

Autistic identity

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REVIEW ARTICLE

Autistic identity: A systematic review of quantitative research

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Ambitious about Autism

Abstract

Autism can be considered both a personal and social identity. Identifying the factors contributing to positive Autistic identity development is crucial given the potential implications for mental health and wellbeing. In this systematic review, we aimed to synthesize quantitative literature on Autistic identity to identify the (individual and environmental) factors associated with Autistic identity, and to ascertain the relationship between Autistic identity and mental health and wellbeing. A total of 3,617 studies were screened and 20 met our inclusion criteria. Results indicated that people developed a more positive Autistic identity when receiving external autism acceptance and external support. The association between individual factors and Autistic identity were largely nonsignificant or inconclusive, highlighting the need for broad support that meets the needs of a range of Autistic people, rather than specific subgroups. Importantly, positive Autistic identity was associated with improved mental health and wellbeing. Peer support and/or self-directed support resources may be valuable mechanisms for supporting Autistic people to cultivate a positive Autistic identity. The evaluation of such support, including the long-term impacts on identity development, will be a critical avenue for future research.

Lay Summary

We reviewed existing research on Autistic identity and its links to mental health and wellbeing. We found that having a positive Autistic identity is important for mental health, and that having support and acceptance from others (e.g., family, friends) helps people to develop a positive Autistic identity. However, lots of Autistic people do not get this support. Peer support groups where Autistic people can speak to each other about their experiences might help them to develop a positive Autistic identity. Future research should see whether such groups improve Autistic identity.

KEYWORDS

autism, identity, mental health, systematic review, wellbeing

INTRODUCTION

Autism was first defined within medical literature in the early 20th century (Asperger, 1944; Kanner, 1943; Zeldovich, 2018) and has been referenced in diagnostic manuals since at least the 1970s (Ousley & Cermak, 2014). Within the medical model of disability, autism is conceptualized as a cluster of “deficits”, relative to normative standards. Conversely, the neurodiversity

paradigm places more emphasis on person-environment fit than within-person “deficits”, considering autism as a naturally occurring aspect of human diversity (Ne’eman & Pellicano, 2022; Walker, 2014). The neurodiversity paradigm urges Autistic¹ people to “embrace

¹As in the Deaf community, some Autistic people capitalize Autistic to emphasize their belonging to a shared community (e.g., Benham & Kizer, 2016).

autism as an inherent and integral part of [their] identity” (Pellicano & Houting, 2022, p. 387).

Within the field of autism research, identity has been conceptualized using multiple theoretical lenses, with measurement of numerous overlapping constructs. Autistic identity can be conceptualized as having two key dimensions: personal identity and social identity (Albarello et al., 2018; Erikson, 1968; Marcia et al., 1993). Personal identity refers to the process of defining oneself according to individual characteristics and how this self-definition influences life choices across different domains, such as education and career choices. When autism is incorporated into a person’s personal identity, it is viewed as a core facet of the self (e.g., Kenny et al., 2015). This understanding may influence key life choices, such as choosing a career that aligns with common Autistic strengths. Autistic people may also choose to define themselves as members of the autistic community, in which case autism becomes a social identity (Cooper, Russell, et al., 2023; Cooper et al., 2021). Social identity theory (Tajfel & Turner, 1979) asserts that belonging to particular social groups informs one’s identity, and this process of identification happens when group membership is used to define oneself. Defining oneself as a group member is thought to improve wellbeing when the group is seen positively, or one experiences a sense of collective self-esteem (Luhtanen & Crocker, 1992). For example, someone with an Autistic social identity may experience strong feelings of solidarity with other autistic people, and may be more likely to emphasize positive aspects of group membership such as stronger feelings of connectedness to other autistic people (Crompton et al., 2020). Personal and social identities are reciprocal in nature and context-dependent (Albarello et al., 2018). For example, if an Autistic person grows up in a social context that frames autism negatively, they may be less inclined to embed being Autistic as a core part of who they are (i.e., personal identity). Similarly, people for whom being Autistic is not core facet of their identity may be less likely to associate with other Autistic people, which could in turn diminish their Autistic social identity. Throughout this review, we use the term Autistic identity broadly to encompass both personal and social aspects of identity, as it relates to being Autistic. This term reflects the sentiment that being part of the community can be an integral aspect one’s identity as an Autistic person.

Identity development is considered a lifelong task. However, it is during adolescence and early adulthood that identity development is thought to be particularly pertinent. The development of a clear and stable identity generates the subjective experience of continuity within the self, as well as differentiation of the self from others within social interactions (Erikson, 1950; Marcia, 1966). During adolescence, young people experience a series of biological, cognitive, and social changes that are likely to prompt introspection about themselves, their aspirations,

and their place within society (Crocetti, 2017). It is these processes and experiences that result in the reevaluation and refinement of one’s identity.

Receiving an autism diagnosis is an important milestone for many Autistic people, and can have a considerable impact on one’s sense of self (Punshon et al., 2009). The timing of the diagnosis may therefore have important implications for identity development. Research with adolescents indicates that integrating the diagnostic label of autism into one’s self-concept can be a challenging process. Indeed, research with Autistic young people (aged 11–17 years) showed that, whereas some adolescents were able to embrace and accept their Autistic selves, others felt as though they had “a bad brain” and wanted to be “normal” (Humphrey & Lewis, 2008). More recent research corroborates these findings, with some Autistic young people describing their diagnosis as “oppressive” and something they want to rid themselves of, and others describing it as positive and even liberating (Mogensen & Mason, 2015). Conflicting feelings toward one’s diagnosis can also co-exist, with a study by Jones et al. (2015) demonstrating that some Autistic young people (aged 13–20 years) discuss both their pride in being Autistic and the perceived need to reduce the social stigma that is associated with the autism label. Other Autistic young people report feeling indifferent about being Autistic, with no strong negative or positive emotions toward their diagnosis (Ruiz Calzada et al., 2012). This complex interplay of emotions underscores the diverse and multifaceted nature of identity formation following an autism diagnosis.

When considering the impact of receiving an autism diagnosis on identity development, it is important to consider the growing number of Autistic people that are diagnosed in adulthood. Indeed, many subgroups of the Autistic population (e.g., those who are girls/women, non-White, and without an intellectual disability) experience delays in accessing an autism diagnosis, and may not find out, or realize, they are Autistic until adulthood (Lewis, 2017; Mandell et al., 2002; Ratto et al., 2016; Wiggins et al., 2020). As such, many Autistic people will be faced with the challenge of navigating a significant period of their life with no clear explanation as to why they may be facing difficulties that their peers are not. This experience will undoubtedly impact their sense of identity, and limit opportunities to connect with a community of other Autistic people. While receiving a diagnosis in adulthood can evoke a sense of relief and validation for some Autistic people, others report the diagnostic process as being highly emotional, evoking feelings of confusion, shame, sadness, and anger (Arnold et al., 2020; Huang et al., 2020; Leedham et al., 2020; Lilley et al., 2021, 2022). These conflicting emotions are not mutually exclusive. Adjusting to an autism diagnosis involves a range of both positive and negative emotional responses (Wilson et al., 2023), and similar findings have been found with Autistic people who self-identify as

Autistic, without the presence of a formal diagnosis (Lewis, 2016; Moseley et al., 2021). Moreover, access to post-diagnostic support is highly inconsistent, and evidence for the effectiveness of such programmes is in its infancy (Beresford et al., 2020). As such, Autistic people may be denied much-needed support to come to terms with their diagnosis and connect with other Autistic people (Beresford et al., 2020).

Emerging work has begun to examine the possible factors that may impact Autistic identity development. For example, Oredipe et al. (2023) spoke to 78 Autistic university students using an online survey about when and how they found out they were Autistic and found that, while participants who learned they were Autistic at a younger age had higher quality of life and wellbeing in adulthood, participants who learned they were Autistic at an older age had more positive initial reactions about being Autistic. Leung et al. (2023), however, failed to find a significant relationship between the age of learning one was Autistic and well-being when Autistic traits were accounted for. Riccio et al. (2021) examined the impact of how one's autism was disclosed to them (i.e., voluntary versus involuntary parental disclosure) and found that adolescents whose parents voluntarily disclosed their autism diagnosis to them were more positive about being Autistic than those whose parents involuntarily disclosed. Other research has pointed toward the possible impact of gender on Autistic identity, with Autistic women in one study explaining that their Autistic identity was in direct conflict with societal expectations of being a woman (Bargiela et al., 2016). These studies provide initial insight into possible factors that could impact the (non)development of a positive Autistic identity. However, since this work appears to be in its infancy, we do not yet have a clear understanding of the factors that underpin variability in Autistic identity.

Understanding factors contributing to positive Autistic identity development is crucial given that there may be implications for mental health and/or wellbeing. In one of the first studies to quantitatively examine the association between Autistic identity and mental health, Cooper et al. (2017) asked 272 autistic people (without a co-occurring intellectual disability, aged 16 years and above) to complete a survey measuring autism social identity, and traits of anxiety and depression. A positive autism social identity was associated with higher collective self-esteem (i.e., positive perceptions of group membership), which was associated with higher personal self-esteem (i.e., positive perceptions of self) and, ultimately, reduced traits of anxiety and depression. Similar findings were identified by Corden et al. (2021) who found a positive association between a facet of autism personal identity (pride in being autistic) and psychological wellbeing in 151 Autistic adults (aged 18 years and above). The apparent association between Autistic identity and mental health is particularly salient as autistic people are

more likely to be diagnosed with mental health conditions, such as anxiety and depression, than non-Autistic people (Lai et al., 2019).

Overall, it is evident that the assimilation of autism as part of one's identity is a complex process that can afford a series of challenges as well as opportunities. We therefore define Autistic identity as a complex and multifaceted construct, encompassing a range of components that contribute to a person's sense of self, as it relates to being autistic. As seen in Table 1, several positive and negative facets of Autistic identity have previously been identified.

This review focuses on quantitative research examining facets of Autistic identity. There were two main aims of the review. First, to examine the individual and environmental factors associated with Autistic identity to establish which, if any, are associated with Autistic identity development. Second, to understand the nature of the association between Autistic identity and mental health and/or wellbeing, to identify whether the development of a positive Autistic identity will be a pertinent target for future interventions aiming to improve mental health for Autistic people. Our specific review questions were:

1. What factors, if any, are associated with Autistic identity?
2. What is the nature of the association between Autistic identity and mental health and/or wellbeing?

METHODS

This systematic review was developed based on preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines (Page et al., 2021). Data were analyzed using a synthesis without meta-analysis approach, and reporting of findings was guided by the nine reported items outlined by Campbell et al. (2020). The review protocol was registered on the Open Science Framework (<https://doi.org/10.17605/OSF.IO/M3KQC>).

Search strategy

The following databases were searched: PsycINFO, Scopus, Web of Science, ERIC, and ProQuest Dissertations & Theses. A search string was developed based on the authors' research expertise and refined following pilot searches. The final search string searched for (*autis* OR asperger* OR "pervasive development" OR PDD OR ASD OR PDDs OR ASDs OR kanner**) AND (*identity OR "self concept" OR "autistic identity" OR "self-acceptance"*) in the title, abstract, and keywords fields. Searches were restricted to peer-reviewed publications in English. No date restrictions were imposed. The first search was conducted in October 2022 and updated in June 2023.

TABLE 1 Summary of aspects of Autistic identity.

Valence ^a	Aspect of Autistic identity	Definition	References
Positive	Autism centrality	The importance one places on their Autistic identity	Cooper et al. (2017); Cooper et al. (2021); Cooper, Russell, et al. (2023); Ferenc et al. (2023); Maitland et al. (2021)
	Autism satisfaction	How positively one feels about their Autistic identity	Cooper et al. (2017); Cooper et al. (2021); Cooper, Russell, et al. (2023); Ferenc et al. (2023); Maitland et al. (2021)
	Autism solidarity	The extent to which one feels a connection to other Autistic people	Cooper et al. (2017); Cooper et al. (2021); Cooper, Russell, et al. (2023); Ferenc et al. (2023); Maitland et al. (2021)
	Individual self-stereotyping	How similar one feels to other Autistic people	Cooper et al. (2017); Cooper et al. (2021); Cooper, Russell, et al. (2023); Ferenc et al. (2023); Maitland et al. (2021)
	In-group homogeneity	The extent to which one thinks that Autistic people are similar to one another	Cooper et al. (2017); Cooper et al. (2021); Cooper, Russell, et al. (2023); Ferenc et al. (2023); Maitland et al. (2021)
	Autism acceptance	The extent to which one personally accepts themselves as an Autistic person	Cage et al. (2018); Lamash & Meyer, (2022); Nguyen et al. (2020)
	Spectrum abilities	The extent to which autism is perceived as being associated with positive abilities	Bury et al. (2022); McDonald (2020)
	Autistic community connectedness	How connected to the Autistic community one feels	Cage et al. (2022)
	Autism/Autistic pride	The perceived importance of, or pride in, being Autistic	Corden et al. (2021)
	Autistic acculturation	The extent to which one identifies with Autistic culture	Cresswell & Cage, 2019
	Changeability	The extent to which one feels autism is something that can be changed if desired	McDonald (2020)
	Collective strategy use	The extent to which one positively re-defines Autistic people compared with non-Autistic people	Perry et al. (2022)
	Enrichment	The perception that being Autistic enriches one's sense of self and life	Lamash and Meyer (2022)
	Identification with the autistic community	The extent to which one identifies with autism as a social group	Cage and Troxell-Whitman (2020)
	Perceived benefits	The extent to which one believes perceives there to be benefits associated with being Autistic	Nguyen et al. (2020)
	Positive difference	The extent to which autism is perceived as a positive difference as opposed to a challenging disability	McDonald (2020)
Negative	Internalized stigma	The extent to which one rejects their status as an Autistic person	Botha and Frost (2020); Bury et al. (2022); Huang et al. (2023)
	Context-dependent	The extent to which one perceives their autism to be context-specific (i.e., salient in some contexts and not others)	McDonald (2020)
	Engulfment	The extent to which one feels being Autistic dominates or invades all domains of life	Lamash and Meyer (2022)
	Exclusion and/or dissatisfaction	Rejection and/or dissatisfaction with being Autistic	Corden et al. (2021)
	Helplessness	The extent to which one feels their autism results in a lack of control and helplessness	Nguyen et al. (2020)
	Individualistic strategy use	The extent to which one dissociates from other Autistic people	Perry et al. (2022)
	Rejection	The extent to which one rejects their status as an Autistic person	(Lamash & Meyer, 2022)

^aValence was determined based on how the developers of the scales described the measures (e.g., if higher scores on the measures represented more positive aspects of Autistic identity, they were included as positively valenced).

Inclusion and exclusion criteria

Studies that examined aspects of Autistic identity (see Table 1) from the perspectives of Autistic children, adolescents, or adults were included, to review this topic from a lifespan perspective. Studies examining other aspects of identity (e.g., gender identity) in Autistic populations and studies that focused on language preferences (e.g., person- versus identity-first) were excluded, to ensure that one's Autistic identity was the primary focus of the review.

We included studies with participants who had a formal diagnosis of autism and/or who self-identified as Autistic to be as inclusive as possible in our search, given that Autistic identity is an emerging area of research. Indeed, most research on adults who self-identify as Autistic focuses on the topic of identity (see Overton et al., 2023), so excluding participants without a formal diagnosis could have reduced the breadth of our review. We were also cognizant of the many and varied barriers that Autistic people can face in accessing an autism diagnosis, especially for underrepresented groups in autism research (e.g., Adak & Halder, 2017; Kentrou et al., 2019; Schmengler et al., 2021; Tromans et al., 2021).

We focused on quantitative data (including from mixed methods studies) given that an initial search on Prospero indicated that a review examining qualitative data on Autistic identity was underway. As yet, this latter review has not been published. Doctoral dissertations/theses were considered, whereas Master's dissertations (which commonly have not undergone peer review) and conference abstracts (which are commonly too brief to extract detailed information from) were excluded.

Study selection

Search results were imported into Endnote for screening, and duplicates were removed. One reviewer (JD) screened all titles and abstracts, with reference to the inclusion/exclusion criteria. All titles and abstracts were also screened by one of three other reviewers (EK, ES, and LC), who independently reviewed a subset of titles and abstracts each (EK and ES reviewed ~1500 articles each, and LC reviewed another ~400 articles). Inter-rater agreement at this stage was good ($\kappa = 0.59$ – 0.78). Discrepancies were resolved through discussion. For example, referring back to the inclusion/exclusion criteria and, where necessary, involving an additional author if discrepancies could not be resolved immediately. In total, 37 studies were considered eligible for full-text review. Two reviewers (JD and EK) conducted full-text screening, with good agreement ($\kappa = 0.75$). Discrepancies at this stage surrounded whether the measures used could be considered relevant to Autistic identity. Such discrepancies were

resolved through discussion with authors with expertise on the topic. In total, 20 studies were identified as being relevant to the review. Details of the studies screened and included at each stage can be found in Figure 1.

Data extraction and quality appraisal

One reviewer (JD) extracted data from all included studies using a pre-determined standardized extraction form in Microsoft Excel. Two other reviewers (EK & ES) checked the data extracted for accuracy and completeness. The following data were extracted: authors, publication year, country of study, study aims, and methodology (including relevant measures used), sample size and characteristics (including data regarding autism diagnosis, age, gender, ethnicity, other diagnoses, sexual identity, relationship status, employment status, and the highest level of education completed). Findings related to our two review questions were extracted separately.

Two reviewers (JD and LC) also independently assessed the quality of all included studies using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018), which enabled us to gather a nuanced, qualitative understanding of the strengths and weaknesses of each study, as opposed to solely a numerical value. Each study was assessed according to five methodological quality criteria, which differed based on whether the manuscript was considered “quantitative non-randomized” ($n = 19$) or “quantitative descriptive” ($n = 1$). Agreement was excellent across all items (96%). Disagreements were discussed, referring back to the MMAT guidance where necessary, to reach consensus.

Data synthesis

The heterogeneity in the outcome measures used in the included studies precluded a formal meta-analysis. Instead, a synthesis without meta-analysis of the literature was considered the most appropriate approach (Campbell et al., 2020). This process involved one researcher (JD) reading and re-reading each manuscript to familiarize themselves with the study aims, methodology, and findings. Next, data perceived relevant to each review question were extracted verbatim into the form outlined above. When all data were extracted, they were grouped conceptually into subthemes (e.g., around Autistic characteristics, anxiety). Three authors (JD, KC, and LC) agreed on refinements to the subthemes. When the grouping was agreed upon, data under each subtheme were further grouped based on whether they related to positive or negative aspects of Autistic identity (see Table 1). Positive aspects of Autistic identity were defined as beliefs and/or attitudes that promote self-acceptance and a sense of belonging within the Autistic community, whereas negative aspects of Autistic identity

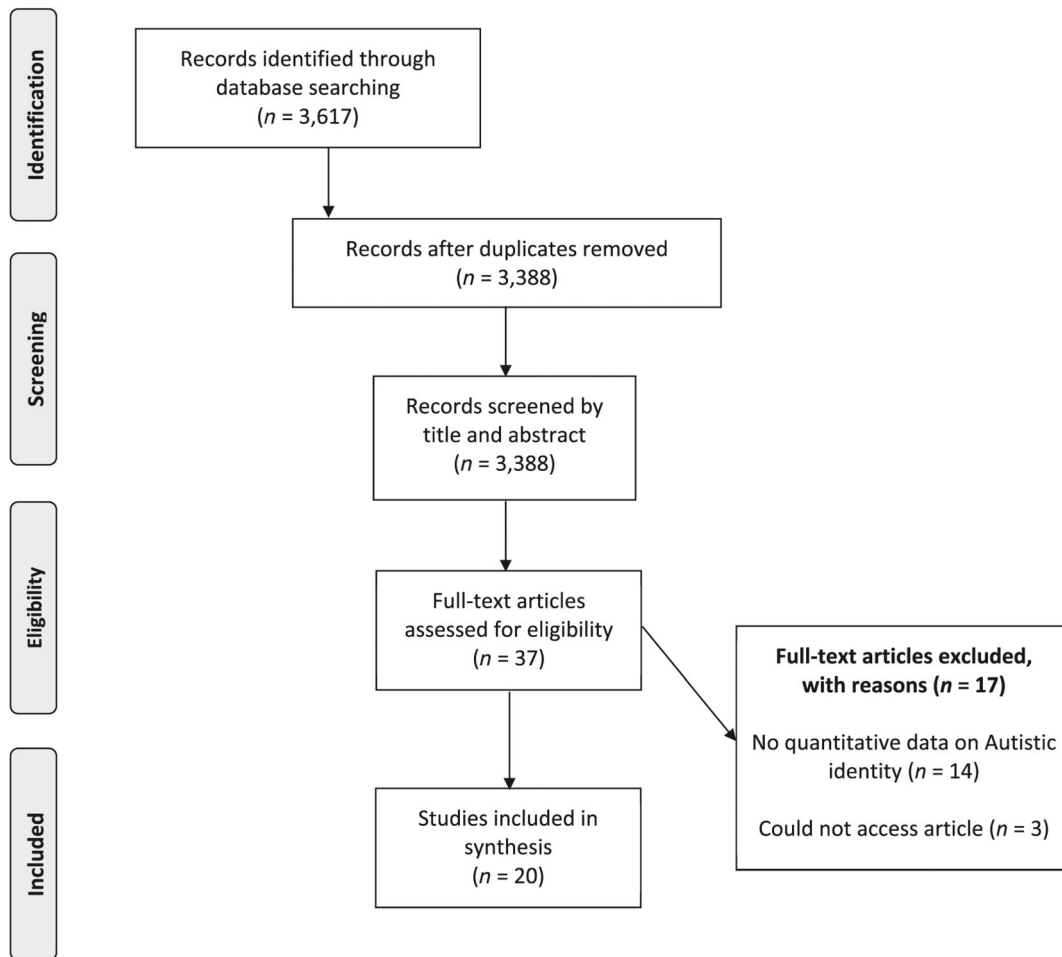


FIGURE 1 PRISMA flowchart.

were defined as beliefs and/or attitudes that lead to self-doubt, rejection of one's status as an Autistic person and internalized stigma. All authors approved the final synthesis.

Community involvement

This review was commissioned by the UK-based charity Ambitious about Autism to inform their ongoing work around the development of post-diagnostic support that fosters positive identity development for Autistic young people. The review is the result of a collaborative effort that involved three co-authors from the charity, two of whom were Autistic young people (MH and GT) and one of whom was a non-Autistic staff member within the charity's national services team (BR). To support our collaborators' involvement, we hosted a series of journal clubs that introduced qualitative and quantitative research about Autistic identity. The journal clubs served as a platform to introduce the concept of Autistic identity and to allow MH, GT and BR to become familiar with the language and structure used in academic research

papers. Our final journal club was dedicated to discussing the findings of this review. During this session, MH, GT, and BR provided valuable feedback on a draft of the manuscript and the overall implications of the review. The feedback received during this session played a crucial role in shaping the final interpretation of the findings and formulating practical recommendations for future research and practice.

RESULTS

Overview of included studies

In total, 20 studies were included in the review (see Figure 1). Of the included studies, nine (45%) were conducted in the United Kingdom, three (15%) in the United States, three (15%) in Australia, one (5%) in Poland, and one (5%) in Israel. The three remaining studies (15%) were conducted in international contexts (i.e., included participants from multiple countries). All studies were published in the last decade, with the earliest study published in 2015.

TABLE 2 Characteristics of the participants in the included studies.

Demographic variable	Number of studies reporting relevant information	Categories	Value
Age (in years)	18 (<i>n</i> = 3,540)	Range	12–72
		Median of the means	33.50
Gender ^a	17 (<i>n</i> = 3,243)	Male	920 (28.4%)
		Female	1928 (59.5%)
		Other gender identities ^b	395 (12.2%)
Ethnicity	11 (<i>n</i> = 1,675)	White	1,485 (88.7%)
		Mixed ethnic background	94 (5.6%)
		Asian	24 (1.4%)
		Black	19 (1.1%)
		Latino/Hispanic	9 (0.5%)
		Other ^c	44 (2.6%)
Highest level of education	8 (<i>n</i> = 2,093)	Undergraduate degree or above	1,152 (55.0%)
		Non-university educated	914 (43.7%)
		No qualifications	27 (1.3%)
Employment status	7 (<i>n</i> = 1,797)	Employed (full-time, part-time, self-employed, student, or carer)	1,264 (70.3%)
		Unemployed (unable to work, retired, volunteer)	533 (29.7%)
Sexual identity	2 (<i>n</i> = 370)	Heterosexual	199 (53.8%)
		Other	171 (46.2%)
Relationship status	3 (<i>n</i> = 271)	Married/in a relationship	148 (54.6%)
		Single	123 (45.4%)

^aIn some studies, transgender participants were reported in a separate gender category, whereas in others, transgender participants were included in their identified gender category.

^bCooper et al. (2017) and Ferenc et al. (2023) only reported *n* (%) for female participants. As such, all other participants (*n* = 170) are represented in the “other gender identities” category.

^cHuang et al. (2023) only reported *n* (%) for White participants. As such, all other participants (*n* = 14) are represented in the “other” category.

Quality appraisal

Results of the quality appraisal using the MMAT are detailed in full in Table S1. Although the quality of the included studies was largely sound, several important methodological issues were identified. Importantly, no study was considered to contain a representative sample of the target population. In most cases, authors stated their target populations were “Autistic adults” but either did not include information around whether participants had a co-occurring intellectual disability or excluded this group from participating (see Russell et al., 2019 for further discussion of this issue in the context of autism research). Similarly, women were considered overrepresented (>60% of the sample) in almost half of the studies (*n* = 9, 45%). Another common issue related to a lack of information in regard to incomplete data (*n* = 12, 60%). For example, not stating whether any participants were removed from the dataset due to incompleteness and/or failing to report the number of participants that completed each

outcome measure. No studies were excluded from the review as a result of the quality appraisal, though issues identified at this stage are considered in the discussion.

Participant characteristics

The included studies involved 3,650 autistic people, with almost one-third of participants (*n* = 1138, 31.2%) coming from one large-scale survey study (McDonald, 2020). Most participants had a formal autism diagnosis (*n* = 3,075 of 3,645, 84.4%), which was received between the ages of two and 70 years (median of the reported means = 29 years). Five studies (Cooper et al., 2017; Cresswell & Cage, 2019; Harmens et al., 2022; Huang et al., 2023; Weiler et al., 2022) reported whether their participants had a co-occurring intellectual disability: 11 (of 549, 2%) participants did, and all of those came from one study (Huang et al., 2023). See Table 2 for full participant characteristics.

Measures and conceptualisations of Autistic identity

In total, sixteen measures were used to assess Autistic identity (see Table 3). The Autism Social Identification scale (adapted from the Multi-Dimensional Scale of Social Identification, Leach et al., 2008) was the most commonly used measure, used in six of the twenty included studies (30%). Two studies (Bury et al., 2022; Huang et al., 2023) utilized two or more measures to assess different aspects of Autistic identity.

Half of the included studies ($n = 10$, 50%) conceptualized Autistic identity in terms of social identity theory (Tajfel & Turner, 1979). Alternative theoretical viewpoints included minority stress theory (Meyer, 2003) ($n = 1$, 5%), disability identity theory (Gill, 1997) ($n = 1$, 5%), and the theory of biographical illumination (Tan, 2018) ($n = 1$, 5%). The remaining studies ($n = 7$, 35%) did not specify the theoretical underpinnings of their approach to Autistic identity.

The included measures examined a range of aspects related to Autistic identity. Most studies ($n = 19$, 95%) measured positive aspects of Autistic identity (e.g., personal autism acceptance, solidarity with other autistic people, pride in being autistic) and/or treated Autistic identity as a continuous variable, where strong identification was considered favorable. Fewer studies ($n = 8$, 40%) included measures of negative aspects of Autistic identity (e.g., internalized stigma, exclusion/dissatisfaction with being autistic, helplessness, individualistic strategy use). For accuracy, we use the terminology used by the study authors when describing specific study measures and findings.

Most studies ($n = 16$, 80%) provided evidence related to the validity and/or reliability of the used measure(s) in their Autistic sample. Internal consistency on the measures ranged between 0.63 and 0.91, with most scales and/or subscales demonstrating at least good internal consistency. Where scales were developed for the Autistic population, they were generally well-validated. Maitland et al. (2021) conducted a confirmatory factor analysis of the Autism Social Identification scale (adapted from the Multi-Dimensional Scale of Social Identification, Leach et al., 2008) in their Autistic sample and found the factor model to be a good fit for social identification with other Autistic people. However, there was limited evidence of the validation of other scales that were not developed for the Autistic population, within an Autistic sample.

Review question 1: what factors are associated with autistic identity?

Table 4 contains a top-level summary of our findings in relation to review question 1. Findings regarding the associations between Autistic identity and individual factors were largely inconclusive. This included findings

relating to sex/gender, Autistic characteristics, diagnosis, recency of diagnosis, and age of diagnosis. Data regarding other demographic factors, such as age, level of education, and ethnicity were nonsignificant. All studies that examined the association between aspects of Autistic identity and external acceptance/support ($n = 6$), self-esteem ($n = 5$), and camouflaging/masking ($n = 4$) found a significant association. Next, we discuss these findings in more depth, with reference to the direction of associations, as well as the specific aspects of Autistic identity that were examined. Further information can be found in the Supplementary Materials (pages 3–8).

Demographic factors

In total, eight studies examined the association between Autistic identity and demographic factors, including (1) sex and/or gender, (2) age, and (3) other demographic factors (e.g., ethnicity, level of education, and employment status).

Sex and/or gender: Of the six studies that examined the association between aspects of Autistic identity and sex/gender, three found a significant association. Males were less likely to engage in collective strategy use than females (Perry et al., 2022), and females and other gender identity groups were less likely to experience internalized stigma than males (Botha & Frost, 2020). There was a significant association between gender and autism social identity, but the nature of the effect was not discussed (Cooper et al., 2021).

Age: Five studies (Cooper et al., 2021; Lamash & Meyer, 2022; Maitland et al., 2021; Nguyen et al., 2020; Perry et al., 2022) examined the association between facets of Autistic identity and age, and none found a significant association.

Other demographic factors: Three studies examined the association between aspects of Autistic identity and other demographic factors, including ethnicity (Botha & Frost, 2020), sexuality (Cooper et al., 2017), employment status (Nguyen et al., 2020), and level of education (Cooper et al., 2017; Nguyen et al., 2020). No significant associations were reported.

Autistic characteristics

Of the eight studies that examined the association between Autistic identity and Autistic characteristics, four studies found a significant association. Autistic people who endorsed higher autism traits reported that their autism social identity was more central (Cooper, Russell, et al., 2023), felt more solidarity with other Autistic people (Cooper, Russell, et al., 2023) and were less likely to engage in individualistic strategy use (Perry et al., 2022). Yet, autistic people with higher Autistic characteristics also reported significantly greater feelings of helplessness

TABLE 3 Summary of Measures Used.

Study (year)	Sample size	Measure(s) name	Summary of measure	Theory	Positive aspects of autistic identity	Negative aspects of autistic identity	Evidence of validity/reliability
Botha and Frost (2020)	111	Internalized stigma scale (adapted from the Internalized Homophobia Scale, Meyer & Dean, 1998)	Ten items measuring the extent to which one rejects their status on the autism spectrum. Eight items were adapted from the internalized homophobia scale (Meyer & Dean, 1998) and two additional items were added by Botha and Frost (2020). Higher scores reflect more intense feelings of internalized stigma, as it relates to autism.	Minority stress theory	N/A	Internalized stigma	Not reported in this sample.
Bury et al. (2022)	198	Autism Social Identification (adapted from the Multi-Dimensional Scale of Social Identification, Leach et al., 2008) Experience of stigma scale (adapted from the Internalized Stigma of Mental Illness Inventory, Boyd Ritsher et al., 2003)	Fourteen items measuring autism social identity. Higher scores represent stronger identification with an autism social identity. Twenty-one items measuring the extent to which one internalizes stigma. Higher scores reflect higher experience of stigma and more intense feelings of internalized stigma, as it relates to autism.	Social identity theory	Autistic identity	N/A	In this sample, internal consistency for the total Autism Social Identification score was $\omega = 0.89$. In this sample, internal consistency for the total internalized stigma score was $\omega = 0.84$.
Cage and Troxell-Whitman (2020)	180	Autism Spectrum Identity Scale-Spectrum Abilities Subscale (McDonald, 2016) Disability Identification Scale (adapted from Nario-Redmond & Oleson, 2016)	Five items measuring the extent to which one believes Autistic people have unique abilities. Higher scores reflect greater belief in special autism abilities. Five items measuring the extent of one's identification with autism as a social group. Higher scores reflect stronger identification with the Autistic community.	Not stated	Spectrum abilities	N/A	In this sample, internal consistency for spectrum abilities subscale was $\omega = 0.81$. In this sample, internal consistency for the total disability identification score was $\alpha = 0.88$.

(Continues)

TABLE 3 (Continued)

Study (year)	Sample size	Measure(s) name	Summary of measure	Theory	Positive aspects of autistic identity	Negative aspects of autistic identity	Evidence of validity/reliability
Cage et al. (2018)	111	Autism acceptance questions	Three questions measuring the extent to which one feels accepted by society, their family and friends, and themselves. Higher scores reflect higher perceived acceptance.	Not stated	Personal autism acceptance	N/A	The three items were assessed using principal component analysis. Factor loadings suggested perceived acceptance from society and family and friends loaded onto one component. These two components were therefore combined as a measure of "external sources of acceptance" and personal autism acceptance was considered as a separate construct.
Cage et al. (2022)	196	Autistic Community Connectedness Scale (Botha, 2020)	Ten items measuring one's perceived connectedness to the Autistic community. Higher scores reflect perceived connection to the Autistic community.	Social identity theory	Autistic community connectedness	N/A	83 items were developed by an Autistic autism researcher. A content comparison was carried out to remove unclear or unconcise items and remove repeating questions. The remaining items were reviewed by a small sample of Autistic advisors ($n = 5$) and research experts ($n = 3$). Confirmatory factor analysis was used to validate and purify the remaining 22 items. Three models were created, with the third (containing 10 items) having good fit. Internal consistency in Cage et al.'s (2022) sample was $\alpha = 0.91$.
Cooper et al. (2017)	272	Autism Social Identification (adapted from the Multi-Dimensional Scale of Social Identification, Leach et al., 2008)	Fourteen items across five components measuring Autism social identity. Higher scores represent stronger identification with an autism social identity. Components include solidarity, satisfaction, centrality, individual self-	Social identity theory	Solidarity, satisfaction, centrality, individual self-stereotyping, in-group homogeneity	N/A	In this sample, internal consistency for the total Autism Social Identification score was $\alpha = 0.87$. Internal consistencies for the subscales were: solidarity ($\alpha = 0.82$), satisfaction ($\alpha = 0.84$), centrality

TABLE 3 (Continued)

Study (year)	Sample size	Measure(s) name	Summary of measure	Theory	Positive aspects of autistic identity	Negative aspects of autistic identity	Evidence of validity/reliability
Cooper et al. (2021)	140	Autism Social Identification (adapted from the Multi-Dimensional Scale of Social Identification, Leach et al., 2008)	Fourteen items across five components measuring Autism social identity. Higher scores represent stronger identification with an autism social identity. Components include solidarity, satisfaction, centrality, individual self-stereotyping, and in-group homogeneity.	Social identity theory	Solidarity, satisfaction, centrality, individual self-stereotyping, in-group homogeneity	N/A	In this sample, internal consistency for the total Autism Social Identification score was $\alpha = 0.91$. ($\alpha = 0.78$), individual self-stereotyping ($\alpha = 0.86$) and in-group homogeneity ($\alpha = 0.66$).
Cooper, Russell, et al. (2023)	121	Autism Social Identification (adapted from the Multi-Dimensional Scale of Social Identification, Leach et al., 2008)	Fourteen items across five components measuring Autism social identity. Higher scores represent stronger identification with an autism social identity. Components include solidarity, satisfaction, centrality, individual self-stereotyping, and in-group homogeneity.	Social identity theory	Solidarity, satisfaction, centrality, individual self-stereotyping, in-group homogeneity	N/A	In this sample, internal consistency for the total Autism Social Identification score was $\alpha = 0.84$. Internal consistencies for the subscales were: solidarity ($\alpha = 0.88$), satisfaction ($\alpha = 0.86$), centrality ($\alpha = 0.79$), individual self-stereotyping ($\alpha = 0.86$) and in-group homogeneity ($\alpha = 0.81$).
Corden et al. (2021)	151	Questionnaire on Disability Identity and Opportunity (adapted from Darling & Heckert, 2010)	Eight items measuring autism personal identity, across two subscales: autism pride and exclusion/dissatisfaction. Higher scores on each subscale reflect more pride or dissatisfaction with being Autistic.	Personal identity	Autism pride	Exclusion/dissatisfaction	In this sample, internal consistency was $\alpha = 0.84$ for autism pride and $\alpha = 0.68$ for exclusion/dissatisfaction.
(Cresswell & Cage, 2019)	24	Autism Identity Scale (adapted from the Deaf Acculturation Scale, Maxwell-McCaw & Zea, 2011)	Thirty-two items assessing cultural acculturation across two subscales: Autistic and non-Autistic. Higher scores on each subscale reflect higher acculturation with that groups culture.	Social identity theory	Autistic acculturation	N/A	In this sample, internal consistency was $\alpha = 0.63$ for the Autistic acculturation subscale and $\alpha = 0.82$ for the non-Autistic acculturation subscale.

(Continues)

TABLE 3 (Continued)

Study (year)	Sample size	Measure(s) name	Summary of measure	Theory	Positive aspects of autistic identity	Negative aspects of autistic identity	Evidence of validity/reliability
Ferenc et al. (2023)	109	Autism Social Identification (adapted from the Multi-Dimensional Scale of Social Identification, Leach et al., 2008)	Fourteen items across five components measuring Autism social identity. Higher scores represent stronger identification with an autism social identity. Components include solidarity, satisfaction, centrality, individual self-stereotyping, and in-group homogeneity. The authors chose not to include the satisfaction subscale in this study.	Social identity theory	Solidarity, centrality, individual self-stereotyping, in-group homogeneity		Not reported in this sample.
Harmens et al. (2022)	96	Autism Spectrum Quality of Life (McConachie et al., 2018)	Nine items measuring quality of life for Autistic people. One item—thought to be a global item—related to acceptance of autism as an aspect of one's identity.	Not stated	Autistic identity	N/A	Not reported in this sample.
Huang et al. (2023)	143	Internalized stigma scale (adapted from the Internalized Stigma of Mental Illness Scale—Brief Version, Hammer & Toland, 2017)	Nine items measuring the extent to which one experiences internalized stigma. Higher scores reflect more intense feelings of internalized stigma, as it relates to autism.	Biographical illumination	N/A	Internalized stigma	Autistic advisors were consulted in the adaptation of the survey. Internal consistency in this sample was $\alpha = 0.69$.
(Lamash & Meyer, 2022)	17	Impact of Diagnosis Scale—Revised (Arnold et al., 2021)	Twenty-two items across four domains, measuring the impact of receiving an autism diagnosis. Domains include: self-understanding (relevant to identity), wellbeing, clinician support, and service access. Higher scores reflect a more positive impact of the diagnosis.	Not stated	Self-understanding	N/A	The scale was developed using a participatory approach whereby Autistic people submitted potential items and ranked items in order of priority. Internal consistency in this sample was $\alpha = 0.81$ for self-understanding, and $\alpha = 0.90$ for the overall scale.
(Lamash & Meyer, 2022)	17	Illness Identity Questionnaire (adapted from Oris et al., 2016)	Twenty-five items across four domains, measuring the extent to which one integrates their “illness” into their identity.	Not stated	Acceptance, enrichment	Rejection, engulfment	Not reported in this sample.

TABLE 3 (Continued)

Study (year)	Sample size	Measure(s) name	Summary of measure	Theory	Positive aspects of autistic identity	Negative aspects of autistic identity	Evidence of validity/reliability
Kidney (2015)	151	Autistic Identity Scale (adapted from the Disability Identity Scale, Gill, 1997)	<p>Domains include: rejection, engulfment, acceptance, and enrichment. Higher overall scores represent a more positive sense of identity.</p> <p>Seventeen items measuring the valence of one's feelings toward being autistic. Higher scores reflect more positive feelings about being Autistic.</p>	Not stated	Autistic identity	N/A	<p>A team of Autistic and non-Autistic researchers adapted the original Disability Identity Scale to improve the language for clarity and appropriateness for Autistic participants. Internal consistency in this sample was $\alpha = 0.73$.</p>
Maitland et al. (2021)	184	Autism Social Identification (adapted from the Multi-Dimensional Scale of Social Identification, Leach et al., 2008)	<p>Fourteen items across five components measuring Autism social identity. Higher scores represent stronger identification with an autism social identity. Components include solidarity, satisfaction, centrality, individual self-stereotyping, and in-group homogeneity.</p>	Social identity theory	Solidarity, satisfaction, centrality, individual self-stereotyping, in-group homogeneity	N/A	<p>In this sample, internal consistency for the total Autism Social Identification score was $\alpha = 0.91$. Goodness of fit was assessed using confirmatory factor analysis and resulting model fit indices indicated the model was a good fit.</p>
McDonald (2020)	1138	Autism Spectrum Identity Scale McDonald, (2016)	<p>Twenty-two items measuring variation in Autistic identity across four domains: positive difference, context-dependent, spectrum abilities, and changeability. Higher scores in positive difference, changeability, and spectrum abilities reflect a more positive Autistic identity.</p>	Not stated	Positive difference, spectrum abilities, changeability	Context-dependent	<p>The author developed items based on Goffman's theory of identity and stigma. Items were piloted with five Autistic people, and feedback was provided. Factor analysis was performed and items that demonstrated low loadings were removed. In this sample, internal consistency was $\alpha = 0.88$ for positive difference, $\alpha = 0.89$ for context-dependent, $\alpha = 0.82$ for spectrum abilities and $\alpha = 0.66$ for changeability.</p>

(Continues)

TABLE 3 (Continued)

Study (year)	Sample size	Measure(s) name	Summary of measure	Theory	Positive aspects of autistic identity	Negative aspects of autistic identity	Evidence of validity/reliability
Nguyen et al. (2020)	71	Autism Self-Appraisals Scale (adapted from the illness cognitions questionnaire, Evers et al., 2001)	Eighteen items assessing three cognitive appraisals related to autism: helplessness, acceptance, and perceived benefits. Higher scores indicate greater appraisals of helplessness, acceptance, and/or perceived benefits.	Not stated	Acceptance, Perceived benefits	Helplessness	Internal consistency in this sample was $\alpha = 0.84-0.88$.
Perry et al. (2022)	223	Individualistic and Collective Strategy Use (Nario-Redmond et al., 2013)	Twenty-six items across two scales examining collective strategy use (positively re-defining Autistic people compared to non-Autistic people) and individualistic strategy use (dissociating from other Autistic people). Higher scores indicate greater use of those strategies.	Social identity theory	Collective strategy use	Individualistic strategy use	In this sample, internal consistency was $\alpha = 0.89$ for collective strategy use and $\alpha = 0.77$ for individualistic strategy use.
Weiler et al. (2022)	14	Identity question	One question: "to what extent do you feel pride in your Autistic identity?"	Not stated	Autistic identity	N/A	Not reported in this sample.

TABLE 4 Top-level summary of review findings in relation to review question 1.

	Number of studies identifying a significant difference in Autistic identity, <i>n</i> (%)	Number of studies not identifying a significant difference in Autistic identity, <i>n</i> (%)
Sex/gender	3 (50%)	3 (50%)
Age	0 (0%)	5 (100%)
Level of education	0 (0%)	2 (100%)
Ethnicity	0 (0%)	1 (100%)
Sexuality	0 (0%)	1 (100%)
Employment status	0 (0%)	1 (100%)
Autistic characteristics	4 (50%)	4 (50%)
Diagnosis versus no diagnosis	1 (50%)	1 (50%)
Age of diagnosis	1 (20%)	4 (80%)
Recency of diagnosis	1 (25%)	3 (75%)
External acceptance/support	6 (100%)	0 (0%)
Self-esteem	5 (100%)	0 (0%)
Camouflaging/masking	4 (100%)	0 (0%)
Self-concept	2 (100%)	0 (0%)
Source of information about autism	1 (100%)	0 (0%)
Self-understanding	1 (100%)	0 (0%)
Self-efficacy	1 (100%)	0 (0%)

associated with being Autistic (Nguyen et al., 2020). Participants who perceived their autism attributes more positively had a stronger autism social identity (Cooper et al., 2021).

Autism diagnosis

Eight studies examined the association between aspects of autistic identity and aspects of autism diagnosis, such as the (1) presence of a formal diagnosis (versus no diagnosis), (2) age of diagnosis, and (3) recency of diagnosis.

Presence of a formal diagnosis (versus no diagnosis): Of the two studies that examined whether there were differences in Autistic identity as a function of diagnostic status, only one found a significant difference. Specifically, McDonald (2020) found that self-diagnosed participants were more likely to report autism being a positive difference as opposed to a challenging disability, and

were more likely to perceive their autism to be context-specific.

Age of Diagnosis: Of the five studies that examined the association between aspects of Autistic identity and age of diagnosis, only one found a significant association. Specifically, Corden et al. (2021) found that participants diagnosed later in life were more likely to experience dissatisfaction with being Autistic. However, age of diagnosis was not a significant individual predictor of dissatisfaction with being Autistic.

Recency of diagnosis: Of the four studies that examined the association between the recency of autism diagnosis and Autistic identity, only one found a significant association. Specifically, Corden et al. (2021) found that the more time that had passed since one received their diagnosis, the more pride they felt in being Autistic, and the less dissatisfaction they felt about being Autistic. Recency of the diagnosis was a significant individual predictor of dissatisfaction with being Autistic.

External acceptance and/or support

All six studies that examined the association between aspects of Autistic identity and the level of external acceptance and/or support one receives found a significant association. Participants who reported higher rates of external acceptance and/or support reported higher personal autism acceptance (Cage et al., 2018; Nguyen et al., 2020) and more perceived benefits of autism (Nguyen et al., 2020). Autistic people that had higher, or more frequent, involvement in the online autism community and/or had a higher sense of community and/or reported involvement in the online autism community as being important to them had stronger Autistic identity (Kidney, 2015). Weiler et al. (2022) found that a mentoring intervention for Autistic adolescents and adults resulted in small to moderate increases in mentee's pride in their Autistic identity according to their parents and a small increase in mentor's pride in their Autistic identity. When Autistic people perceived a lack external acceptance and/or support, they were more likely to experience internalized stigma (Botha & Frost, 2020; Huang et al., 2023) and feelings of helplessness associated with being Autistic (Nguyen et al., 2020).

Self-esteem

All five studies that examined the association between aspects of Autistic identity and aspects of self-esteem found a significant association. Higher personal self-esteem was associated with higher autism social identity (Cooper et al., 2017), more pride in being Autistic (Corden et al., 2021), higher autism acceptance (Nguyen et al., 2020) and more perceived benefits of autism (Nguyen et al., 2020). Conversely, lower personal self-

esteem was associated with higher dissatisfaction with being Autistic (Corden et al., 2021) and higher helplessness associated with being Autistic (Nguyen et al., 2020). Autism pride, perceived benefits of autism, dissatisfaction with being Autistic, and helplessness associated with being Autistic were all significant individual predictors of personal self-esteem (Corden et al., 2021; Nguyen et al., 2020). Other studies also found that higher collective self-esteem was associated with stronger Autistic social identification (Cooper et al., 2017, 2021) and that self-definition (i.e., feeling the same as other Autistic people) was a significant individual predictor of global self-esteem (Ferenc et al., 2023).

Camouflaging/masking

All four studies that examined the association between aspects of Autistic identity and camouflaging/masking behaviors found a significant association. Having an Autistic social identity (Cage & Troxell-Whitman, 2020) and feeling connected to the Autistic community (Cage et al., 2022) were associated with more camouflaging and/or masking behaviors. However, when including the effects of diagnostic disclosure, Autistic identity indirectly reduced camouflaging through greater disclosure (Cage & Troxell-Whitman, 2020). Higher collective strategy use was associated with greater camouflaging (Perry et al., 2022). Both collective strategy use and individualistic strategy use individually predicted camouflaging behavior (Perry et al., 2022). Finally, higher internalized stigma was associated with significantly more concealment of Autistic behaviors (Botha & Frost, 2020).

Self-concept

Two studies examined the association between Autistic identity and self-concept and found significant associations. Cresswell and Cage (2019) examined the percentage of positive and negative statements their adolescent participants wrote about themselves and found that participants classified as assimilated (i.e., aligned to neither Autistic or non-Autistic culture) wrote significantly more positive statements about themselves, compared with those who were classified as marginalized (i.e., aligned to non-Autistic culture). Nguyen et al. (2020) found that higher autism acceptance and more perceived benefits of autism were associated with greater global self-concept. Perceived benefits of autism individually predicted global self-concept.

Source of information about autism

Bury et al. (2022) examined the association between how one learns about autism and their Autistic identity.

Learning about autism via parents or professionals was associated with weaker Autistic identity, while learning about autism via autism advocates, social media, online blogs, or other Autistic people, was associated with stronger Autistic identity. Further, learning about autism via parents, TV, or the media was associated with higher internalized stigma, while learning about autism via social media or online blogs was associated with reduced internalized stigma. The association between internalized stigma and learning about autism via online blogs did not remain significant when controlling for gender. Finally, those who learned about autism via parents or professionals were less likely to believe that Autistic people have unique abilities, whereas those who learned about autism via autism advocates, social media, online blogs, or personal experience were more likely to believe that Autistic people have unique abilities.

Self-understanding

Huang et al. (2023) found that those with higher self-understanding experienced reduced internalized stigma.

Self-efficacy

Lamash and Meyer (2022) found that those with higher work-related self-efficacy had stronger Autistic identity.

Review question 2: what is the nature of the association between Autistic identity and mental health and/or wellbeing?

Table 5 contains a top-level summary of our findings in relation to review question 2. All studies that examined the association between aspects of Autistic identity and wellbeing ($n = 7$), depression ($n = 3$), and stress ($n = 1$) found a significant association. Data regarding the association between aspects of Autistic identity and anxiety were less conclusive with half of the studies ($n = 2$, 50%)

TABLE 5 Top-level summary of review findings in relation to review question 2.

	Number of studies identifying a significant (positive or negative) association, n (%)	Number of studies not identifying a significant (positive or negative) association, n (%)
Wellbeing	7 (100%)	0 (0%)
Anxiety	2 (50%)	2 (50%)
Depression	3 (100%)	0 (0%)
Psychological distress	2 (67%)	1 (33%)
Stress	1 (100%)	0 (0%)

identifying a significant association, and half not ($n = 2$, 50%). Similarly, two-thirds of the studies ($n = 2$, 67%) examining the association between aspects of Autistic identity and psychological distress found a significant association, and one-third did not ($n = 1$, 33%). We discuss these findings in more depth below, with reference to the direction of the associations, as well as the specific aspects of Autistic identity that were examined. Further information can be found in the Supplementary Materials (pages 9–11).

Wellbeing

All seven studies that examined the association between aspects of Autistic identity and wellbeing found a significant association. Higher wellbeing scores were associated with stronger overall autism identification (Lamash & Meyer, 2022; Maitland et al., 2021), with autism social identification being a significant individual predictor of wellbeing. Higher wellbeing scores were also associated with higher Autistic community connectedness (Cage et al., 2022), higher satisfaction with being Autistic (Cooper, Russell, et al., 2023), more pride in being Autistic (Corden et al., 2021), more solidarity with Autistic people (Cooper, Russell, et al., 2023), and more collective strategy use (Perry et al., 2022). Solidarity with Autistic people and satisfaction with being Autistic were significant individual predictors of wellbeing (Cooper, Russell, et al., 2023). Conversely, lower wellbeing scores were associated with higher internalized stigma (Botha & Frost, 2020), dissatisfaction with being Autistic (Corden et al., 2021), and engulfment (Lamash & Meyer, 2022). Internalized stigma was a significant individual predictor of emotional wellbeing (Botha & Frost, 2020).

Anxiety

Of the four studies that examined the association between aspects of Autistic identity and anxiety, two found a significant association. Cooper et al. (2017) identified a negative indirect path from autism social identification to anxiety, through both collective and personal self-esteem. Cooper, Russell, et al. (2023) found that participants for whom being Autistic was a more central aspect of their identity were more likely to experience social anxiety.

Depression

All three studies that examined the association between aspects of Autistic identity and depression found a significant association. Specifically, more depressive symptoms were associated with reduced personal autism acceptance (Cage et al., 2018) as well as reduced overall autism social identification (Maitland et al., 2021). Personal

autism acceptance and autism social identification were both significant individual predictors of depressive symptoms (Cage et al., 2018; Maitland et al., 2021). Finally, while Cooper et al. (2017) found no significant direct association between autism social identification and depression, path analyses highlighted a significant, negative indirect path from autism social identification to depression, through both collective and personal self-esteem.

Psychological distress

Two of the three studies that examined the association between aspects of Autistic identity and psychological distress found a significant association. Higher scores on measures of psychological distress were associated with feeling more like other Autistic people (Ferenc et al., 2023) and experiencing more internalized stigma (Botha & Frost, 2020). Both internalized stigma and feeling like other Autistic people were individual predictors of psychological distress (Botha & Frost, 2020; Ferenc et al., 2023). However, feeling like other Autistic people only predicted psychological distress in participants that adopted a medical model definition of autism.

Stress

Cage et al. (2018) found that higher reported personal autism acceptance was associated with significantly lower rates of stress.

DISCUSSION

In this systematic review, we synthesized quantitative research on autistic identity, with two main aims: (1) to identify the factors associated with Autistic identity, and (2) to ascertain the nature of the association between Autistic identity and mental health and/or wellbeing. We identified a range of measures used to assess Autistic identity, with most assessing Autistic social identity. Only two measures were developed specifically for the Autistic population: the Autism Community Connectedness Scale (Botha, 2020) and the Autism Spectrum Identity Scale (McDonald, 2016). Only one measure that was developed for a non-Autistic population had been validated within an Autistic sample: the Autism Social Identification scale (adapted from Leach et al.'s (2008) Multi-Dimensional Scale of Social Identification) (Maitland et al., 2021). The validation of alternative measures of Autistic identity will be a crucial avenue for future research. Next, we provide an overview of the most salient findings related to our two review questions, and provide key suggestions for future research and practice.

Data regarding the individual factors associated with Autistic identity were largely nonsignificant or inconclusive. For example, key participant characteristics such as age, ethnicity, sexuality, employment status, and level of education were not related to Autistic identity development (Botha & Frost, 2020; Cooper et al., 2017; Cooper et al., 2021; Lamash & Meyer, 2022; Maitland et al., 2021; Nguyen et al., 2020; Perry et al., 2022). Similarly, findings regarding the impact of gender/sex, Autistic characteristics and diagnosis (including if one had a formal autism diagnosis, and the recency of this diagnosis) were inconclusive, with studies finding conflicting results (Botha & Frost, 2020; Cooper et al., 2017; Cooper, Russell, et al., 2023; Cooper et al., 2021; Corden et al., 2021; Ferenc et al., 2023; Huang et al., 2023; Maitland et al., 2021; McDonald, 2020; Nguyen et al., 2020; Perry et al., 2022). As such, there remains a lack of clarity regarding which individual factors, if any, make Autistic people more likely to develop a positive/negative Autistic identity. The presence of inconclusiveness may point toward individual differences in the impact of individual factors on Autistic identity development. Taking these results within an intersectionality framework (Crenshaw, 1989), there are likely to be varied experiences of Autistic identity dependent on the particular identities of each individual. For example, Autistic young people who are gender diverse may experience their autism identity differently due to focusing on gender-related identities and needs (Cooper, Mandy, et al., 2023), compared with cisgender Autistic young people. However, it should be emphasized that relatively few studies assessed each of the identified variables, and none specifically sought to examine the impact of such variables on Autistic identity development. This may be a key avenue for future research, which raises theoretical and methodological issues, since measures of other non-autistic identities in the autistic population should be theory-driven and validated for use with Autistic people.

In the absence of conclusive information regarding which subgroups of Autistic people, if any, may particularly benefit from support with identity development, we suggest that broader support, aimed at a wide range of Autistic people, may be beneficial. One recommendation in this regard may be peer support that enables people to understand, accept, and strengthen their Autistic identity. This suggestion aligns with our finding that features of the environment, such as the level of external support and acceptance one receives, may be better predictors of Autistic identity than individual factors (Botha & Frost, 2020; Cage et al., 2022; Huang et al., 2023; Kidney, 2015; Nguyen et al., 2020; Weiler et al., 2022). This is in line with research with other minoritized groups (e.g., LGBTQ+) which also underscores the importance of social support, including support from family, friends, and the community for mental health and wellbeing (Chang et al., 2021; McDonald, 2018; Snapp et al., 2015). Yet, many Autistic people report facing

stigma and discrimination, and, perhaps relatedly, many experiences a disconnect between the number of social connections they desire and the number of social connections they possess (Botha et al., 2022; Ee et al., 2019; Elmose, 2020; Umagami et al., 2022). As such, Autistic people may not be afforded adequate opportunities to develop a positive sense of self, as it relates to being Autistic. Providing meaningful opportunities for Autistic people to develop connections with others through dedicated social support programmes may therefore be warranted. This could shape an individual's social identification with other Autistic people, for example through increasing their collective self-esteem (positive view of the Autistic community), sense of affiliation with other Autistic people, as well as autism community connectedness. Indeed, the proposal of peer support that assists Autistic people to positively reframe their Autistic identity has been endorsed by Autistic people in recent work (e.g., Crompton et al., 2022).

Peer support groups have been shown to foster positive identity development and improve self-esteem and community belonging among people in other minority groups, including those with disabilities, acquired injuries, and LGBTQ+ people (Borthwick et al., 2020; Davis et al., 2014; Embuldeniya et al., 2013; Johnson & Rogers, 2020; Thompson et al., 2022). Several specific mechanisms through which peer support can be effective in fostering positive identity development have been identified. For example, the act of connecting with similar others has been shown to provide validation and normalization of experiences, reducing self-stigma and shame (Embuldeniya et al., 2013; Johnson & Rogers, 2020) while the mutual exchange of support builds confidence and empowers participants to become active supports for others in their community (Johnson & Rogers, 2020; Thompson et al., 2022). In peer mentoring scenarios, mentors that demonstrate pride in their identity and model self-advocacy enable mentees to reframe their disability more positively (Embuldeniya et al., 2013). Similar peer interventions that facilitate connections with understanding peers who provide validation, model pride in their identity, and build confidence through mutual exchange may therefore aid positive autistic identity development.

Encouragingly, emerging evaluations of peer support programmes for Autistic people have yielded positive results. For example, Crane et al., (2021) evaluated a 10-week Autistic-led post-diagnostic support programme for 16 Autistic adults, and qualitative findings indicated that the programme provided attendees with a sense of belonging, and, importantly, a more positive outlook on being Autistic. Promisingly, the attendees also found "unity in diversity" and highlighted the benefits of being part of a diverse group with varied experiences, suggesting that broader support may be embraced, and even welcomed, by Autistic people (Crane et al., 2021). Emerging evidence also suggests that peer support programmes

may yield positive outcomes for Autistic youth. For example, based on their interviews with Autistic school leavers, Crompton et al. (2023) suggested that autism-specific social support may be “wanted and beneficial” (p. 85) within mainstream secondary schools.

Nonetheless, such programmes remain underfunded and limited in scope, meaning they will be inaccessible to many Autistic people (Crompton et al., 2022). Even where programmes do exist, attendees report a need for continued peer support and connection following the end of the programme, further highlighting the importance of continued external acceptance and support (Crane et al., 2021). The internet may prove a useful tool in this regard. Indeed, one of the studies in this review (Kidney, 2015) highlighted the potential for engagement with online Autistic communities to bolster identity development, while another highlighted social media, online blogs, and autism advocates as potentially useful sources of information about autism, as it relates to Autistic identity development (Bury et al., 2022). It is important to recognize, however, that not all Autistic people will desire or find comfort in such social interaction. Indeed, some Autistic people report finding solace and contentment in solitude (Hebron & Humphrey, 2014; Hwang et al., 2017). Further, some Autistic people, particularly those who have not yet come to terms with their Autistic identity, may not feel comfortable openly discussing their experiences with others (Han, Scior, Heath, et al., 2023). Yet, it is these individuals who are likely to need the most support in coming to terms with their Autistic identity. Indeed, the findings of this review suggest that those who subscribe to more negative aspects of their Autistic identity are more likely to engage in camouflaging behaviors (Botha & Frost, 2020; Perry et al., 2022). As such, the initial journey toward developing a positive Autistic identity may be best facilitated through self-directed support resources. Indeed, emerging evidence points to the potential success of self-directed learning about autism on the development of a positive Autistic identity and a recent pilot study of a self-directed disclosure decision-making programme for autistic people yielded promising results (Bury et al., 2022; Han, Scior, Umagami, et al., 2023). A comprehensive evaluation of such self-directed programmes of support is warranted.

Overall, our findings highlight the critical importance of positive Autistic identity development. Indeed, we found that positive Autistic identity was associated with higher scores on measures of self-esteem, self-concept and wellbeing, and with lower scores on measures of anxiety, depression, and stress (Cage et al., 2018, 2022; Cooper et al., 2017; Cooper, Russell, et al., 2023; Cooper et al., 2021; Corden et al., 2021; Ferenc et al., 2023; Lamash & Meyer, 2022; Maitland et al., 2021; Nguyen et al., 2020; Perry et al., 2022). This is in line with the self-esteem hypothesis within social identity theory which posits that group membership should boost psychological

well-being and reduce mental health problems through increasing self-esteem (Rubin & Hewstone, 1998). These findings are particularly concerning given that Autistic people are already considered vulnerable to poor mental health (Lai et al., 2019). As such, we assert that measures to improve feelings toward one’s identity as an Autistic person, or at least to neutralize such feelings, must be considered a high priority. While, as above, some peer support programmes have been developed and evaluated, there remains a lack of high-quality empirical assessment of the long-term impacts of such programmes on Autistic identity, beyond qualitative self-report. Further, there is limited research taking an intersectional perspective and considering multiple identities and how they relate to one another over time. Similarly, interventions that directly seek to improve Autistic identity appear to be lacking. Future work may therefore seek to extend existing evaluations by conducting longer-term evaluations, comparing Autistic identity pre- and post-intervention. Alternatively, the co-development and evaluation of new (peer or self-directed) programmes, specifically seeking to improve Autistic identity may be supported.

Limitations

Inevitably, the limitations of the studies included in this review extend to the review itself. Most notably, most of the included studies aimed to examine the experiences of “Autistic adults” yet the researchers only included very narrow samples of mostly White, highly-educated, females, without co-occurring intellectual disability. This observation is in line with existing evidence suggesting that samples recruited through social media tend not to be representative of the broader Autistic population (Rødgaard et al., 2022; Rubenstein & Furnier, 2021). It may also be the result of us not including intellectual disability as a search term in the review, as many studies that include Autistic participants with intellectual disability are subsumed within broader studies of “intellectual disability” (Blacher & Kasari, 2016; Thurm et al., 2019; see Kuld et al., 2023 for an example). It is also worth considering that people more invested in their Autistic identity may be more likely to take part in these studies than those for whom being Autistic is not a salient aspect of their identity. As such, the findings of this review are unlikely to be generalisable beyond a narrow group of Autistic people. Future research on Autistic identity must seek to be more explicit about discrepancies between the target sample and the actual sample, and take steps to improve the diversity of the participant base (Rubenstein & Furnier, 2021).

It is also noteworthy that identity was narrowly defined and measured within studies included in this review, generally based on social identity theory. These measures were commonly used as a “catch all” for identity (i.e., assuming that a higher score on the measure

equates to a more positive or stronger Autistic identity), which overlooks the multidimensional and complex nature of Autistic identity and is likely not how such measures were intended to be used. Qualitative methods are best placed to capture such complexity, and indicate that many individuals will identify both strengths and weaknesses in relation to their identity as an Autistic person, and may see autism as a personal, or social identity, or indeed neither (Wilson et al., 2023). Moreover, none of the included studies accounted for, or explored, intersectionality in relation to Autistic identity. Intersectionality refers to the multiple-stigmatized identities one can possess (e.g., Autistic and non-White; Autistic and LGBTQ+) which contributes to compounding discrimination (Crenshaw, 1989). Yet, one's intersecting identities may have important implications for the type of support they need or feel able to access. Indeed, research with parents of Autistic children from minority communities highlights a perceived need for tailored, culturally sensitive support to ensure such support adequately meets their needs (Hussein et al., 2019; Papoudi et al., 2021). Moving forward, it will be essential for future Autistic identity research to acknowledge, and explore, people's multifaceted identities, and how they interact with one another, to establish the most successful forms of support.

Finally, this review is limited in that only articles published in English were included. Although very few studies were screened out on the basis that they were not published in English, experiences and perceptions of Autistic identity are likely to be influenced by one's broader context and culture, and those from less neurodiversity-affirmative geographical regions may therefore have different experiences of Autistic identity development. This will be an important avenue for future research.

Conclusion

Our findings emphasize the critical importance of positive Autistic identity development for the mental health and wellbeing of Autistic people. Based on our findings, we suggest that research efforts in this field are directed toward three key areas. First, researchers should use theory-driven measures of different facets of Autistic identity which have been validated in the autistic community (e.g., Maitland et al., 2021). Second, researchers should specifically look to examine the impact of key individual characteristics on Autistic identity development. Although the findings of the studies included in this review regarding the impact of demographic factors were largely inconclusive, the importance of external acceptance and support in positively shaping Autistic identity was highlighted, so these could be two potential targets to focus on. Finally, we call for the development, and rigorous empirical evaluation, of targeted

interventions that aim to enhance Autistic identity as an urgent priority. To that end, peer support groups may be one useful way to improve Autistic identity. Alternatively, for those who do not feel comfortable accessing group support, self-directed support programmes may be beneficial.

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DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

ETHICS STATEMENT

This study gained ethical approval from the Research Ethics Committee at IOE, UCL's Faculty of Education and Society (REC1682).

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REFERENCES

- Adak, B., & Halder, S. (2017). Systematic review on prevalence for autism Spectrum disorder with respect to gender and socioeconomic status. *Journal of Mental Disorders and Treatment*, 03(1), 1–9. <https://doi.org/10.4172/2471-271X.1000133>
- Albarello, F., Crocetti, E., & Rubini, M. (2018). I and us: A longitudinal study on the interplay of personal and social identity in adolescence. *Journal of Youth and Adolescence*, 47(4), 689–702. <https://doi.org/10.1007/s10964-017-0791-4>
- Arnold, S., Huang, Y., Higgins, J., Hwang, Y. I., Richdale, A., Trollor, J., & Lawson, L. P. (2021). The Impact of Diagnosis Scale-Revised (IODS-R). *International Society for Autism Research 2021 Virtual Annual Meeting*.
- Arnold, S. R. C., Huang, Y., Hwang, Y. I. J., Richdale, A. L., Trollor, J. N., & Lawson, L. P. (2020). "The single Most important thing that has happened to me in my life": Development of the impact of diagnosis scale—preliminary revision. *Autism in Adulthood*, 2(1), 34–41. <https://doi.org/10.1089/aut.2019.0059>
- Asperger, H. (1944). "Autistic psychopathy" in childhood. In U. Frith (Ed.), *Autism and Asperger syndrome*. Cambridge University Press.
- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism Spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46(10), 3281–3294. <https://doi.org/10.1007/s10803-016-2872-8>
- Benham, J. L., & Kizer, J. S. (2016). Aut-ors of our experience: Interrogating intersections of autistic identity. *Canadian Journal of Disability Studies*, 5(3), 77. <https://doi.org/10.15353/cjds.v5i3.298>
- Beresford, B., Mukherjee, S., Mayhew, E., Heavey, E., Park, A.-L., Stuttard, L., Allgar, V., & Knapp, M. (2020). Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: The SHAPE mixed-methods study.

- Health Services and Delivery Research*, 8(48), 1–200. <https://doi.org/10.3310/HSDR08480>
- Blacher, J., & Kasari, C. (2016). The intersection of autism spectrum disorder and intellectual disability. *Journal of Intellectual Disability Research*, 60(5), 399–400. <https://doi.org/10.1111/jir.12294>
- Borthwick, J., Jaffey, L., & Snell, J. (2020). Exploration of Peer Support Models to Support LGBTQ+ People with their Mental Health. In Centre for Mental Health.
- Botha, M. (2020). Autistic community connectedness as a buffer against the effects of minority stress. University of Surrey.
- Botha, M., Dibb, B., & Frost, D. M. (2022). “Autism is me”: An investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, 37(3), 427–453. <https://doi.org/10.1080/09687599.2020.1822782>
- Botha, M., & Frost, D. M. (2020). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health*, 10(1), 20–34. <https://doi.org/10.1177/2156869318804297>
- Boyd Ritsher, J., Otilingam, P. G., & Grajales, M. (2003). Internalized stigma of mental illness: Psychometric properties of a new measure. *Psychiatry Research*, 121(1), 31–49. <https://doi.org/10.1016/j.psychres.2003.08.008>
- Bury, S. M., Haschek, A., Wenzel, M., Spoor, J. R., & Hedley, D. (2022). Brief report: Learning about autism: Is the source of autism knowledge associated with differences in autism knowledge, autism identity, and experiences of stigma. *Journal of Autism and Developmental Disorders*, 1–8. <https://doi.org/10.1007/s10803-022-05823-5>
- Cage, E., Cranney, R., & Botha, M. (2022). Brief report: Does autistic community connectedness moderate the relationship between masking and wellbeing? *Autism in Adulthood*, 4(3), 247–253. <https://doi.org/10.1089/AUT.2021.0096>
- Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, 48(2), 473–484. <https://doi.org/10.1007/s10803-017-3342-7>
- Cage, E., & Troxell-Whitman, Z. (2020). Understanding the relationships between autistic identity, disclosure, and camouflaging. *Autism in Adulthood*, 2(4), 334–338. <https://doi.org/10.1089/aut.2020.0016>
- Campbell, M., McKenzie, J. E., Sowden, A., Katikireddi, S. V., Brennan, S. E., Ellis, S., Hartmann-Boyce, J., Ryan, R., Shepperd, S., Thomas, J., Welch, V., & Thomson, H. (2020). Synthesis without meta-analysis (SWiM) in systematic reviews: Reporting guideline. *BMJ*, 16890, 1–6. <https://doi.org/10.1136/bmj.16890>
- Chang, C. J., Feinstein, B. A., Meanley, S., Flores, D. D., & Watson, R. J. (2021). The role of LGBTQ identity pride in the associations among discrimination, social support, and depression in a sample of LGBTQ adolescents. *Annals of LGBTQ Public and Population Health*, 2(3), 203–219. <https://doi.org/10.1891/LGBTQ-2021-0020>
- Cooper, K., Mandy, W., Butler, C., & Russell, A. (2023). Phenomenology of gender dysphoria in autism: A multiperspective qualitative analysis. *Journal of Child Psychology and Psychiatry*, 64(2), 265–276. <https://doi.org/10.1111/jcpp.13691>
- Cooper, K., Russell, A. J., Lei, J., & Smith, L. G. (2023). The impact of a positive autism identity and autistic community solidarity on social anxiety and mental health in autistic young people. *Autism*, 27(3), 848–857. <https://doi.org/10.1177/13623613221118351>
- Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, 47(7), 844–854. <https://doi.org/10.1002/ejsp.2297>
- Cooper, R., Cooper, K., Russell, A. J., & Smith, L. G. E. (2021). “I’m proud to be a little bit different”: The effects of autistic Individuals’ perceptions of autism and autism social identity on their collective self-esteem. *Journal of Autism and Developmental Disorders*, 51(2), 704–714. <https://doi.org/10.1007/s10803-020-04575-4>
- Corden, K., Brewer, R., & Cage, E. (2021). Personal identity after an autism diagnosis: Relationships with self-esteem, mental wellbeing, and diagnostic timing. *Frontiers in Psychology*, 12, 1–12. <https://doi.org/10.3389/fpsyg.2021.699335>
- Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2021). Supporting newly identified or diagnosed autistic adults: An initial evaluation of an autistic-led Programme. *Journal of Autism and Developmental Disorders*, 51(3), 892–905. <https://doi.org/10.1007/s10803-020-04486-4>
- Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine. Feminist Theory and Antiracist Politics University of Chicago Legal Forum.
- Cresswell, L., & Cage, E. (2019). ‘Who Am I?’: An exploratory study of the relationships between identity, acculturation and mental health in autistic adolescents. *Journal of Autism and Developmental Disorders*, 49(7), 2901–2912. <https://doi.org/10.1007/s10803-019-04016-x>
- Crocetti, E. (2017). Identity formation in adolescence: The dynamic of forming and consolidating identity commitments. *Child Development Perspectives*, 11(2), 145–150. <https://doi.org/10.1111/cdep.12226>
- Crompton, C. J., Hallett, S., Axbey, H., McAuliffe, C., & Cebula, K. (2023). ‘Someone like-minded in a big place’: Autistic young adults’ attitudes towards autistic peer support in mainstream education. *Autism*, 27(1), 76–91. <https://doi.org/10.1177/13623613221081189>
- Crompton, C. J., Hallett, S., McAuliffe, C., Stanfield, A. C., & Fletcher-Watson, S. (2022). A group of fellow travellers who understand: Interviews with autistic people about post-diagnostic peer support in adulthood. *Frontiers in Psychology*, 13, 76–91. <https://doi.org/10.3389/fpsyg.2022.831628>
- Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). ‘I never realised everybody felt as happy as I do when I am around autistic people’: A thematic analysis of autistic adults’ relationships with autistic and neurotypical friends and family. *Autism*, 24(6), 1438–1448. <https://doi.org/10.1177/1362361320908976>
- Darling, R. B., & Heckert, D. A. (2010). Orientations toward disability: Differences over the lifecourse. *International Journal of Disability, Development and Education*, 57(2), 131–143. <https://doi.org/10.1080/10349121003750489>
- Davis, T., Gorgens, K., Shriberg, J., Godleski, M., & Meyer, L. (2014). Making meaning in a burn peer support group. *Journal of Burn Care & Research*, 35(5), 416–425. <https://doi.org/10.1097/BCR.000000000000011>
- Ee, D., Hwang, Y. I. J., Reppermund, S., Srasuekul, P., Trollor, J. N., Foley, K.-R., & Arnold, S. R. C. (2019). Loneliness in adults on the autism spectrum. *Autism in Adulthood*, 1(3), 182–193. <https://doi.org/10.1089/aut.2018.0038>
- Elmose, M. (2020). Understanding loneliness and social relationships in autism: The reflections of autistic adults. *Nordic Psychology*, 72(1), 3–22. <https://doi.org/10.1080/19012276.2019.1625068>
- Embudenya, G., Veinot, P., Bell, E., Bell, M., Nyhof-Young, J., Sale, J. E. M., & Britten, N. (2013). The experience and impact of chronic disease peer support interventions: A qualitative synthesis. *Patient Education and Counseling*, 92(1), 3–12. <https://doi.org/10.1016/j.pec.2013.02.002>
- Erikson, E. H. (1950). *Childhood and society* (1st ed.). Norton & Company.
- Erikson, E. H. (1968). *Identity: Youth and crisis* (7th ed.). Norton & Company.
- Evers, A. W. M., Kraaimaat, F. W., van Lankveld, W., Jongen, P. J. H., Jacobs, J. W. G., & Bijlsma, J. W. J. (2001). Beyond unfavorable thinking: The illness cognition questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology*, 69(6), 1026–1036. <https://doi.org/10.1037/0022-006X.69.6.1026>
- Ferenc, K., Platos, M., Byrka, K., & Król, M. E. (2023). Looking through rainbow-rimmed glasses: Taking neurodiversity

- perspective is related to subjective well-being of autistic adults. *Autism*, 27(5), 1348–1361. <https://doi.org/10.1177/13623613221135818>
- Gill, C. J. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation*, 9(1), 39–46. <https://doi.org/10.3233/JVR-1997-9106>
- Hammer, J. H., & Toland, M. D. (2017). Internal structure and reliability of the internalized stigma of mental illness scale (ISMI-29) and brief versions (ISMI-10, ISMI-9) among Americans with depression. *Stigma and Health*, 2(3), 159–174. <https://doi.org/10.1037/sah0000049>
- Han, E., Scior, K., Heath, E., Umagami, K., & Crane, L. (2023). Development of stigma-related support for autistic adults: Insights from the autism community. *Autism*, 136236132211435, 1676–1689. <https://doi.org/10.1177/13623613221143590>
- Han, E., Scior, K., Umagami, K., Heath, E. L., Dufresne, S., & Crane, L. (2023). Who, When, How to Share: Pilot study of a new disclosure decision-making programme for autistic adults. <https://doi.org/10.31219/osf.io/bz2tq>
- Harmens, M., Sedgewick, F., & Hobson, H. (2022). Autistic women's diagnostic experiences: Interactions with identity and impacts on well-being. *Women's Health*, 18, 1–11.
- Hebron, J., & Humphrey, N. (2014). Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: A comparative study. *Journal of Research in Special Educational Needs*, 14(1), 22–32. <https://doi.org/10.1111/j.1471-3802.2012.01246.x>
- Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., O' Cathain, A., Rousseau, M.-C., Vedel, I., & Pluye, P. (2018). The mixed methods appraisal tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, 34(4), 285–291. <https://doi.org/10.3233/EFI-180221>
- Huang, Y., Arnold, S. R., Foley, K.-R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: A scoping review. *Autism*, 24(6), 1311–1327. <https://doi.org/10.1177/1362361320903128>
- Huang, Y., Trollor, J. N., Foley, K.-R., & Arnold, S. R. C. (2023). "I've spent my whole life striving to be normal": Internalized stigma and perceived impact of diagnosis in autistic adults. *Autism in Adulthood*, 5, 423–436. <https://doi.org/10.1089/aut.2022.0066>
- Humphrey, N., & Lewis, S. (2008). Make me normal. *Autism*, 12(1), 23–46. <https://doi.org/10.1177/1362361307085267>
- Hussein, A. M., Pellicano, E., & Crane, L. (2019). Understanding and awareness of autism among Somali parents living in the United Kingdom. *Autism*, 23(6), 1408–1418. <https://doi.org/10.1177/1362361318813996>
- Hwang, Y. I. J., Foley, K.-R., & Trollor, J. N. (2017). Aging well on the autism spectrum: The perspectives of autistic adults and carers. *International Psychogeriatrics*, 29(12), 2033–2046. <https://doi.org/10.1017/S1041610217001521>
- Johnson, A. H., & Rogers, B. A. (2020). "We're the normal ones here": Community involvement, peer support, and transgender mental health. *Sociological Inquiry*, 90(2), 271–292. <https://doi.org/10.1111/soin.12347>
- Jones, J. L., Gallus, K. L., Viering, K. L., & Oseland, L. M. (2015). "Are you by chance on the spectrum?" Adolescents with autism spectrum disorder making sense of their diagnoses. *Disability & Society*, 30(10), 1490–1504. <https://doi.org/10.1080/09687599.2015.1108902>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Pathology*, 2(3), 217–250.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462. <https://doi.org/10.1177/1362361315588200>
- Kentrou, V., de Veld, D. M., Mataw, K. J., & Begeer, S. (2019). Delayed autism spectrum disorder recognition in children and adolescents previously diagnosed with attention-deficit/hyperactivity disorder. *Autism*, 23(4), 1065–1072. <https://doi.org/10.1177/1362361318785171>
- Kidney, C. A. (2015). Rethinking Autism, Communication, and Community Involvement: Exploring Involvement in Online Communities, Communication Preference, Autistic Identity, and Self-Determination. Portland State University.
- Kuld, P. B., Frielink, N., Zijlmans, M., Schuengel, C., & Embregts, P. J. C. M. (2023). Promoting self-determination of persons with severe or profound intellectual disabilities: A systematic review and meta-analysis. *Journal of Intellectual Disability Research*, 67(7), 589–629. <https://doi.org/10.1111/jir.13036>
- Lai, M. C., Kasse, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry*, 6(10), 819–829. [https://doi.org/10.1016/S2215-0366\(19\)30289-5](https://doi.org/10.1016/S2215-0366(19)30289-5)
- Lamash, L., & Meyer, S. (2022). Work-related self-efficacy and illness identity in adults with autism. *International Journal of Environmental Research and Public Health*, 20(1), 122. <https://doi.org/10.3390/ijerph20010122>
- Leach, C. W., van Zomeren, M., Zebel, S., Vliek, M. L. W., Pennekamp, S. F., Doosje, B., Ouwerkerk, J. W., & Spears, R. (2008). Group-level self-definition and self-investment: A hierarchical (multicomponent) model of in-group identification. *Journal of Personality and Social Psychology*, 95(1), 144–165. <https://doi.org/10.1037/0022-3514.95.1.144>
- Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). "I was exhausted trying to figure it out": The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, 24(1), 135–146. <https://doi.org/10.1177/1362361319853442>
- Leung, F. Y., Shah, P., Mason, D., & Livingston, L. A. (2023). Re-examining the association between the age of learning one is autistic and adult outcomes. *Autism*, 1–16. <https://doi.org/10.1177/13623613231173056>
- Lewis, L. F. (2016). Exploring the experience of self-diagnosis of autism spectrum disorder in adults. *Archives of Psychiatric Nursing*, 30(5), 575–580. <https://doi.org/10.1016/j.apnu.2016.03.009>
- Lewis, L. F. (2017). A mixed methods study of barriers to formal diagnosis of autism spectrum disorder in adults. *Journal of Autism and Developmental Disorders*, 47(8), 2410–2424. <https://doi.org/10.1007/s10803-017-3168-3>
- Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., Arnold, S., Trollor, J., Yudell, M., & Pellicano, E. (2022). "Peas in a pod": Oral history reflections on autistic identity in family and community by late-diagnosed adults. *Journal of Autism and Developmental Disorders*, 53(3), 1146–1161. <https://doi.org/10.1007/s10803-022-05667-Z>
- Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., Arnold, S. R. C., Trollor, J. N., Yudell, M., & Pellicano, E. (2021). "A way to be me": Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. *Autism*, 26(6), 1395–1408. <https://doi.org/10.1177/13623613211050694>
- Luhtanen, R., & Crocker, J. (1992). A collective self-esteem scale: Self-evaluation of one's social identity. *Personality and Social Psychology Bulletin*, 18(3), 302–318. <https://doi.org/10.1177/0146167292183006>
- Maitland, C. A., Rhodes, S., O'Hare, A., & Stewart, M. E. (2021). Social identities and mental well-being in autistic adults. *Autism*, 25(6), 1771–1783. <https://doi.org/10.1177/13623613211004328>
- Mandell, D. S., Listerud, J., Levy, S. U. S. A. N. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41(12), 1447–1453. <https://doi.org/10.1097/00004583-200212000-00016>
- Marcia, J. E. (1966). Development and validation of ego-identity status. *Journal of Personality and Social Psychology*, 3(5), 551–558. <https://doi.org/10.1037/h0023281>

- Marcia, J. E., Waterman, A. S., Matteson, D. R., Archer, S. L., & Orlofsky, J. L. (1993). *Ego identity: A Handbook for Psychosocial Research*. Springer Verlag.
- Maxwell-McCaw, D., & Zea, M. C. (2011). The deaf acculturation scale (DAS): Development and validation of a 58-item measure. *Journal of Deaf Studies and Deaf Education*, 16(3), 325–342. <https://doi.org/10.1093/deafed/enq061>
- McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the validity of a quality of life measure for autistic people. *Journal of Autism and Developmental Disorders*, 48(5), 1596–1611. <https://doi.org/10.1007/s10803-017-3402-z>
- McDonald, K. (2018). Social support and mental health in LGBTQ adolescents: A review of the literature. *Issues in Mental Health Nursing*, 39(1), 16–29. <https://doi.org/10.1080/01612840.2017.1398283>
- McDonald, T. A. M. (2016). Identity as a Mediator between Stigma and Stereotype Threat on Postsecondary Outcomes for Adults on the Autism Spectrum. University of Wisconsin-Madison.
- McDonald, T. A. M. (2020). Autism identity and the “lost generation”: Structural validation of the autism Spectrum identity scale and comparison of diagnosed and self-diagnosed adults on the autism Spectrum. *Autism in Adulthood*, 2(1), 13–23. <https://doi.org/10.1089/aut.2019.0069>
- Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, 129(5), 674–697. <https://doi.org/10.1037/0033-2909.129.5.674>
- Meyer, I. H., & Dean, L. (1998). Internalized homophobia, intimacy, and sexual behavior among gay and bisexual men. In G. M. Herek (Ed.), *Stigma and sexual orientation: Understanding prejudice against lesbians, gay men, and bisexuals* (Vol. 4). SAGE Publications.
- Mogensen, L., & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder. *Children, Health and Well-Being: Policy Debates and Lived Experience*, 37, 83–97. <https://doi.org/10.1002/9781119069522.CH7>
- Moseley, R. L., Druce, T., & Turner-Cobb, J. M. (2021). Autism research is ‘all about the blokes and the kids’: Autistic women breaking the silence on menopause. *British Journal of Health Psychology*, 26(3), 709–726. <https://doi.org/10.1111/bjhp.12477>
- Nario-Redmond, M. R., Noel, J. G., & Fern, E. (2013). Redefining disability, Re-imagining the self: Disability identification predicts self-esteem and strategic responses to stigma. *Self and Identity*, 12(5), 468–488. <https://doi.org/10.1080/15298868.2012.681118>
- Nario-Redmond, M. R., & Oleson, K. C. (2016). Disability group identification and disability-rights advocacy. *Emerging Adulthood*, 4(3), 207–218. <https://doi.org/10.1177/2167696815579830>
- Ne’eman, A., & Pellicano, E. (2022). Neurodiversity as politics. *Human Development*, 66(2), 149–157. <https://doi.org/10.1159/000524277>
- Nguyen, W., Ownsworth, T., Nicol, C., & Zimmerman, D. (2020). How I see and feel about myself: Domain-specific self-concept and self-esteem in autistic adults. *Frontiers in Psychology*, 11, 1–12. <https://doi.org/10.3389/fpsyg.2020.00913>
- Oredipe, T., Kofner, B., Riccio, A., Cage, E., Vincent, J., Kapp, S. K., Dwyer, P., & Gillespie-Lynch, K. (2023). Does learning you are autistic at a younger age lead to better adult outcomes? A participatory exploration of the perspectives of autistic university students. *Autism*, 27(1), 200–212. <https://doi.org/10.1177/13623613221086700>
- Oris, L., Rassart, J., Prikken, S., Verschuere, M., Goubert, L., Moons, P., Berg, C. A., Weets, I., & Luyckx, K. (2016). Illness identity in adolescents and emerging adults with type 1 diabetes: Introducing the illness identity questionnaire. *Diabetes Care*, 39(5), 757–763. <https://doi.org/10.2337/dc15-2559>
- Ousley, O., & Cermak, T. (2014). Autism spectrum disorder: Defining dimensions and subgroups. *Current Developmental Disorders Reports*, 1(1), 20–28. <https://doi.org/10.1007/s40474-013-0003-1>
- Overton, G. L., Marsà-Sambola, F., Martin, R., & Cavenagh, P. (2023). Understanding the self-identification of autism in adults: A scoping review. *Review Journal of Autism and Developmental Disorders*, 1–21. <https://doi.org/10.1007/s40489-023-00361-x>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *International Journal of Surgery*, 88, 105906. <https://doi.org/10.1016/j.ijsu.2021.105906>
- Papoudi, D., Jørgensen, C. R., Guldberg, K., & Meadan, H. (2021). Perceptions, experiences, and needs of parents of culturally and linguistically diverse children with autism: A scoping review. *Review Journal of Autism and Developmental Disorders*, 8(2), 195–212. <https://doi.org/10.1007/s40489-020-00210-1>
- Pellicano, E., & Houting, J. (2022). Annual research review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381–396. <https://doi.org/10.1111/jcpp.13534>
- Perry, E., Mandy, W., Hull, L., & Cage, E. (2022). Understanding camouflaging as a response to autism-related stigma: A social identity theory approach. *Journal of Autism and Developmental Disorders*, 52(2), 800–810. <https://doi.org/10.1007/s10803-021-04987-w>
- Punshon, C., Skirrow, P., & Murphy, G. (2009). The not guilty verdict. *Autism*, 13(3), 265–283. <https://doi.org/10.1177/1362361309103795>
- Ratto, A. B., Reznick, J. S., & Turner-Brown, L. (2016). Cultural effects on the diagnosis of autism spectrum disorder among Latinos. *Focus on Autism and Other Developmental Disabilities*, 31(4), 275–283. <https://doi.org/10.1177/1088357615587501>
- Riccio, A., Kapp, S. K., Jordan, A., Dorelien, A. M., & Gillespie-Lynch, K. (2021). How is autistic identity in adolescence influenced by parental disclosure decisions and perceptions of autism? *Autism*, 25(2), 374–388. <https://doi.org/10.1177/1362361320958214>
- Rødgaard, E., Jensen, K., Miskowiak, K. W., & Mottron, L. (2022). Representativeness of autistic samples in studies recruiting through social media. *Autism Research*, 15(8), 1447–1456. <https://doi.org/10.1002/aur.2777>
- Rubenstein, E., & Furnier, S. (2021). #Bias: The opportunities and challenges of surveys that recruit and collect data of autistic adults online. *Autism in Adulthood*, 3(2), 120–128. <https://doi.org/10.1089/aut.2020.0031>
- Rubin, M., & Hewstone, M. (1998). Social identity Theory’s self-esteem hypothesis: A review and some suggestions for clarification. *Personality and Social Psychology Review*, 2(1), 40–62. https://doi.org/10.1207/s15327957pspr0201_3
- Ruiz Calzada, L., Pistrang, N., & Mandy, W. P. L. (2012). High-functioning autism and Asperger’s disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders*, 42(2), 230–243. <https://doi.org/10.1007/s10803-011-1238-5>
- Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T., & Ford, T. (2019). Selection bias on intellectual ability in autism research: A cross-sectional review and meta-analysis. *Molecular Autism*, 10(1), 9. <https://doi.org/10.1186/s13229-019-0260-x>
- Schmengler, H., Cohen, D., Tordjman, S., & Melchior, M. (2021). Autism spectrum and other neurodevelopmental disorders in children of immigrants: A brief review of current evidence and implications for clinical practice. *Frontiers in Psychiatry*, 12, 1–12. <https://doi.org/10.3389/fpsyg.2021.566368>
- Snapp, S. D., Watson, R. J., Russell, S. T., Diaz, R. M., & Ryan, C. (2015). Social support networks for LGBT young adults: Low cost strategies for positive adjustment. *Family Relations*, 64(3), 420–430. <https://doi.org/10.1111/fare.12124>
- Tajfel, H., & Turner, J. (1979). An integrative theory of intergroup conflict. In M. J. Hatch & M. Schultz (Eds.), *Organizational Identity: A Reader* (pp. 56–65). Oxford University Press.

- Tan, C. D. (2018). "I'm a normal autistic person, not an abnormal neurotypical": Autism spectrum disorder diagnosis as biographical illumination. *Social Science & Medicine*, 197, 161–167. <https://doi.org/10.1016/j.socscimed.2017.12.008>
- Thompson, D. M., Booth, L., Moore, D., & Mathers, J. (2022). Peer support for people with chronic conditions: A systematic review of reviews. *BMC Health Services Research*, 22(1), 427. <https://doi.org/10.1186/s12913-022-07816-7>
- Thurm, A., Farmer, C., Salzman, E., Lord, C., & Bishop, S. (2019). State of the field: Differentiating intellectual disability from autism spectrum disorder. *Frontiers in Psychiatry*, 10, 1–10. <https://doi.org/10.3389/fpsy.2019.00526>
- Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G. L., & Brugha, T. (2021). Autism identification across Ethnic groups: A narrative review. *Advances in Autism*, 7(3), 241–255. <https://doi.org/10.1108/AIA-03-2020-0017>
- Umagami, K., Remington, A., Lloyd-Evans, B., Davies, J., & Crane, L. (2022). Loneliness in autistic adults: A systematic review. *Autism*, 26(8), 2117–2135. <https://doi.org/10.1177/13623613221077721>
- Walker, N. (2014). Neurodiversity: Some basic terms & definitions. *Neuroqueer* <https://Neuroqueer.Com/Neurodiversity-Terms-and-Definitions>
- Weiler, L. M., Goerdt, A. K., Kremer, K. B., Goldberg, E., & Hudock, R. L. (2022). Social validity and preliminary outcomes of a mentoring intervention for adolescents and adults with autism. *Focus on Autism and Other Developmental Disabilities*, 37(4), 215–226. <https://doi.org/10.1177/10883576211073687>
- Wiggins, L. D., Durkin, M., Esler, A., Lee, L., Zahorodny, W., Rice, C., Yeargin-Allsopp, M., Dowling, N. F., Hall-Lande, J., Morrier, M. J., Christensen, D., Shenouda, J., & Baio, J. (2020). Disparities in documented diagnoses of autism spectrum disorder based on demographic, individual, and service factors. *Autism Research*, 13(3), 464–473. <https://doi.org/10.1002/aur.2255>
- Wilson, R. B., Thompson, A. R., Rowse, G., & Freeth, M. (2023). The experience of seeking, receiving, and reflecting upon a diagnosis of autism in the UK: A meta-synthesis of qualitative studies conducted with autistic individuals. *Research in Autism Spectrum Disorders*, 103, 102135. <https://doi.org/10.1016/j.rasd.2023.102135>
- Zeldovich, L. (2018). How History Forgot the Woman Who Defined Autism-Scientific American. <https://www.scientificamerican.com/article/how-history-forgot-the-woman-who-defined-autism/>

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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