are there any other factors you feel have impacted on your diagnosis story?

Is there anything else you'd like the share with me?

Appendix L: Interview protocol for young people

Interview Schedule for young people

Demographic questionnaire:
Name:
Age:
Gender:
Ethnicity:
First language:
Faith group:
When did you access the service?

Opening explanation
Start with an explanation of the project, including researching autism identity, autism journey through services and how this affected by the community around you. Acknowledge that ethnicity can play a factor in people’s experience and that we may be from different ethnicities and communities, but I’d like to invite any comments relating to that if they feel able to do so. There is no right and wrong answers, I am just curious about your experiences.

What words do you when talking about autism? ASD? Autistic? Has Autism?

Narrative interview
Narrative interview with open questions exploring their story of ASC and aspects of identity. Follow up questions asked if needed exploring stories of autism identity, diagnosis pathway, culture, ethnicity.

Send out spider diagram of topics around a week to three days before. Provide enough structure for interview.

Draft narrative interview schedule for YPs:
Tell me the story of your life, including your autism journey

Visual prompts:

Draw a cultural genogram together that includes anyone/services/communities they feel are important.

Option for the young person to bring in a photo about their story (photos will be described in the work rather than copied, participants will take the photo away with them again, so there will be no identifying information)

Spider diagram they were sent with the information sheet to be available during the interview as well.

Verbal prompts:
Individual story
What was your childhood like?
Looking back at life, were there any early ‘signs’ of autism you didn’t recognise before diagnosis?
How has an autism diagnosis/having autism influenced the story of your life? [Rephrase in the way they prefer]
What is your understanding of autism?
What has been your experience of healthcare professionals and their understanding of autism?
Do you think generic mental health services have an understanding of autism?
Are there any ways you feel autism has impacted your mental health? Positive, negative
Have you been supported for any mental health difficulties before you were diagnosed or currently? Elaborate…
What hopes do you have for the future?

Diagnosis story
What made you seek a diagnosis?
What was the diagnosis process like for you?
What impact has the diagnosis had?
What do you think would have been different, if anything, if you received the diagnosis earlier?

[Do you feel you have to mask/hide your autism?] Could you tell me about a time, if any, you have had to change your behaviour in order to fit in?
Do you think there are strengths associated with being on the spectrum?
Have you aware of any support services for anyone with autism? What's your view of the supports available to people with autism? What, if anything, could be done to improve this?

Community story

What communities and groups are you a part of?
If there anything else about you and your community that you thinks impacts how you see your diagnosis?
Do you think your culture/community has impacted how you see your autism?
Can you tell me about your relationships with friends and family?
Do you come into contact with others with autism?
What is your wider network/family's ideas of autism and are they different to your own?

Intersectional factors

What does ethnicity mean to you?
Have there been times you've experienced discrimination?
Do you think your gender has impacted your autism?
Are there any other factors you feel have impacted on your diagnosis story?

Is there anything else you'd like the share with me?

Appendix M: Distress protocol

Distress Protocol

Distress

- A participant indicates they are experiencing a high level of stress or emotional distress
- A participant exhibits behaviours suggestive that the discussion/interview is too stressful such as crying or shaking etc.

Stage 1 Response

- Stop the interview
- The researcher (who is a trainee psychologist) will offer immediate support
- Assess mental status:
  - Tell me what thoughts you are having
  - Tell me what you are feeling right now?
  - Do you feel you are able to go on about your day/?
  - Do you feel safe

Review

- If participant feels they would like to carry on then resume the interview - making clear the interview can be stopped at any point and that they can have breaks at any point.
- Discuss if there are particular topics they would prefer not to focus on and anything else that would help them to feel comfortable.

- If participant is unable to carry on go to stage 2

Stage 2 Response

- Discontinue the interview and give them space in a quiet place if in the room or some time if online
- Discuss with participants the coping skills they have used previously that may be helpful
- Discuss sources of support they have access to and encourage them to contact them - friends and family, mental health services etc.
- Facilitate grounding skills to support the individual to regain a sense of safety
- Offer, with participant consent, to contact their named contact.

Follow up

- Follow up participant with a check in call (if particpant consents) a week later
- Remind them of the sources of support on the participant information sheet
- Send Lead Professional letter to relevant clinician

Appendix N: Lead professional letter

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

Beth Copping
Trainee Clinical Psychologist
Email: bc410@canterbury.ac.uk

Date:

Version No: #1

To whom it may concern,

I am writing to you regarding [insert participant name].

This letter is to inform you that [participant name] has consented to take part in a Doctoral research study titled: **Understanding the stories of young people of the global majority and their families after receiving a diagnosis of Autism Spectrum Condition (ASC): exploring the interplay of culture, neurodiversity, and other aspects of identity.**

As part of this study [participant name] will be asked to complete a one-to-one interview with myself covering individual's experiences of self pre and post their ASC diagnosis. The interview is not expected to last more than 90 minutes in total. Interviews may be conducted in one session or across two depending on the needs of the participant.

Please see attached a copy of the Study Information Sheet and Interview Schedule so that you may have an idea of some of the topics potentially covered in the research interview.

We are mindful that the topic of the research interview may at times evoke some difficult emotions or some mild level of distress. We are therefore informing you of [participant name]'s engagement with this process so that you may be prepared to adequately support them further should the need arise. I will signpost [participant] to relevant support where appropriate.

Please do not hesitate to contact me should you have any questions.

Beth Copping
Trainee Clinical Psychologist

Appendix O: Example narrative summary sheet

Participant: 004	Findings
Personal stories	
Where do people's narratives begin?	At the birth of his daughter
Were there significant events?	School pointing out that they should observe daughter as it appears she may have additional needs. Diagnosis – hadn't come across autism before \, helps to be more empathetic towards his daughter
What is the tone?	Initial surprise, Hopeful
What metaphors do they use?	
What meaning has been made of their experiences?	Finding belonging with other parents of children with SEN needs. Medical diagnosis is a relief.
Dialogical/positional	
How is the narrative created?	Participant mainly constructed narrative, with some prompting from the researcher. Participant moves through in a chronological order from bith, to
What are the key narratives?	Advocating for change in systems to support those with autism Understanding and knowledge are important
What was the function of the narrative for the interviewee?	Educating the researcher about the experience of autism diagnosis
What messages were they trying to convey?	Black people may have a delay in autism being recognised Autism isn't just in white people and people being from minority ethnic groups shouldn't be a barrier to assessment Early recognition is key in getting access to the right support Battles are constant, now thinking about transition to adulthood. Psychoeducation is important
What gaps or omissions were there in the narrative?	Support from family & friends
Community narratives	
What community narratives have come up?	**Finding belonging with other parents of children with SEN needs.** "*When parents share their their own experiences, it's, it's built a sense of, of togetherness that, well, I'm not the only parent in this and we just need to look for ways to really collaborate with schools to improve SEN packages in most schools to support children and because it was it's it's affects one, it affects all*" **Christianity – using the power of prayer to get through difficulties and praying for the daughters future** "*Yeah, [faith] really affects the way I see how it is. I mean, I just believe she's going to get through this stage with constant prayers*."
Dominant autism narratives	
What dominant cultural narratives have come up?	Medical model provided a sense of relief and helpful to understand his daughter

Were counter-cultural narratives present?	**Dominant narrative in the family was that behaviours were being caused by spirits.** "*speaking to most of my families, the fact when I really spoke with my most extended relatives about what we were really facing about Adina, behaviors towards communication, it sounds so strange and and more like she was being possessed by some spirits which made her really think made people really think she was abnormal. And I, I at some point I was almost beginning to believe the same thing. Not until when I had some discussions with my GP*"
Themes	
What themes were identified	**Autism alien to black race** "*Well, umm, i've been able to understand that. In the same way, being able to shape my own understanding of autism. Initially, when I was thinking I I I thought it was in some that was alien to the black race, you know, but I've come to understand that it can really cut across every every race and it's not something that has to do with race. It's it's just a childhood disorder and can affect anyone and and people who have this disabilities really need care wherever we are.*" **Identification of autism through school** "*I I didn't notice more of it until her a teacher draw drew my attention to it ….Isolating herself from peers. Not something the family had come across before so it was a surprise She had a bit of behaviors that seem distinct, so different from her peers. We observe differences in more of our our connections with people that she really like in a communication*" **Helpful GP in explaining autism** "*Not until when I had some discussions with my GP and I had the understanding of the whole medical condition related with my, my daughter and, and what, what she needed. umm, was support and umm, sort of ways of helping her navigate through this challenges because she wasn't really finding it so easy for herself, was a whole strange thing for everyone*" **Stigma and misconceptions of autism** "*There are several myths of autism has been related to families because, umm, it's more like people think that it's, umm, genetic and autism is something that the child feels inferior and makes people, autistic children are inferior and and and violent and dangerous to be with, so, so we'll try the best to really, umm, come on, make awareness of this misconceptions of this.* ***So it sounds like maybe there's some stigma around the diagnosis.*** *So stigma being associated with with autistic children*

being being violent."

Post-diagnosis support helpful
"[CAMHS] involved it involved the the child's pediatric psychologist who gave us, umm, a little. Umm pep talk about her and and how to navigate, umm, her diagnosis. Then the clinicians explained Adina's unique traits and told us it could be different.
Mm-hmm.
It could be different and then this brought clarity to us and understanding and support, support needed in her development.
Mm-hmm.
It was more after the referral. You know the initial assessment and then you know, specialized."

Educating the community
"*Yeah, they have been have been able to be power of advocacies and umm for autism awareness and acceptance within communities, because I feel it's it's really important that people understand the difficulties of of parents in even, umm, the children living with this disability, they are still part of the community and spoken local forums and and and and and on trying to dispel the myths surrounding autism, particularly with with within the black community as they're much more pronounced*."

Advocates for changes in services

Strengths: creativity, caring, drawing, good memory, paying attention to detail
Challenges: changing environments, loud noises

Hopes and dreams for young person
"*Well, I want her to be a nurse because she's quite because of the empathy she has found around the whole family setting. She's, she feels she's so caring and whenever you are around her*"

Delay to getting diagnosed
Umm, initially I think I'm not the only one who have had that misconception about autism, I think most of the healthcare professionals have been able to meet really felt it quite strange for my daughter to actually be, be autistic on when when her symptoms kept on kept on display in and kept on getting worse and worse. It was really a concern for me because we really needed to have a diagnosis before we could really get the support and and the diagnosis took a whole lot of time and that was that was really that really caught my mind and made me to understand that a lot of people think it's couldn't or it's not been associated with the black race. It seems so a little percentage, or if not so infinitesimal. You get so it poses it a whole challenge in getting a diagnosis.

Appendix P: Thematic narrative analysis data synthesis for young people

<table>
<tr><td colspan="5">Personal stories: Meaning making of autism   Important people   Awareness of self
Shared stories: Autism in the family   School support   Post diagnosis support
Cultural and community narratives: Cultural   Stigma   Faith Narratives   Intersectionality</td></tr>
<tr><td>Participant</td><td>101</td><td>102</td><td>103</td><td>105</td></tr>
<tr><td>Themes</td><td>Loneliness
Family and friends big support
Shares diagnosis with friends but not wider
Differences pointed out by others
Rejection of support at school
Autism as spectrum
Believes family views are important rather than ethnicity
Describes autism as a difference in thinking
Sickness of parent
Diagnosis increased understanding of the self
Can relate to others with autism / Group identity
Strengths: different ways of thinking, happy person, smart
Future hopes
Girls and masking
Need more societal awarenessof autism
Religion and purpose</td><td>Anxiety, particularly around time and unpredictability
Disruptive doctors appointments
Ambivalence about autism diagnosis
Autism is your brain wired differently
Strengths: social skills, cooking, reading
Friendship group important
Feels different to others with autism
Stigma from those who don’t understand autism
Sees autism and anxiety as separate
Post diagnosis support
Hopes for the future: teacher or psychologist
Wants to have her own apartment and independence
Family and holidays are important
Repetitive interests and getting attached to things makes it hard to move on
Girls and autism
Cultural community and celebrations and family friends
Post-diagnosis education through CAMHS</td><td>Likes to travel
Family is important
ASC is a disability
Sensitive to others
Autism pointed out by others
Shares diagnosis with friends
Friendships important
Sensory factors impacting school
Conflict with peers
Neutral or negative perception of autism by peers
Surprise at diagnosis
Healthcare staff see autism as positive
Happy to have diagnosis as a teenager because of stigma
Post diagnosis workshop was helpful
Special interests and strengths: sports and videogames
Future hopes: sixth form, travel, apprenticeship, time with family
School had been helpful</td><td>Rejection of the diagnosis at first
Neurodiversity
Reflective of strengths and challenges
Aware of spectrum
Doesn’t want to stereotype
Masks emotions & keeps things to self
Hopes and dreams – independence and become an animator
Strengths: drawing
Finding acceptance and belonging in a neurodiverse friendship group.
Excusing others actions, I don’t really blame them’
Friendship group important
Confusion around whether it’s a disability
Neurodivergent people are more likely to have depression
Struggles with socialising
Aware of differences between mainstream and special school, feels lucky to be there
Wonders whether parents are autistic
Doesn’t share that she has autism
Discrimination for being Asian
Expects to be independent in future, but still have emotional support</td></tr>
</table>

Appendix Q: Thematic narrative analysis data synthesis for parents

Personal narratives: Identifiying autism Barriers to assessment Emotional coping Professional roles Hopes for young person’s future Shared narratives: Autism in the family School support Post diagnosis support Cultural and community narratives: Cultural Stigma Faith Narratives Intersectionality					
Participant	001	002	003	004	005
Themes	Dual identities, mother and working Emotional dysregulation Dealing with comorbidities (dyslexia) Bullying Sensory sensitivities Advocating and pushing for assessment Mental health struggles of child Questioned whether herself and eldest daughter had autism Long waiting list for assessment School support helpful Time consuming process Complexity with diagnosis No staff consistency in assessment Young person made own adjustments after watching videos on social media Cultural community less likely to acknowledge neurodiversity Well spoken so may be treated better by services Is autism a disability? Hopes and dreams for young person	Mental health difficulties (anxiety and self-harm) Difficult sibling relationships Impacts family life Family becoming increasingly isolated Impacts neighbours Parenting courses helpful Feeling unheard by services Being passed between services seeking an assessment Home/school discrepancy in behaviours delayed diagnosis Young person being intense in friendships Experiences of bullying Sensory sensitivities and repetitive behaviours Masking and camouflaging of behaviours, linked to gender Sibling with autism, different presentation Emotional dysregulation Mother’s job gives specialist knowledge Father questions whether he is autistic	Access to interpreters through NHS Hopes and dreams for the future Emotional regulation difficulties Communication difficulties Strengths School support helpful Faith had helped acceptance: God made him that way Motor difficulties	Autism alien to black race Identification through school Helpful GP in explaining autism Cultural differences in understanding autism Stigma and misconceptions of autism Post-diagnosis support helpful School pointed out autism Educating the community Building community/support with other parents of young people with special needs Advocates for changes in services Strengths: creativity, caring, drawing, good memory, paying attention to detail Challenges: changing environments, loud noises Message: autism isn’t just in white people and people being from minority ethnic groups shouldn’t be a barrier to assessment Hopes and dreams for young person	Importance of independence Shock to be minority when moving out of London Battles against the system Educating others about autism Job gives specialist knowledge Rejection by GP Bullying Hopes and dreams for young person: being happy Stories of discrimination Prepares child for people seeing them as ‘Asian first’ Specialist school support Advocate as parent Challenging behaviours

Appendix R: Example transcript

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Appendix S: Feedback to ethics panel

Dear Ethics Panel,

I am writing to advise you that the following research project has now been completed:

Understanding the stories of young people of the global majority and their families after receiving a diagnosis of autism: exploring the interplay of culture, neurodiversity, and other aspects of identity.

Introduction

Several studies indicate that PoGM do not have or are reluctant to access health and mental health services due to institutional racism and clinicians’ unconscious bias. Experiences of contact with services can be further impacted by the diagnosis of autism. Research proposes that culture influences families on many levels when looking after a child with a developmental disability; detecting and making sense of differences, communications with healthcare organisations, selecting treatment approaches, and future hopes. There is limited research which involves hearing from autistic young PoGM. This study sought to understand the stories of young PoGM and their families, explore their personal narratives, and understand how these are shaped by the diagnosis process of autism, as well as cultural, community, and dominant narratives.

Aims

1. What are the personal stories of young people of the global majority who have received an autism diagnosis?
2. What are the personal stories of their family members of their child, including autism assessment and diagnosis?
3. Are there shared narratives about autism between the young people and their families?
4. Do community and cultural narratives of autism feature in the personal stories?

Method

Narrative analysis was used to interpret interviews. Nine interviews were conducted, four with young people, and five with parents. A summary of the participants' narratives was shared with them, and they had the opportunity to edit them.

Results

Findings highlighted the unique stories people of the global majority tell after receiving an autism diagnosis. Personal narratives were influenced by family, community, and cultural narratives.

Six areas emerged from the young peoples' narratives in relation to their personal stories; these were meaning-making of autism, important people, awareness of self over time, post-diagnosis support, school support, and autism in the family.

Eight areas emerged in the parents' narratives; these were identifying autism, battle and barriers to services, emotional dysregulation, professional roles, hopes and dreams for their young person, post-diagnosis support, school support, and autism in the family.

Cultural and community narratives that emerged were: cultural narratives of autism, intersectionality (gender, discrimination, bullying), stigma, and faith narratives.

Clinical implications are discussed for creating culturally sensitive services, increasing community presence and challenging dominant medical narratives of autism. Of particular note were increased barriers to services, cultural and faith narratives, increased bullying and stigma.

I appreciate your support with the study.

Best wishes,

Trainee Clinical Psychologist

Appendix T: End of study form

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