Does Learning You Are Autistic at a Younger Age Lead to Better Adult Outcomes?

A Participatory Exploration of the Perspectives of Autistic University Students

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Abstract

Many autistic people do not learn they are autistic until adulthood. Parents may wait to tell a child they are autistic until they feel the child is "ready." In this study, a participatory team of autistic and non-autistic researchers examined if learning one is autistic at a younger age is associated with heightened well-being and Autism-Specific Quality of Life (ASQoL) among autistic university students. Autistic students ($n = 78$) completed an online survey. They shared when and how they learned they were autistic, how they felt about autism when first learning they are autistic and now, and when they would tell autistic children about their autism. Learning one is autistic *earlier* was associated with *heightened Quality of Life and well-being* in adulthood. However, learning one is autistic at an *older* age was associated with *more positive emotions about autism* when first learning one is autistic. Participants expressed both positive and negative emotions about autism and highlighted contextual factors to consider when telling a child about autism. Findings suggest that telling a child that they are autistic at a younger age empowers them by providing access to support and a foundation for self-understanding that helps them thrive in adulthood.

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Autistic university students often exhibit academic strengths relative to their non-autistic peers, however, they may also face mental health challenges (e.g., Fernandes et al., 2021; Sturm & Kasari, 2019). Consequently, identifying factors that support the well-being of autistic students has been identified as a priority (Gunin et al., 2021). The current study aims to determine if learning one is autistic at a younger age is associated with higher well-being and Quality of Life among autistic university students.

Why Might Learning One is Autistic Earlier Lead to Better Outcomes?

To the best of our knowledge, no prior study has directly investigated if *learning* one is autistic at a younger age is associated with better adult outcomes. Receiving autism-related support earlier is often associated with better outcomes (Towle et al., 2020). Timely identification as autistic is a first step toward obtaining support (Isawa et al., 2019; Mazurek et al., 2019). However, many autistic people, particularly females, ethnic/racial minorities, and people with limited resources, are diagnosed years after characteristics are first noticed (Durkin et al., 2017; McDonnell et al., 2020). Indeed, many autistic people do not receive their diagnosis until adulthood (Fusar-Poli et al., 2020). Parents may also wait to tell a child that they are autistic until they feel the child is "ready," leading some autistic people to learn they are autistic years after their diagnosis (Huws & Jones, 2008; Smith et al., 2018).

A shorter delay between seeking and obtaining a diagnosis was associated with heightened satisfaction with the diagnostic process among autistic adults (Jones et al., 2014). The quality of information and support obtained also impacted satisfaction. Parents also report more

satisfaction with the diagnostic process when their child is diagnosed earlier (McCrimmon & Gray, 2020). Unlike diagnoses in childhood, adult diagnoses rarely provide clear pathways to formal support (Huang et al., 2020). Indeed, 41.9% of participants in Jones and colleagues' study received no post-diagnostic support. Nevertheless, growing evidence suggests that support from autistic peers often helps autistic people make sense of their diagnosis (Crane et al., 2020; Hickey et al., 2018; Tan, 2018).

Research examining the experience of receiving an autism diagnosis as an adult indicates that this experience often has a strong and complex emotional impact (Huang et al., 2020). By providing a framework to interpret experiences, an autism diagnosis can confer self-understanding, self-compassion, and coping strategies (Arnold et al., 2020; Hickey et al., 2018; Huws & Jones, 2008; Leedham et al., 2020; Punshon et al., 2009; Tan et al., 2018). While many people diagnosed as adults interpret autism as a positive difference, others view their diagnosis as unpleasant and stigmatizing (Huws & Jones, 2008; Powell & Acker, 2016).

When asked to indicate how they felt upon first receiving their autism diagnosis, participants in Jones and colleagues' (2014) study most frequently selected relief. Relief is a particularly common emotional response to receiving an autism diagnosis in adulthood (Arnold et al., 2020; Johnson & Joshi, 2016; Jones, 2001; Powell & Acker, 2016). However, those who receive an autism diagnosis in adulthood also report difficulty adjusting to their new identity, increased susceptibility to discrimination, and feelings of low self-worth (Stagg & Belcher, 2019). People who learn they are autistic as adults also report grief for the struggles of their pre-diagnosis self and sorrow that they blamed themselves for difficulties before understanding that they were autistic (Leedham et al., 2020). A qualitative study of autistic students at a college for people with disabilities noted that four of the nine participants were not told they were autistic

until years after their diagnosis (Huws & Jones, 2008). Emotional reactions were complex and included relief, shock and/or disappointment.

Huang et al. (2020) noted that autistic people diagnosed in adulthood often wished they had been diagnosed earlier, but only one prior study directly has compared the outcomes of autistic people diagnosed in adulthood to those diagnosed in childhood: Marriage et al. (2009) used a chart review process to compare the adult outcomes of 45 autistic people diagnosed before age 18 to 35 autistic people diagnosed as adults. Interpretation of findings is complicated by pronounced age differences between participants diagnosed in childhood vs. adulthood and the fact that analyses were based on sub-groups of as few as four participants. However, Marriage and colleagues' findings suggest that autistic people diagnosed in adulthood may have better educational outcomes but be more prone to depression than those diagnosed in childhood. Similarly, a study of work-related discrimination and well-being revealed that being diagnosed later was associated with higher educational levels but less organizational support among 193 autistic survey respondents, all of whom were employed (Johnson & Joshi, 2016). Being diagnosed later was associated with heightened workplace discrimination (this association only became apparent after sociodemographic factors were accounted for) but was *not* associated with work-related well-being or anxiety. The researchers did not ask participants when they *learned* they were autistic.

People who learn they are autistic later in life face many barriers that could lead to discrimination and/or mental health difficulties, including years of not understanding why they are different and potentially trying to hide their differences and having their lived experiences overlooked and/or invalidated by medical professionals (Crane et al., 2018; Hickey et al., 2018; Leedham et al., 2020). Camouflaging, or hiding one's autistic characteristics, may negatively

impact mental health (Botha & Frost, 2020; Cage & Troxell-Whitman, 2019; Cassidy et al., 2020). Prior research provides a foundation for our hypothesis that learning one is autistic at a younger age may foster positive adult outcomes.

Disclosure: A double-edged sword?

A primary benefit of learning one is autistic is the opportunity to connect with other autistic people (Hickey et al., 2018; Tan, 2018). Autistic people may feel more comfortable expressing themselves around other autistic people (Crompton et al., 2020). However, autistic university students do not always feel connected to an autistic community and may avoid participating in groups that require disclosing a diagnosis due to fear of discrimination (Frost et al., 2019). Many autistic students delay identifying themselves as autistic to accessibility offices; such students report reduced satisfaction with the university experience and fewer supports (Anderson et al., 2018). Unfortunately, concerns about disclosure may in many cases be warranted. While research examining impacts of disclosing an autism diagnosis on non-autistic people typically suggests that disclosure is beneficial (e.g., Austin et al., 2018; Gillespie-Lynch et al., 2019), autistic people and their family members express substantially more concerns about the unpredictable consequences of disclosure than non-autistic people (Thompson-Hodgetts et al., 2020). Given the complexities of disclosure, some parents may feel unsure when or how to talk about autism with their autistic children and may wait to disclose their child's autism diagnosis to their child until later in life.

A review of research examining parents' and/or children's viewpoints about the process of disclosing a child's autism diagnosis to a child identified very few studies (Smith et al., 2018). Delays between diagnosis and disclosure were noted across all of the studies. No studies examined whether the timing of disclosure impacted well-being. However, other research

suggests that learning about one's differences at a younger age may foster well-being; youth who were told that they were conceived by reproductive donation by the time they were seven reported heightened well-being and better family relationships than those informed later (Iloi et al., 2017).

Since Smith et al.'s (2018) review, additional research examined autistic and non-autistic parents' viewpoints about talking with their autistic child about autism (Crane et al., 2019; 2021), compared experiences of parents who had or had not yet disclosed their child's autism to their child (Smith-Demers, 2018) and examined associations between mothers' decisions about whether to talk about autism with their teenagers' self-perceptions (Riccio et al., 2020a). Parents expressed difficulty processing their child's diagnosis and concerns that their child would not understand the diagnosis, or that the diagnosis could confer stigma, lower expectations for their child, and/or harm their child's self-image and mental health (Cadogan, 2015; Crane et al., 2019; Finnegan et al., 2014; Riccio et al., 2020a; Smith-Demers, 2018; Ward, 2014). While most parents who had not yet talked about the diagnosis with their child planned to do so in the future, some did not plan to ever discuss autism with their children. Parents indicated that sharing a diagnosis with a child is a complex, context-dependent, and ongoing process that is often unplanned (e.g., sometimes initiated by the child) and is influenced by both parents' and children's feelings and evolving understandings. Similar complexities have been reported by parents of children with other conditions (Dennis et al., 2015; Gallo et al., 2015; Gratton et al., 2016).

Both autistic and non-autistic parents indicate that talking openly with their children about autism promotes self-understanding and collaborative development of coping strategies (Crane et al., 2019; 2021; Smith et al., 2018). They recommend that the process of disclosure be

tailored to each child, emphasizing the importance of gradually presenting information in a way their children can understand that builds from their strengths and interests. Unlike non-autistic parents, 34 autistic parents in a recent online study did *not* focus on potential negative impacts of disclosure (Crane et al., 2021). They indicated that their lived expertise gave them shared understanding with their autistic children, contrasting the often humorous, everyday discussions in which they talked about autism with their children with the more deficit-oriented approaches used by professionals. They recommended telling a child they are autistic as soon as possible, emphasizing that honesty promotes mental health and self-understanding.

Autistic college students have also reported that learning they are autistic helped them understand themselves (Huws & Jones, 2008). Autistic adolescents whose parents talked to them openly about being autistic tended to describe themselves and autism more positively than peers whose parents had not voluntarily told them they were autistic (Riccio et al., 2020a). Anecdotal accounts suggest that people who learn they are autistic as children may regard their autism as a positive or neutral aspect of themselves (Mogensen & Mason, 2015), or understand themselves through a neurodiversity-aligned lens where autism is considered a valuable form of human diversity (Singer, 2016). People who are told they are autistic years after their diagnosis may perceive autism as something shameful that should be hidden because their parents hid it from them. However, some autistic people learn they are autistic and come to appreciate autism as an important part of their identities even though their parents never discuss autism with them (e.g., Daley & Weisner, 2003), as is often the case for people diagnosed in adulthood.

Research Aims and Hypotheses

The present study is the first, to our knowledge, to examine if the age at which one learns one is autistic impacts the well-being, Quality of Life, and feelings about autism of autistic

university students. Two university students (one autistic and one non-autistic) collaboratively developed the following hypotheses:

Hypothesis 1: Learning one is autistic at a younger age will be associated with heightened well-being and Quality of Life among autistic students.

Hypothesis 2: Learning one is autistic at a younger age will be associated with more positive perspectives on autism in adulthood.

Methods

Community Involvement

This research was conducted by a participatory group of autistic and non-autistic researchers, including the authors of this paper and a larger group that collaborated more distally. Collaborators included leaders within a participatory mentorship program for autistic and non-autistic university students and members of the College Autism Network (CAN), an online community of individuals dedicated to advocacy and research about autistic university students. Co-authors include three autistic group members (one academic, one graduate student, and one then-undergraduate and current graduate student) and five non-autistic group members (one then undergraduate, one then-doctoral student, who led survey development and recruitment as part of her dissertation research, and three academics).

Autistic and non-autistic co-authors collaboratively developed and revised study measures and hypotheses by co-writing a Google document. We began developing measures in April 2018 and continued revising until recruitment began in February 2019. Most revisions occurred via edits and/or comments in the Google document. However, a core group of collaborators, leaders in the mentorship program, discussed research questions, hypotheses, and measures during meetings which occurred in-person or virtually (depending on location and/or

preference) via Skype using speech or chat as preferred. Guided by AASPIRE's guidelines (Nicolaidis et al., 2019), we strove to use flexible modalities, to provide sufficient processing time, to encourage transparency and power sharing, and to disseminate findings collaboratively. The survey was posted on the Open Science Framework before recruitment began. However, the hypotheses described in this report were developed by the first two authors with guidance from the last author after data collection was complete but before viewing the data.

Participants

Research activities were approved by our Institutional Review Board. Collaborators recruited autistic students at their universities or through social media. Interested participants contacted the third author via email and received a link to participate in an online survey hosted by Qualtrics. Students enrolled in any institution of higher education were eligible to participate. Student status was confirmed by contacting the research team using an institutional email address.

A total of 84 students completed the survey. Most participants self-reported an autism diagnosis by a clinician ($n = 81$). In response to reviewer feedback, three participants who identified as autistic without a formal diagnosis and three participants who could not remember when they learned they were autistic were excluded from analyses. These exclusions did not change the pattern of findings.

The final sample of 78 autistic students represented 8 countries (n=53 from the United States, 16 from the United Kingdom; 3 from Canada, 2 from Germany, and 1 each from Australia, Hungary, Norway, and South Africa) and 50 institutions, including community colleges, private, and public universities which varied from not selective to highly selective.

Participants' ages ranged from 18 to 50 (*M*= 24.15; *SD*= 7.20). Participants reported

mean RAADS-14 scores of 27.73 (*SD* = 9.19); 5 participants reported RAADS-14 scores below

the cut-off for probable autism of 14. See Table 1 for other characteristics. Participants received

a $20 gift card.

Measures

Quality of Life. Autism-Specific Quality of Life was assessed using the ASQoL

(McConachie et al., 2018). ASQoL development was guided by feedback from autistic adults in

the UK about ways that existing QoL measures may overlook autism-specific aspects of QoL.

Evidence of its reliability and validity was obtained in the initial validity study (McConachie et

al., 2018). However, a more recent evaluation of the measure reveals that it underestimates the

QoL of autistic women (Williams & Gotham, 2021). Nine items (three reverse-scored), assessing

formal and informal supports, sensory and financial barriers, and comfortableness being and

expressing oneself, e.g., "Are you at ease (OK) with 'Autism' as an aspect of your identity?",

were rated using a 5-point scale ('not at all' to 'totally'; α=.85). ASQoL scores can range from 9

to 45. The ASQoL was not designed to be a stand-alone measure (Rodgers, 2021). Therefore,

we also included a global item from the WHO QoL-Bref (1998), "How would you rate your

Quality of Life?", with five response options ranging from very poor to very good. For both

measures, higher scores indicate heightened QoL.

RAADS-14. The Ritvo Autism and Asperger Diagnostic Scale (RAADS-14; Eriksson et

al., 2013) is a self-report autism screener (α=.85). Participants rated whether they experienced

each of 14 survey items (one reverse-scored), e.g., "I focus on details rather than the overall

idea.", always, only at their present age, only when younger than 16, or never. Scores can range

from 0 to 42. Higher scores indicate heightened autistic traits. A cut-off score of 14 or higher on

the RAADS-14 had high sensitivity (97%) but variable specificity (46% ASD relative to ADHD; 95% ASD vs. non-psychiatric controls) in identifying autism in a validation study in Sweden (Eriksson et al., 2013). Of the 135 autistic participants in the validation study, 9 scored below the cut-off for likely autism of 14. We included this measure to determine what proportion of our sample would be classified as likely to be autistic using a commonly used autism screener and to have a brief measure of autistic traits, given evidence that higher autistic traits are often related to lower well-being (e.g., Scheeren et al., 2021). The RAADS-14 typically exhibits satisfactory psychometric properties and includes a focus on sensory differences, which is often lacking in autistic trait measures (Baghdadli et al., 2017; Riccio et al., 2020b).

Well-Being. The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS; Tennant et al., 2007) consists of 14 items (none reverse-scored) assessing positive affect, functioning, and interpersonal relationships, e.g., "I've been feeling loved." Items are rated using a 5-point scale ('none of the time' to 'all of the time'; α=.91). WEMWBS development was guided by community feedback on an existing well-being measure. Validation testing in the UK revealed evidence of the WEMWBS's reliability and validity (Tennant et al., 2007). Scores can range from 14 to 70. Higher scores indicate more well-being.

Open-ended questions.

Participants were asked the following open-ended questions: "How old were you in years when you first learned you were autistic?" "How did you learn you were autistic?" "How did you feel when you learned you were autistic? Please share what you feel comfortable sharing." How do you feel about being autistic now? Please share what you feel comfortable sharing." "If you had a child with autism, when would you tell them about autism?" "If you had a child with autism, what would you tell them about autism?"

Data Analysis Approach

We used content analysis to code open-ended responses (Hsieh and Shannon, 2005; Kondracki et al., 2002). Content analysis is a broad approach to deriving meaning that varies along two primary spectrums: manifest (or apparent on the surface) to latent (deeper implied meanings) themes and inductive (data-driven) to deductive (theory-driven). We focused on manifest meanings. A few codes were developed deductively. For example, the code "positive emotions about autism" was developed to address an a priori hypothesis. However, most codes were developed inductively through an independent review of the data by the first two co-authors. For example, recurring patterns in the data sparked sub-codes of the major code "positive feelings about autism", including "curiosity to learn more about autism" and "better understanding of why they are different". The first author (a non-autistic student) and the second author (an autistic student) developed the coding schemes with guidance from the last author and feedback from co-authors. They achieved $\geqq 80\%$ agreement on at least 20% of responses in each category. See Appendix A for coding schemes. To learn from participants' insights, we reviewed their open-ended responses about how they learned they were autistic, their emotional responses to autism, and their recommendations for how to talk to autistic children about autism and selected illustrative quotes.

For quantitative analyses, we first examined data distributions. The age at which participants learned they were autistic and their current age exhibited excessive kurtosis and skew. Therefore, non-parametric Kendall's Tau-b correlations were used to identify predictors for the regressions. We verified that the assumptions of linear regression were met, i.e., linear relationships, independent errors (Durbin-Watson values of ~ 2.0), normally distributed residuals exhibiting homoscedasticity, and multicollinearity was not a major concern (VIF < 2.0). One

outlier was observed when predicting ASQoL (standardized residual > 3). Findings remained

unchanged when this outlier was removed. Therefore, the outlier is included in analyses.

To examine our first hypothesis, that learning one is autistic at a younger age is

associated with heightened well-being and Quality of Life, we conducted linear regressions

examining predictors that were correlated with well-being and ASQoL in baseline correlations

(i.e., age of learning one is autistic, RAADS-14, current age, and gender).

To evaluate our second hypothesis, that learning one is autistic at a younger age is

associated with more positive perspectives on autism in adulthood, we examined correlations

between the age of learning one is autistic and positive current emotions about autism. Given that

perceptions of autism may change with time (Huws & Jones, 2015), we also examined

associations between age of learning one is autistic and feelings when first learning one is

autistic.

The large number of analyses used increased the risk of Type 1 errors. However,

Bonferroni corrections have been critiqued for increasing the risk of Type 2 errors (Nakagawa,

2004). To address difficulties balancing Type 1 and Type 2 errors and other limitations of null

hypothesis testing, researchers (and the American Statistical Association) recommend focusing

on effect sizes and confidence intervals (Nakagawa & Cuthill, 2007; Wasserstein et al., 2019).

We report effect sizes and confidence intervals using SPSS 24.0. Following Benjamin and

Berger's (2019) recommendations, we describe two-tailed *p* values less than .05 and greater than

.005 as suggestive.

Results

When and How Did Participants Learn They Were Autistic?

Participants learned they were autistic at a mean age of 14.71 years (SD= 8.83). Some

participants (29.5%) learned they were autistic in childhood; 48.7% of participants learned they

were autistic in adolescence (Table 2).[1] A similar number of participants first learned they were

autistic from family members (39.7%) and clinicians (34.6%); 14.1% of participants found out

on their own, 5.1% were informed by an educator, 3.8% had "always known," and 2.6% did not

remember how they learned.

Baseline Correlations

Males learned they were autistic at a younger age than others (Table 3). Participants'

current age was positively correlated with the age when they learned they were autistic (Figure

1). As hypothesized, the age at which one learned one was autistic was negatively associated

with adult ASQoL and well-being (Table 3). RAADS-14 scores were also negatively associated

with both outcomes.

Is Learning One is Autistic Younger Associated with Well-being and QoL?

A regression predicting ASQoL from age of learning one is autistic, current age,

RAADS-14, and male gender revealed that learning one is autistic at a younger age, being older

currently, and lower RAADS-14 scores, but not gender, were associated with heightened ASQoL

($R^2 = .51$; Table 4).[2] An identical pattern was observed with the QoL item from the WHOQOL-

Bref ($R^2 = .30$; Appendix B).

A regression predicting well-being from the same predictors revealed that learning one is

autistic at a younger age, being older, and lower RAADS-14 scores, but not gender, were

associated with heightened well-being ($R^2 = .35$; Table 5). Together, these findings support our

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[1] Although the age span comprising adolescence is contested, we defined adolescence as 10-19 years of age following the WHO (1998).

[2] The same associations between key predictors and outcomes is obtained if graduate status and race are included in regressions. However, their inclusion induces autocorrelation.

first hypothesis that learning one is autistic at a younger age is associated with heightened well-being and QoL.

Is Learning One is Autistic Younger Associated with More Positive Feelings About Autism?

We found no evidence for our second hypothesis; the age at which one learned one was autistic was *not* correlated with positive emotions about autism in adulthood, $\tau_b(75) = .15$, $p = .12$ (Table 3). Instead, learning one is autistic at an *older age was* correlated with more positive emotions when *first learning* one was autistic, $\tau_b (75) = .39$ $p < .001$, and particularly relief, $\tau_b (75) = .46$ $p < .001$.[3]

To better understand these patterns, we grouped responses by the developmental stage when participants first learned they were autistic. Positive responses to first learning one is autistic, particularly relief, increased from childhood through adolescence to adulthood (Table 6). Participants who learned they were autistic as a child or adolescent were numerically more likely to report a negative or neutral response to first learning they were autistic than people who learned they were autistic in adulthood.

Table 7 depicts frequencies of emotional responses upon first learning one is autistic and now. No overall changes in the frequency of emotional responses were apparent. Illustrative quotes (Appendix C) highlight the diversity and complexity of participants' feelings about autism. Some participants highlighted improvements in their feelings about autism across time. As one reported, "When I first found out I was autistic I was only six years old so it did not mean

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[3] A binary logistic regression with the same predictors as in the prior regressions revealed evidence suggesting that not being male ($p = .006$) and learning one is autistic at an older age ($p = .02$) predicted more positive initial perspectives about being autistic. An identical binary logistic regression with relief as the outcome revealed that learning one is autistic at an older age ($p = .001$) and not being male ($p = .03$; suggestive) were associated with relief.

much of anything to me… I gradually accepted being autistic" (6)[4]. Another initially felt "ashamed and confused" but now feels "awesome and proud" (16). Participants' varied and complex responses to learning they were autistic included "joy"(12) "relief and sadness" (13), feeling "curious" (15), "broken" (18), "stigmatized" (17) or "a little bit worried… upset… and disgusted" (10). For some, such negative feelings persisted, represented as shame in "admitting to people I have Autism (10)"; whereas others reported growing more self-assured and "proud (8)" of their autistic identity with time. When asked how they feel about being autistic now, one participant wrote "AWESOME" (47) while others described feeling "much better" (18), "more positive" (20) and "proud to be autistic" (20). Quotes provide clues about why learning one is autistic earlier may lead to better outcomes; participants highlighted self-awareness and access to support as key benefits of learning one is autistic. For example, a number of participants recognized the importance of being part of "a community of people just like me in which we can support and empower one another (18)".

When Would Participants Tell Their Own Child About Autism?

When asked "If you had a child with autism, when would you tell them about autism?", only 18 (24.7%) of participants provided an age (see Appendix D for illustrative quotes). Four participants responded about their existing children. No participants pointed to adulthood as the appropriate time to tell one's child they are autistic. Fifty-six participants (76.7%) highlighted factors to consider when telling their child about autism, including curiosity, personality, and support needs. As one participant put it, "I would tell them (slowly, as appropriate, and in age-appropriate language) about sensory overload, stimming, executive dysfunction, spoons, alexithymia, face-blindness, and all of the important aspects so that they felt less alone and

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[4] The age of learning one is autistic in years is included in parentheses following each in-text quote.

broken. I would tell them about their community and offer to let them seek out other autistic

people (10)."

Twenty-one participants (28.1%) indicated that they would tell their child as soon as they

were old enough to understand the diagnosis and themselves. One participant wrote "I would tell

them as early as I could. Kids can understand a lot more than adults think that they can, you just

have to phrase it in the right way with the right amount of information. I would make it a normal

part of their life, and teach them more about it as time went on (17)." Participants often intended

to frame being autistic positively while recognizing potential challenges. For example, one

participant wrote, "I would tell my child that autism is a different way of thinking, that it can be

challenging and beautiful and powerful and exhausting and impactful, that autistic people

deserve to be themselves, to be proud of their identity, and have supports that help them meet

their needs (20)".

Discussion

As hypothesized, autistic university students who learned that they were autistic when

they were younger reported higher well-being and Quality of Life relative to students who did

not gain access to this important information about themselves until they were older. Adult

autism diagnoses rarely provide clear pathways to formal support (Huang et al., 2020), which

might contribute to reduced well-being and QoL among some people who learn they are autistic

later in life. Participants' descriptions of how they felt about autism when they first learned they

were autistic and now, as university students, highlights the emotional complexity of learning

about and having an autism diagnosis. Illustrative quotes suggest that learning about one's

diagnosis can empower autistic people by helping them make meaning of their experiences and

build self-understanding and compassion. Participants also highlighted material benefits that can come with learning you are autistic, including access to autistic allies and other forms of support.

Unexpectedly, earlier recognition that one is autistic was *not* associated with more positive emotions about autism in adulthood. Instead, participants who learned they were autistic *later* in life were more likely to express *positive emotions* about autism *when they first learned they were autistic* than participants who learned they were autistic at younger ages. Consistent with prior work (Huang et al., 2020), people who learned they are autistic later in life often received this news positively, largely due to relief that they finally had an explanation for their differences. People who learn they are autistic later in life may also have more autonomy to connect with autistic communities, including the neurodiversity movement, which respects diversity in ways of thinking and being and rejects deficit-focused, medicalized discourses (Kapp et al., 2013; Singer, 2016).

Autistic people are often exposed to prejudice and discrimination, which can make processing an autism diagnosis challenging (Botha et al., 2021). The pressure to fit in that adolescents often experience has led researchers to speculate that learning one is autistic may be particularly challenging for adolescents (e.g., Humphrey & Lewis, 2008; Mesa & Hamilton, 2021). However, our findings suggest that both children and adolescents may be susceptible to initial negative feelings when first learning they are autistic despite potential long-term mental health benefits of gaining access to this important information earlier. Some people who learn they are autistic at younger ages, when their prior awareness of their own differences from others is limited, might more directly associate the diagnosis of autism with the challenges and difficulties they experience. Instead of viewing the label of autism as a helpful explanation for already-known challenges, these younger individuals might only gradually become aware of

experiencing challenges, and as they do so, they may be more likely to see "autism" as a cause of those challenges and as a source of shame, relating to internalized stigma (den Houting et al., 2021).

However, our data also indicate that some people who learn they are autistic when they are young simply view being autistic as a natural part of who they are. Some participants shared how their experiences with other people shaped how they feel about being autistic. Although we did not observe overall improvements in how participants reported feeling about autism when they first learned vs. at the time of our study, some participants did report improvements in their perspectives over time. With time, opportunities to find fellow autistic people may increase and support more positive feelings as autistic people find 'a home' (Botha et al., 2021). Indeed, the amount of time that had passed since diagnosis was associated with less dissatisfaction about being autistic among 151 autistic adults (Corden et al., 2021). Knowing about and accepting being autistic may help autistic people gain self-confidence in themselves and their relationships. Future research should explore whether there are specific factors that might be linked to such improvements, such as intersectional identities (given that non-males seemed to respond particularly positively to learning they were autistic in our sample), psychological resilience, positive autistic role models, supportive families and friends, and exposure to neurodiversity-aligned narratives.

What Do Our Data Tell Us About When and How Should Parents Tell Their Child About Autism?

When asked when and how they would tell their own autistic child about autism, autistic students did not provide simple answers. Participants recommended considering the child's developmental level, curiosity, support needs, and personality. No participants recommended

disclosure in adulthood. As in prior work (Smith et al., 2018; Crane, 2019; 2021) participants

emphasized the importance of disclosing autism to a child when the child is deemed "ready". If

participants feel nervous or anxious about disclosing autism to their child, they can connect with

autistic people and other stakeholders to obtain advice about how to talk to their own autistic

child about autism.

Limitations and Future Directions

Our data is reliant on retrospective self-report. Subsequent research should incorporate

longitudinal designs. We did *not* ask participants when they were *diagnosed*. We only asked

them when they first *learned* they were autistic. Therefore, our data does not allow us to

disentangle the underlying reasons for and consequences of learning one is autistic later because

one was diagnosed later vs. learning one is autistic later because people kept this information

hidden when it became available. Future research should ask participants both when they were

diagnosed and when they learned they were autistic to examine if the timing of the diagnosis

itself (and associated factors that may contribute to late diagnosis like gender and the types of

autistic characteristics a person presents with: Lai & Szatmari, 2020) or potential delays between

being diagnosed and learning one is autistic are more impactful on adult outcomes.

In our sample, participants who learned they were autistic *later* reported heightened

autistic traits. This finding contrasts with prior work, suggesting that people with heightened

autistic traits are often diagnosed earlier (Mandell et al., 2005). Exploratory analyses to explicate

this unexpected finding revealed that participants who learned they were autistic later reported

specific difficulties socializing (e.g., difficulties with group interactions); restricted interests and

repetitive behaviors were *not* associated with age of learning one was autistic. Therefore, future

longitudinal research should investigate if learning one is autistic at older ages leads to reduced self-understanding which, in turn, makes adapting to social groups more difficult.

Although our sample was substantially more racially/ethnically diverse than prior research in this area (e.g. Crane et al., 2019), most of our participants were white and from the US or UK. We also did not seek out the perspectives of autistic people who are not seeking higher education. Insufficient diversity greatly limits the generalizability of these findings to people representing other cultural backgrounds and educational trajectories. Subsequent research should endeavor to attain more diverse samples through anonymous population-based surveys as well as qualitative studies focused on cultural groups who are underrepresented in autism research (e.g., non-speaking people).

Conclusions

This is the first study, to our knowledge, to demonstrate that learning that one is autistic at a younger age may have positive impacts on emotional health among autistic university students. Hopefully, this finding may begin to address concerns parents have reported in the literature, that they are not sure how to begin to talk to their child about autism (e.g., Smith-Demers, 2018), by pointing out that *when* the conversation begins may be particularly important. Our findings suggest that learning one is autistic at a younger age can help autistic people develop self-understanding and access supports, thus providing the foundations for well-being in adulthood.

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Table 1
Participant Demographics (N = 78)

	%(n)
Gender:	
Male	51.3(40)
Female	35.9(28)
Non-binary	10.3(8)
Prefer not to answer	2.6(2)
Sexuality:	
Heterosexual	44.9(35)
Bisexual/Pansexual	19.2(15)
Homosexual	16.7(13)
Asexual	9.0(7)
Prefer not to answer	7.7(6)
Unsure	2.6(2)
Co-occurring conditions	
Anxiety	33.3(26)

Depression	26.9(21)
Other psychological diagnosis/es	23.1(18)
ADHD	20.5(16)
Other medical diagnosis/es	17.9(14)
Study level:	
Associate/Pre-BA	19.2(15)
Bachelor's	52.6(41)
Graduate	23.1(18)
Certificate	3.8(3)
Other	1.3(1)
Race/ethnicity	
White	67.9(53)
Mixed Race	20.5(16)
Asian	6.4(5)
Black	5.1(4)

Table 2
Age of Learning One is Autistic (N = 78)

Age of Learning one is Autistic	Percentage of sample (n)
3-5 Years	14.1%(11)
6-9 Years	15.4%(12)
10-12 Years	14.1%(11)
13-15 Years	14.1%(11)

16-19 Years	20.5%(16)
20-22 Years	10.2%(8)
26-29 years	6.4%(5)
37-39 Years	3.9%(3)
47 Years	1.3%(1)

Table 3

Kendall's Tau Correlations Between Measures (N = 78)

	Age now	White	Male	Grad	RAADS-14	Well-being	ASQoL	Positive Then	Positive Now
Age learned	.44**	.03	-.29*	.30*	.18^	-.24*	-.33**	.39**	.15

Age now	-.10	-.22^	.49**	.11	-.03	-.06	.35**	.15
White		.09	-.09	.03	-.09	-.12	-.06	.002
Male			-.25^	-.32**	.16	.18	-.46**	-.16
Grad student				.18	-.06	.01	.31^	.11
RAADS-14					-.28**	-.42**	.21^	-.02
Well-being						.51**	-.16	-.07
ASQoL							-.18	.08
Positive Then								.26^

Note. **= *p <=.001, *= p< .005, ^= p<=.05*
White, male, grad student, and positive perspectives on autism then and now were dichotomous categories, comparing participants who identified as only white or male or a graduate student or whose perspectives on being autistic when they first learned they were autistic and now were coded as "positive" to all other participants.

Table 4
Regression Predicting ASQoL from Age of Learning One Is Autistic and Other Characteristics

	B(SE)	95%CI B	β	p
Intercept	42.50(2.92)	[36.67, 48.32]		< .001
Age Learned	-.45(.09)	[-.63, -.26]	-.56	.002
Current age	.36(.11)	[.14, .58]	.37	< .001
RAADS-14	-.44(.07)	[-.57, -.30]	-.58	< .001
Male	-1.33(1.25)	[-3.83, 1.17]	-.10	.29

Table 5

Regression Predicting Well-Being from Age of Learning One Is Autistic and Other Characteristics

	B(SE)	95%CI B	β	p
Intercept	50.19(4.77)	[40.69, 59.69]		< .001
Age Learned	-.58(.15)	[-.88, -.28]	-.52	.002
Current age	.69(.18)	[.33, 1.05]	.50	< .001
RAADS-14	-.46(.11)	[-.68, -.24]	-.43	< .001
Male	.17(2.05)	[-3.91, 4.24]	.01	.94

Table 6

Emotional Responses to First Learning one is Autistic by Developmental Stage at Time

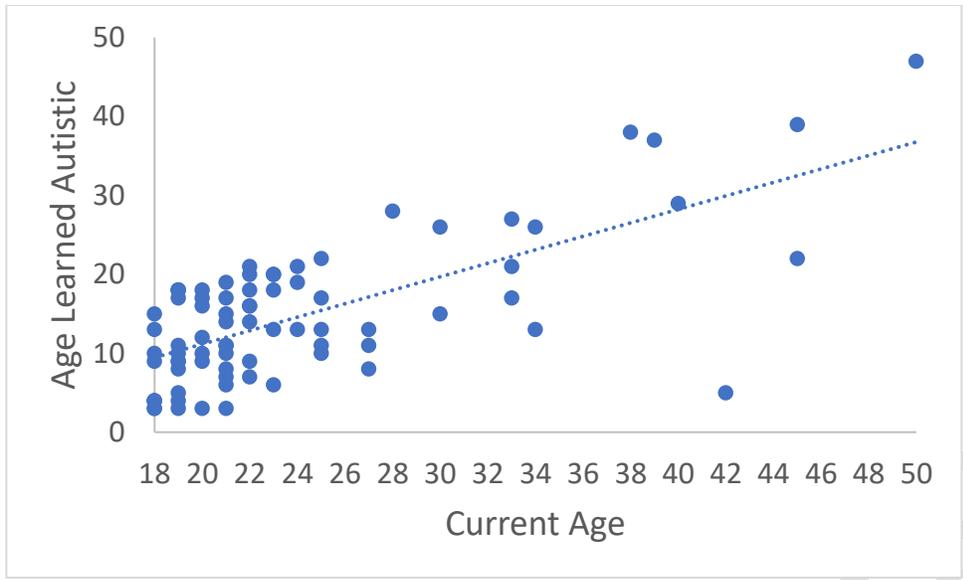|	Positive	SC: Relief	Negative	Disbelief	Neutral	Don't Know
Childhood	26.1%	8.7%	34.8%	21.7%	13.0%	13.0%
Adolescence	55.3%	31.6%	31.6%	16.2%	13.2%	2.6%
Adulthood	88.2%	82.4%	17.6%	11.8%	0	0

Table 7

Feelings about Autism When First Learned Autistic and Now (n= 77)

	First Learned Autistic %(*n*)	Feelings Autism Now %(*n*)
Positive Emotions	54.5%(42)	63.6%(49)
Sub-code: Relief	37.7%(29)	Not noted/coded
Negative Emotions	31.2%(24)	23.4%(18)
Sub-code: Ashamed	9.1%(7)	12.8%(10)
Improves with Time	11.7%(9)	20.8%(16)
Neutral Feelings	10.3%(8)	18.2%(14)
Don't know	3.8%(3)	2.6%(2)

Note. Although possible changes in emotional reactions across time were *not* a focus of

this retrospective study, we highlight for interpretive clarity that none of the

numerical differences between feelings about autism then and now documented

in this table were statistically significant (McNemar's tests, *p*s > .26).

Figure 1
Association Between Age of Learning One is Autistic and Current Age (N = 78)