Open camera or QR reader and
scan code to access this article
and other resources online.

"I've Spent My Whole Life Striving to Be Normal": Internalized Stigma and Perceived Impact of Diagnosis in Autistic Adults

Yunhe Huang,[1,2] Julian N. Trollor,[1,2] Kitty-Rose Foley,[1,3] and Samuel R.C. Arnold[1,2]

Abstract

Background: Receiving an autism diagnosis in adulthood often leads to improved self-understanding and deeper self-reflection, which can have major impacts on people's well-being and sense of identity. However, autism diagnosis also exposes individuals to societal stigma, which may become internalized over time. This study aimed to explore relationships between psychological and service-related impacts of diagnosis and internalized stigma using mixed methods.

Methods: One hundred forty-three autistic adults completed an online survey involving impact of diagnosis domains of Self-Understanding, Well-being, Clinician Support, and Service Access, internalized stigma, and open-ended questions on beliefs about autism diagnosis.

Results: On average, participants reported mild levels of internalized stigma and positive impact of diagnosis in all domains except Service Access. Older age at diagnosis was positively associated with Clinician Support only. The path analysis model showed positive relationships between impact of diagnosis domains, with Self-Understanding having a positive effect on Well-being via lowered internalized stigma. We developed four themes of *Continuity and Acceptance*, *Late Diagnosis as Regret and Freedom*, *Coming to Terms with Being Autistic*, and *Stigma Resistance* from qualitative data.

Conclusions: Self-understanding protects against the development of internalized autism stigma. Diagnosticians and service providers play an important role in improving self-understanding and well-being in autistic adults. More research is needed to understand the role of age at diagnosis and mechanisms behind positive identity development after autism diagnosis.

Keywords: autism, adults, diagnosis, stigma, well-being, mixed methods

Community Brief

Why is this an important issue?

Receiving an autism diagnosis in adulthood can help people understand themselves better. This can help them feel better too. Autistic adults' experiences during diagnosis and their experience with support services after diagnosis might also affect how they think and feel about themselves. There are many negative beliefs about autism in society. Some autistic people might think more negatively about themselves because of these beliefs.

---

[1]Department of Developmental Disability Neuropsychiatry (3DN), University of New South Wales Sydney, Sydney, New South Wales, Australia.
[2]The Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia.
[3]Faculty of Health, Southern Cross University, Gold Coast, Queensland, Australia.

What was the purpose of this study?

This study tries to understand relationships between the impact of autism diagnosis and negative beliefs about autism in autistic adults. We also wanted to know if age at diagnosis is related to these factors.

What did the researcher do?

One hundred forty-five autistic adults filled in an online survey. We asked questions about the impact of autism diagnosis on four aspects: how they understand themselves, their well-being, experiences with the professional who gave the diagnosis, and support services after diagnosis. We also asked questions about autistic adults' negative beliefs about autism. We used the answers to these questions to test a model of how we think these factors might affect each other: good experiences with the professional who gave the diagnosis help with self-understanding and getting support services. Better self-understanding helps autistic adults think less negatively about autism. Better self-understanding, less negative thinking about autism, and better support services all help improve well-being after diagnosis.

We asked autistic adults some general questions about the effect of autism diagnosis on their lives. We asked autistic adults whether they think being diagnosed at an older or younger age made a difference. We also asked autistic adults about negative beliefs that some autistic people might have about their autism. We then read these answers and made a list of the important and common ideas in people's answers.

What were the results of the study?

In general, autism diagnosis improved autistic adults' self-understanding and well-being. Most autistic adults had good experiences with the diagnosing professional but did not have good support services after diagnosis. On average, autistic adults had a small amount of negative beliefs about autism. People diagnosed at older ages had better support from the health professional who diagnosed them. We did not find any other differences between people diagnosed at different ages. We successfully tested our model of relationships between self-understanding, well-being, experiences with the diagnosing professional, experience of support services, and negative beliefs about autism.

Autistic adults said getting the diagnosis did not change who they are. It helped them understand and accept themselves. Some late-diagnosed autistic adults wished they were diagnosed earlier. Others said being diagnosed younger might make you think less of yourself because there was less autism acceptance in society at that time. Both early-diagnosed and late-diagnosed autistic adults said growing older helped them understand what it means to be autistic. Autistic adults also talked about autistic and non-autistic people's negative beliefs about autism. Some autistic adults said that negative beliefs are caused by society not being accepting enough, not because autism itself is bad. This thinking helps autistic adults think more positively about autism.

What do these findings add to what was already known?

This is the first study to measure and develop a model of the relationships between impacts of diagnosis and negative beliefs about autism in autistic adults.

What are potential weaknesses in this study?

Most people who did our survey were diagnosed as teens and adults. It was hard to measure the effects of age at autism diagnosis because we did not have enough participants diagnosed at young ages. The people who did our survey were mostly female, White, spoke English only, and did not have intellectual disability. This means that the people in our study are not a good representation of all autistic adults in Australia. The questions we used to measure negative beliefs about autism were originally made for people with mental illness. There might be negative beliefs specific to autism that we did not measure.

How will these findings help autistic adults now or in the future?

Our findings tell professionals who diagnose or support autistic adults that it is important to help autistic adults understand what it means to be autistic in a positive way. This will help autistic adults form more positive beliefs about autism and live happier lives.

Introduction

FIRST-TIME AUTISM DIAGNOSIS in adulthood can be a life-changing event that influences people's sense of self.[1,2] Late-diagnosed autistic adults have often lived with significant challenges before diagnosis,[3] including interpersonal difficulties,[4] struggles with employment,[5] and elevated risks of mental ill-health and suicidal ideation.[6,7] Existing research in this area, mainly qualitative, has highlighted several factors influencing the post-diagnosis experiences of autistic adults. However, few studies have attempted to quantify these concepts and systematically examine their interrelationships.

Impact of autism diagnosis

In several studies, receiving an autism diagnosis helped adults understand themselves better, leading to improved self-acceptance and subjective well-being. Autistic adults reported feeling immediate relief as the diagnosis helped explain their experiences.[2,8,9] Understanding autism helped adults reduce self-blame and develop greater self-acceptance.[2,10] Improved self-understanding also helped adults develop coping strategies that increased their well-being and functioning.[8,10] However, studies also reported cases where the autism diagnosis led adults to believe that their difficulties were insurmountable, which worsened their well-being.[9] These findings suggest that self-understanding may be an important contributor to well-being after adulthood autism diagnosis. Measurement of self-understanding, well-being, and their relationship to other factors would contribute to a more comprehensive understanding of post-diagnosis experiences.

Service-related impact of diagnosis. Interactions with professionals during diagnosis and subsequent support can also influence the psychological impact of autism diagnosis. Studies highlighted that diagnosing clinicians' provision of information on post-diagnosis support and strength-based framings of autism during diagnosis contribute to positive diagnosis experiences.[11,12] Studies typically reported a shortage of autism services for people diagnosed in adulthood,[8,11] although adults who were able to access support reported improved self-understanding and well-being.[9,13,14] More comprehensive examination of the quality of professional care during diagnosis and access to post-diagnosis support would be valuable, as they may have significant effects on autistic adults' self-understanding and well-being.

Theories and measurement. Theories of impact of diagnosis have traditionally focused on physical illnesses, characterizing the event as either a *biographical disruption* to everyday life, relationships and the future,[15] or the *biographical continuity* of ongoing ill-health.[16,17] While researchers have described the reinforcement of other identities[18] and the eventual formation of positive disability identity after diagnosis,[19] these characterizations are not fully congruent with narratives of autistic adults who experienced relief and elation from the diagnosis itself. Tan[10] proposed the term ''biographical illumination'' in a study of autistic self-advocates to illustrate how adulthood autism diagnosis led participants to embrace autism as intrinsic to their identities, reduce self-blame, and develop kinship with other autistic individuals.

The idea of positive autistic identity is in line with the neurodiversity paradigm, which views autism positively as a natural human variation and minority group identity.[20,21] Past research showing negative reactions after adulthood autism diagnosis[9] suggests that this positive characterization is not universally applicable. Nevertheless, the concept of biographical illumination is a novel illustration of diagnosis as a source of personal growth rather than a burden.

To date, few quantitative tools have been developed to measure the subjective impact of diagnosis. Courtney and Makinen[22] devised the 10-item Impact of Diagnosis Scale (IODS) to measure the experience of being diagnosed with borderline personality disorder in a small sample of 21 adolescents, with a modest internal consistency of Cronbach's alpha = 0.66. To adapt the IODS for an autistic population, Arnold et al.[1] used a participatory approach to develop a preliminary revision (Impact of Diagnosis Scale–Revised [IODS-R]) involving three domains of *Service Access*, *Being Understood*, and *Self-Understanding and Acceptance*. An expanded revision involving psychological and service-related impact domains is currently being developed (Arnold et al., unpublished data, 2022). The ability to measure these aspects of impact of diagnosis would allow examination of their relationship with other concepts.

Autism diagnosis and internalized stigma

A possible negative impact of autism diagnosis is exposure to stigma, defined as negative stereotypes, prejudiced beliefs, and discriminatory behavior toward a minority group.[23] For example, some may believe that autistic individuals cannot form interpersonal relationships or lead independent lives.[24,25] Studies have found a negative relationship between exposure to stigma and well-being in autistic people,[26] who may hide their diagnosis[27] or camouflage their autistic traits to avoid discrimination.[28]

Stigma becomes internalized when individuals endorse negative societal beliefs about their own group, leading to deteriorated self-esteem and self-efficacy.[29] Corrigan and Watson[29] theorized that internalized stigma consists of three components: self-stereotype (awareness of negative beliefs), self-prejudice (endorsement of negative beliefs and subsequent emotional reactions), and self-discrimination (self-destructive behavioral responses). Only a few studies have measured internalized stigma in autistic individuals, all of them using adaptations of scales originally developed for other populations.[30–33] Botha and Frost[33] found that societal and internalized stigma predicted poorer mental health in autistic adults, suggesting that internalized stigma may contribute to lowered well-being. However, further research is needed to understand how changes in self-understanding and experience of services following adulthood autism diagnosis may influence the internalization of autism stigma and subsequent effects on well-being.

Internalized stigma and self-understanding. Emerging research into mental illness stigma suggested that improving knowledge may help prevent and reduce internalized stigma. Studies of people with schizophrenia[34] and integrated care patients[35] showed a negative relationship between mental health literacy and internalized stigma of mental illness. A systematic review also found that psychoeducation

interventions were effective for reducing internalized stigma in people with a range of mental illnesses.[36] These findings suggest that improved self-understanding may protect against internalization of stigmatizing beliefs, although their generalizability to autistic people requires further study.

Internalized stigma and age at diagnosis. As autism is a developmental condition often visible from early childhood, earlier diagnosed individuals may have more opportunities to internalize negative beliefs from sources, such as caregiver affiliate stigma.[37,38] In an ethnographic study of five autistic adolescents, a participant diagnosed in childhood described that early intervention made her more aware of her own difficulties and intensified her sense of alienation.[39] A recent quantitative study also found that autistic people who learned of the diagnosis at older ages had more positive emotions about autism.[40] Thus, it may be worthwhile to explore the effects of age at diagnosis on impact of diagnosis and internalized stigma in autistic adults.

The present study

Past research highlighted several factors that may influence subjective well-being after autism diagnosis, including self-understanding,[10] quality of professional care during diagnosis,[12] post-diagnosis service access,[14] and internalized stigma.[33] Studies also suggested that age at autism diagnosis may influence individuals' beliefs about autism diagnosis and internalization of stigma.[39] Developing a statistical model of relationships between these concepts will help unify past findings, allowing for evaluation and comparison of measures to improve post-diagnosis outcomes. Additional qualitative exploration of autistic adults' perspectives would help add depth to the model and improve relevance to lived experience.

We developed a hypothesized model based on the existing literature. Improved self-understanding would protect against internalized stigma by increasing knowledge.[34–36] Reduced internalized stigma would then contribute to better subjective well-being after diagnosis.[33] Self-understanding would also directly contribute to improved well-being through self-acceptance and learned coping strategies.[8,10] As the diagnosing clinician is a key provider of information and support pathways,[11] more positive clinician support would predict better self-understanding and service access. Better service access would in turn improve well-being as the adult's support needs are addressed.[9,14]

The present study has the following aims: (1) to explore relationships between internalized stigma, impact of diagnosis, and individual characteristics including age at diagnosis in autistic adults; (2) to test our hypothesized model of interrelationships between internalized stigma and the impact of diagnosis domains of Self-Understanding, Well-being, Clinician Support, and Service Access in autistic adults; and (3) to explore autistic adults' perspectives on these concepts and triangulate with quantitative findings.

Methods

This study is part of a larger project on pathways, predictors, and impact of autism diagnosis in adulthood. The project was approved by the University of New South Wales Human Research Ethics Committee, project number HC190582. This study used the data-validation variant of triangulation mixed methods design, using qualitative analysis of open-ended survey responses to supplement quantitative findings.[41] We present quantitative and qualitative findings separately in the Results section before comparing and integrating them in the Discussion section.

Participants

For this study, participants ($N = 143$) were required to be 18 years or older, have received an autism spectrum diagnosis at any age (including Asperger's Syndrome and Pervasive Developmental Disorder–Not Otherwise Specified), and have completed the relevant survey sections on demographics, impact of diagnosis, and internalized stigma (see the Measures section). We have provided more details of recruitment methods and procedure of the larger project in a previous publication.[42] In brief, we recruited a voluntary sample through advertisements placed with existing research studies, autism and disability organizations, service providers, and social media, who then completed an online survey on experiences of autism diagnosis. Participants provided consent via a question at the start of the survey. Researchers conducted five prize draws where a $100 AUD gift card was awarded to a randomly selected participant each time. Individuals without a formal autism diagnosis participated in the larger project but were not included in this study.

Measures

Demographics. Participants answered demographic questions on date of birth, gender, autism diagnosis, ethno-cultural background, intellectual disability, psychiatric history, occupation, and geographic location. Age of autism diagnosis was calculated from reported year of diagnosis and birth year. Data on socioeconomic status and educational attainment were not recorded.

Autistic traits. We measured autistic traits using the 28-item Autism Spectrum Quotient–Short (AQ-28),[43] an abridged version of the original scale.[44] The AQ-28 is a self-report autism screening tool intended for verbal adults without intellectual disability. Each item is rated on a 4-point Likert scale from 1 (strongly disagree) to 4 (strongly agree). Total score is calculated from the sum of all items, with higher scores indicating greater levels of autistic traits. While our hypotheses do not specifically involve autistic traits, we have included the AQ-28 to support the validity of self-reported autism diagnosis and to explore potential associations with the variables of interest. We did not exclude participants based on AQ scores as it does not necessarily indicate their level of autistic traits at time of diagnosis. However, only two participants scored below the screening cutoff of >65, suggesting that most of our sample exhibits significant autism characteristics.

Internalized stigma. We measured internalized autism stigma using the Internalized Stigma of Mental Illness Scale–Brief Version (ISMI-9),[45] a unidimensional 9-item abridged version of the original 29-item scale.[46] Both the full ISMI and the abridged ISMI-10 have previously been used to compare autistic adults and adults with mental illnesses.[31,32] However, we chose the ISMI-9 over other versions because its items rely less on specific mental illness stereotypes such as tendency toward violence. The ISMI-9 was composed of two

items selected from each of the Alienation, Stereotype Endorsement, Social Withdrawal, and Stigma Resistance domains, and one item from the Discrimination Experience domain of the original ISMI.

Each item is rated on a Likert scale from 1 (strongly disagree) to 4 (strongly agree), with the mean of all answered items as the final score. Higher scores indicate greater levels of internalized stigma, with recommended cutoffs of >2.0 for mild stigma, >2.5 for moderate stigma, and >3.0 for severe stigma.[45] We obtained permission from authors of the ISMI-9 to alter the wording of items for use in an autistic sample, where we replaced the word ''mental illness'' with the participant's specific autism diagnosis. We edited the item ''I can have a good, fulfilling life, despite my mental illness'' to ''I can have a good, fulfilling life with my [diagnosis]'' following consultation with autistic advisors to reflect the idea that autism diagnosis may be perceived positively.

Impact of diagnosis. The IODS-R (Arnold et al., unpublished data, 2022) is an adaptation of the original IODS for adolescents with borderline personality disorder[22] and the preliminary revision for use in an autistic population.[1] The IODS-R was developed with a participatory approach, where autistic community members submitted potential new items and ranked items in order of priority. The IODS-R measured the subjective impact of autism diagnosis in adults across four domains of Self-Understanding (knowledge and evaluation of self after diagnosis), Well-being (positive emotions and improved coping), Clinician Support (care from diagnosing clinician), and Service Access (support from professional services).

There are 22 items in total, including 2 screening items on whether the participant remembers being diagnosed and 5 items for each domain. We excluded participants ($n = 2$) who answered ''disagree'' or ''strongly disagree'' to both screening items. Each item is scored on a Likert scale from 1 (strongly disagree) to 7 (strongly agree) with the option to mark ''not applicable'' (NA). To assist with participants' understanding, equivalent percentages (e.g., $1 = 0\%$, $2 = 16\%$, ... $7 = 100\%$) were presented alongside numbers 1–7 on the scale. Domain (Self-Understanding, Well-being, Clinician Support, Service Access) and full-scale totals are calculated as the mean score of all non-screening and non-NA items, with higher scores indicating more positive impact.

As the IODS-R is yet to be published, a prepublication version (Supplementary Material) was used.

Open-ended questions. Participants also completed open-ended questions on their own and others' beliefs about autism diagnosis, whether age at diagnosis affected their understandings, and any additional comments for qualitative analysis. Online survey data collection has been successfully used in qualitative research to reduce participant burden and broaden the sample without sacrificing depth.[47]

Procedure

Data for this study were collected in the online survey for the larger project. Participants completed the survey via Qualtrics. See Huang et al.[42] for further survey procedure details.

The ISMI-9 and IODS-R were only displayed to participants with a formal autism spectrum diagnosis. At the start of the section, participants typed in the autism spectrum diagnosis they received. Questionnaire items then automatically displayed the entered diagnosis where applicable. For example, ''Stereotypes about ____ apply to me'' automatically became ''Stereotypes about Asperger's Syndrome apply to me'' if ''Asperger's Syndrome'' was entered as a diagnosis.

Data analysis

Quantitative analysis. We used Stata 17 for all quantitative data analysis. We used descriptive statistics to summarize participant characteristics and variables of interest (internalized stigma and four impact of diagnosis domains). We also conducted exploratory analysis of relationships between participant characteristics and scores on the five variables of interest, using *t*-tests for binary categorical participant characteristics variables and correlational analysis for continuous variables. Scale and domain internal consistency were calculated using Cronbach's alpha. Where applicable, we have indicated the number of participants with missing data separately for each variable. Pairwise deletion was used in correlational analyses of variables with missing data. We excluded missing responses to individual items in the ISMI and IODS-R when calculating scale and domain mean scores for each participant. We used an alpha level of 0.05 for all analyses. We opted not to adjust for multiple comparisons to avoid unnecessarily reducing statistical power when many of our analyses are exploratory.[48,49]

We used path analysis with maximum likelihood estimation to test our hypothesized model of relationships between internalized stigma and the four IODS-R domains. Visual inspection of P-P, Q-Q, and residual-versus-fitted plots revealed non-normality and heteroscedasticity in several of the paths. Both the Huber–White (robust to non-normality and heteroscedasticity)[50,51] and the Satorra–Bentler (robust to non-normality)[52] standard error adjustments showed minimal differences in our data. We chose the Satorra–Bentler adjustment to allow calculation of adjusted estimates of model fit indices.

We used the Satorra–Bentler scaled chi-square test statistic to compare the proposed model against the saturated model under non-normality.[52] We also used the following fit statistics with cutoff points recommended by Hu and Bentler[53]: the root mean squared error of approximation (RMSEA) ≤ 0.06, comparative fit index (CFI) ≥ 0.95, Tucker–Lewis index (TLI) ≥ 0.95, and standardized root mean squared residual (SRMR) ≤ 0.08. The RMSEA, CFI, and TLI were computed from the Satorra–Bentler scaled chi-square test statistic to account for non-normality.

Qualitative analysis. We used reflexive thematic analysis,[54,55] a method where the researcher deeply engages with the data and generates themes from shared patterns of meaning, to analyze qualitative data. We chose this flexible method as it provides both a primarily realist paradigm for triangulation with quantitative findings and an opportunity to actively engage with participants' subjective beliefs. The approach to coding and theme development was mostly inductive but guided by theoretical concepts related to the

research question. We used NVivo 12 to manage and code open-ended responses.

Y.H. first coded for recurrent ideas during immersion into the data and then developed themes based on shared meanings, reviewing the data throughout to refine each theme. Y.H. also kept a journal of reflections, decisions, and justifications throughout analysis. While reflexive thematic analysis is an inherently subjective method that does not require objectivity in the form of inter-rater reliability, Y.H. discussed the resultant codes and themes with all co-authors to improve cohesion and relevance to research aims.

Community involvement

We consulted several autistic advisors and advisors with intellectual disability during survey development to improve the relevance and accessibility of materials.[42] Additionally, four autistic research advisors provided feedback on our interpretation of results, which included comments on improving sensitivity to autistic experiences and suggestions for practical implications and priorities for future research. Advisors were offered compensation of $35 AUD per hour.

Results

Table 1 shows demographic characteristics of 143 participants. Participants' age at time of survey ranged from 20 to 72 years ($M = 41.21$, standard deviation [SD] = 12.31). Age of autism diagnosis ranged from 2 to 70 years ($M = 37.40$, SD = 13.83). Only 5.6% ($n = 8$) of participants were diagnosed before age 18. On average, participants received their autism diagnosis 4.13 years before the survey (SD = 5.63, range 0–23). The AQ-28 showed good internal consistency ($\alpha = 0.79$), with a mean score of 89.71 (SD = 9.27, $n = 7$ missing).

Internalized stigma

Internal consistency of the ISMI-9 in our sample ($\alpha = 0.69$) was lower than the original study by Hammer and Toland[45] ($\alpha = 0.86$) and slightly below the recommended 0.7–0.8.[56] On average, participants reported mild internalized stigma regarding their autism diagnosis ($M = 2.46$, SD = 0.46, range 1.22–4.00). Scores showed 18.2% ($n = 26$) of participants had no internalized stigma, 41.3% ($n = 59$) mild stigma, 30.1% ($n = 43$) moderate stigma, and 10.5% ($n = 15$) severe stigma. The item with the highest endorsement was "I feel out of place in the world because of _____" ($M = 3.03$, SD = 0.83), while the item with the lowest endorsement was "I can't contribute anything to society because of _____" ($M = 1.56$, SD = 0.79).

Independent samples t-tests found internalized stigma to be higher in participants with intellectual disability [$t(141) = 2.46$, $p = 0.02$], lifetime anxiety [$t(132) = 2.04$, $p = 0.04$, $n = 9$ missing], post-traumatic stress disorder (PTSD) [$t(135) = 2.61$, $p = 0.01$, $n = 6$ missing], and participants not in paid employment [$t(141) = 2.09$, $p = 0.04$]. No significant relationships were found with other demographic variables including gender.

Impact of diagnosis

Internal consistency measures for the prepublication version of IODS-R were high, with $\alpha = 0.81$ for Self-Understanding, $\alpha = 0.82$ for Well-being, $\alpha = 0.88$ for

TABLE 1. PARTICIPANT CHARACTERISTICS ($N = 143$)

Characteristic	n	%
Gender		
Male	36	25.2
Female	91	63.6
Another term	13	9.1
Missing	3	2.1
Intellectual disability	11	7.7
Type of autism diagnosis		
Autism or autism spectrum disorder/condition	81	56.6
Asperger's syndrome	50	35.0
"High-functioning" autism	9	6.3
Missing	3	2.1
Ethnicity[a]		
Caucasian	125	87.4
Non-Caucasian	14	9.8
Missing	7	4.9
Language spoken at home[a]		
English	135	94.4
Other	12	8.4
Missing	6	4.2
Geographical remoteness[a,b]		
Major city	104	72.7
Regional	52	36.4
Remote	3	2.1
Any additional lifetime psychiatric diagnosis[a]	129	90.2
Depression		
Yes	117	81.8
No	20	14.0
Missing	6	4.2
Anxiety disorders[c]		
Yes	114	79.7
No	20	14.0
Missing	9	6.3
ADHD		
Yes	59	41.3
No	77	53.9
Missing	7	4.9
Post-traumatic stress disorder		
Yes	40	28.0
No	97	67.8
Missing	6	4.2
Other diagnoses		
Yes	61	42.7
No	76	53.2
Missing	6	4.2
No additional diagnosis	8	5.6
Day activities[a]		
Paid work	88	61.5
Study	33	23.1
Volunteer work	19	13.3
No structured activities[d]	23	16.1
Other	26	18.2

[a]Categories are not mutually exclusive.
[b]By postcode according to the Australian Statistical Geography Standard (Australian Bureau of Statistics, 2018),[82] with inner/outer divisions collapsed for regional and remote categories.
[c]Includes anxiety, panic disorder, social anxiety, and agoraphobia.
[d]Defined as not in employment, education/training, disability-specific day programs, volunteering, or retirement.
ADHD, attention-deficit/hyperactivity disorder.

Clinician Support, $\alpha = 0.83$ for Service Access, and $\alpha = 0.90$ overall. Participants on average reported positive impact of autism diagnosis on Self-Understanding ($M = 5.81$, SD = 1.13), positive Clinician Support ($M = 5.61$, SD = 1.42), mildly positive impact on Well-being ($M = 4.67$, SD = 1.43), and mildly negative impact on Service Access ($M = 3.47$, SD = 1.71). The mean overall impact of diagnosis score was mildly positive ($M = 4.89$, SD = 1.09).

IODS-R Self-Understanding was lower in participants with intellectual disability [$t(141) = 2.02$, $p = 0.046$] and in participants who spoke a language other than English [$t(135) = 2.24$, $p = 0.03$]. Well-being scores were lower in participants who spoke a language other than English [$t(135) = 2.21$, $p = 0.03$] and in participants living in regional or remote areas [$t(141) = 2.14$, $p = 0.03$]. Clinician Support scores were lower in participants with intellectual disability [$t(141) = 2.49$, $p = 0.01$] and in participants with mental illnesses other than depression, anxiety, attention-deficit/hyperactivity disorder, or PTSD [$t(135) = 2.06$, $p = 0.04$]. Service Access scores were not significantly related to any demographic variable.

Correlations between age at diagnosis, internalized stigma, impact of diagnosis, and other diagnosis-related variables

Table 2 shows correlations between age at diagnosis, years since diagnosis, AQ-28, ISMI-9, and IODS-R domain and overall scores. Older diagnosis age was weakly associated with better clinician support during diagnosis but not any other measures. Greater number of years since diagnosis was moderately associated with older diagnosis age, and weakly associated with less positive impact of diagnosis on Self-Understanding, Well-being, and overall impact of diagnosis. Higher AQ-28 score was associated with more positive impact of diagnosis on Self-Understanding, Well-being, and overall impact of diagnosis. Higher internalized stigma was moderately associated with less positive impact of diagnosis on Self-Understanding, Well-being, Service Access,

and overall impact of diagnosis. IODS-R domains showed moderate-to-high intercorrelations, with the highest correlation between Self-Understanding and Well-being.

Path model of impact of diagnosis and internalized stigma

Figure 1 shows the path diagram of the proposed model with standardized regression coefficients. Due to the lack of association between age at diagnosis and most variables of interest, the model made no distinction between adults diagnosed at different ages. As hypothesized, more positive impact of diagnosis on Self-Understanding was associated with lower internalized stigma and more positive impact on Well-being, while internalized stigma was negatively associated with well-being. Better Clinician Support was associated with more positive impact on both Self-Understanding and Service Access. Impact on Service Access was positively associated with impact on Well-being. All hypothesized relationships were statistically significant.

Model level goodness-of-fit statistics were satisfactory overall. The model versus saturated chi-square test was nonsignificant [$\chi^2(4) = 7.24$, $p = 0.12$], suggesting that our model was a good fit. Most other model fit indices were within recommended cutoffs (RMSEA = 0.08, CFI = 0.98, TLI = 0.96, SRMR = 0.07), except RMSEA, which was slightly above the recommended ≤ 0.06 (see Figure 1 for a diagram of this model).

Qualitative themes

We developed four themes of *Continuity and Acceptance*, *Late Diagnosis as Regret and Freedom*, *Coming to Terms with Being Autistic*, and *Stigma Resistance* from open-ended responses. These themes relate to participants' beliefs about their diagnosis, reflections upon their age of diagnosis, and negotiation of societal and internalized stigma.

TABLE 2. CORRELATION MATRIX OF DIAGNOSIS-RELATED VARIABLES, INTERNALIZED STIGMA OF MENTAL ILLNESS SCALE–BRIEF VERSION, AND IMPACT OF DIAGNOSIS SCALE–REVISED DOMAIN AND TOTAL SCORES ($N = 145$)

	Age at diagnosis	Years since diagnosis	AQ-28 (n=6 missing)	ISMI-9	IODS-R Self-Understanding	IODS-R Well-being	IODS-R Clinician Support	IODS-R Service Access
Years since diagnosis	−0.46***							
AQ-28 (n=6 missing)	0.08	−0.06						
ISMI-9	0.01	0.04	0.06					
IODS-R Self-Understanding	0.03	−0.18*	0.38***	−0.35***				
IODS-R Well-being	−0.08	−0.11	0.19*	−0.42***	0.80***			
IODS-R Clinician Support	0.20*	−0.32***	0.10	−0.09	0.31***	0.31***		
IODS-R Service Access	−0.11	0.00	−0.04	−0.20*	0.31***	0.48***	0.48***	
IODS-R full	0.00	−0.19*	0.18*	−0.34***	0.75***	0.83***	0.69***	0.78***

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.
AQ-28, 28-item Autism Spectrum Quotient–Short; IODS-R, Impact of Diagnosis Scale–Revised; ISMI-9, Internalized Stigma of Mental Illness Scale–Brief Version.
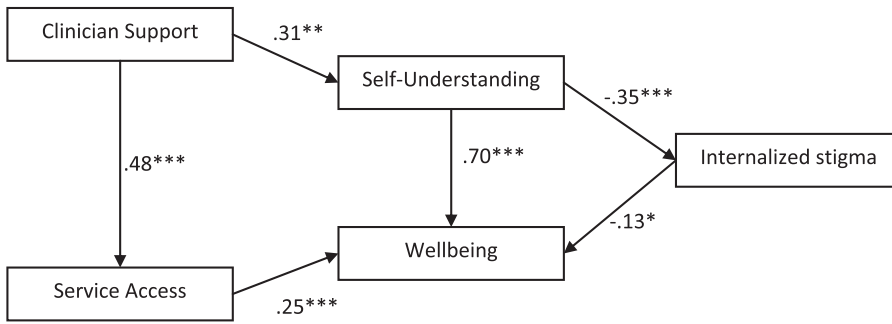
FIG. 1. Model of internalized stigma and impact of autism diagnosis with standardized regression coefficients.
$*p < 0.05$; $**p < 0.01$; $***p < 0.001$.

Continuity and acceptance. For late-diagnosed participants, receiving the diagnosis offered relief and certainty by giving an official explanation to past and current experiences. For some, it led to further discovery through learning and self-reflection. Although the diagnosis confirmed participants' perceived differences from the majority, it also absolved the participant of shame from not meeting societal expectations:

"I've spent my whole life striving to be normal so finding out it's a neurological difference meant this hope died in an instant. But then there was relief knowing that for the first time I have evidence on paper that I'm not making it all up … I now have an authoritative explanation to people who say I just need to try harder" (Participant diagnosed age 27).

While many participants described the diagnosis as a revelational event, they also explained that the diagnosis did not change who they always were. Instead, changes in understanding, beliefs, and expectations helped them get closer to their true selves: "A benefit of late diagnosis was that I had sought to understand myself … why I was different and didn't fit in, so my self-awareness was not primarily a result of diagnosis but rather confirmed by it" (Participant diagnosed age 62). Thus, the new interpretations brought forth by diagnosis did not disrupt but instead affirmed their ongoing experiences and identities.

Late diagnosis as regret and freedom. Participants diagnosed in adulthood often expressed disappointment over not having been diagnosed earlier. Growing up undiagnosed, these participants struggled with mainstream expectations that became internalized over time: "I frequently felt that if I just tried harder, I would be normal" (Participant diagnosed age 45). Not having an explanation for these struggles led to feelings of shame and inadequacy. While the diagnosis relieved participants from these expectations, the decades of effort had taken a toll on their well-being: "I can still feel the stress in my body from up to 37 years of pushing myself to do things I 'should' have been able to do" (Participant diagnosed age 37).

A common sentiment among late-diagnosed participants was grief over the wasted potential for a better life. Participants believed that earlier diagnosis and support would have helped them understand themselves and find strategies to overcome challenges. The relief at receiving the diagnosis was accompanied by a sense of despair as some participants felt powerless to re-learn and alter their life course at their age:

"I wish I had been diagnosed at a younger age, as I feel too old, tired and burnt out to learn new tricks to make things work for me. I do believe that there was a point in my diagnosis, though … as it has given me a framework to start to work on small changes and some self-acceptance" (Participant diagnosed age 44).

However, late-diagnosed participants described benefits of growing up without predefined labels. These participants were thankful they avoided the intense autism stigma in past decades, which allowed them to develop a more positive view of autism based on their experiences. Some also believed that growing up with a stigmatized diagnosis would have given them more pressure to conform to societal standards. In line with these concerns, an early-diagnosed participant described negative experiences of growing up with an autism diagnosis:

"I think people looked at me different. My mother still treats me different and says 'oh that's just her problems' so I think it honestly has affected the way I grew up, and I think I have lost my childhood because of that. Now I keep it a secret cause I'm scared others will react the same" (Participant diagnosed age 2).

Some late-diagnosed participants expressed that knowing they have a disability from a young age would have led to lowered self-expectations and reduced motivation to challenge themselves. One participant described how the lack of diagnosis allowed him to strive for his goals unhampered by self-doubt:

"I got a degree, had a twenty-year career in IT, worked in London, New York and Tokyo, performed in amateur theatre … If I'd been diagnosed earlier, I may have avoided these things, thinking that I would not be able to cope with them and wouldn't be the person I am today" (Participant diagnosed age 45).

Coming to terms with being autistic. The maturity and life experience that come with adulthood helped participants make sense of their diagnoses. Late-diagnosed participants expressed that reflecting upon their existing self-understanding and past events helped them contextualize and accept the diagnosis. In a similar vein, an early-diagnosed participant explained that the diagnosis did not make sense until he had more life experience:

"When I was young, I didn't really think about my diagnosis. It was not until I was older … I started to become more aware of my difficulties and what they were leading me to miss out on … I think this means that I didn't really have a

single big 'ah-ha' moment, as I hear some people who are diagnosed late can have. I always had an idea that I was different, but when I was little, it didn't cause things that upset me, so I didn't think about it" (Participant diagnosed age 9).

While most participants accepted the diagnosis, their views on what it means to be autistic varied. Some participants expressed that being different from the majority is not a bad thing as autism also gave them unique strengths. Others framed autism in terms of negative experiences such as missing out on social connections or professional success. Some participants reconciled their positive view of autism with its negative impact by attributing these difficulties to the wider society. As one participant explained, it is not autism itself but living in an unsuitable environment that causes these negative experiences:

> "My difficulties were not caused my multiple inadequacies … but rather my Asperger's was the unifying aspect to my difference and difficulties I have with living in an unaccommodating Typical world" (Participant diagnosed age 62).

In light of the merging of previous autism subtypes in DSM-5, participants grappled with the meaning of the diagnostic term given to them. While participants considered the *Asperger's syndrome* label less stigmatizing due to its connotations of high intelligence, the very same assumptions also resulted in their support needs not being taken seriously. Many participants viewed the newer *autism spectrum disorder* (*ASD*) term positively as it includes all autistic people regardless of abilities, but some wished that there were more specific descriptors for their characteristics. The *disorder* part of ASD also received criticism from participants who viewed autism positively. One participant describes how she navigated the change in diagnostic terminology:

> "Asperger's is a controversial diagnosis—but I liked the 'smart' and 'gifted' associations of Asperger's rather than autism when I was diagnosed. I'm much happier now accepting an ASD diagnosis and understanding it's a spectrum, and however smart I am, I'm part of the spectrum" (Participant diagnosed age 44).

Stigma resistance. Participants described various stigmatizing views that they or other autistic people may have about their own diagnosis, such as believing that they are inferior to non-autistic people, cannot enjoy close relationships, or cannot participate fully in the community. These statements often involved negative predictions of the future: "They … might believe their lives are doomed as they will forever be the odd one out" (Participant diagnosed age 25). Participants also reported the negative impact of stereotypes on others' treatment of them and their self-esteem. One participant described the consequences of being stereotyped as unemotional:

> "The most harmful thing we can do is treat people with ASD as having no emotion, in turn teaching society to shun or even be afraid of talking to us in turn isolating us further. People with ASD might believe that they're inferior, especially when Neurotypical people disagree or feel frustrated with us … As someone with Autism, I can always sense that I am doing the wrong thing" (Participant diagnosed age 8).

In line with external attribution of negative experiences, participants expressed that internalized stigma is not a natural consequence of autism but a result of society's intolerance of differences. One participant said: "It is very easy to internalise that our differences are 'less than' when the neuromajority [sic] impose negative beliefs" (Participant diagnosed age 67).

Discussion

This study was the first to explore relationships between perceived impact of diagnosis and internalized stigma in an autistic population. We identified positive relationships between IODS-R Self-Understanding and Well-being domains, mediated by reduced internalized stigma. Clinician Support and Service Access were also positively related with Self-Understanding and Well-being, with implications for professionals working with autistic adults. Qualitative findings helped illustrate how autistic adults navigated both societal and internalized stigma while developing their personal understandings of autism. These results have implications for understanding how psychological and service-related impact of diagnosis may interact with the development of internalized stigma in autistic adults.

Internalized stigma partially mediated the relationship between Self-Understanding and Well-being after autism diagnosis. As internalized stigma involves endorsement of negative societal beliefs, greater understanding of autism in relation to one's own strengths and difficulties may help adults resist harmful stereotypes and develop more balanced views of themselves. This is consistent with mental health research demonstrating the effectiveness of psychoeducation interventions against internalized stigma.[36] The negative relationship between internalized stigma and well-being is consistent with past research in people with mental illness.[57] These findings suggest that it would be helpful for diagnosing clinicians to educate newly diagnosed adults and their families on common autism stereotypes and misconceptions to enhance stigma resistance. Additionally, psychoeducation programs that incorporate strength-based approaches to foster positive identity development may be an important aspect of post-diagnosis support.

Positive relationships between Clinician Support, Service Access, and the psychological impact of diagnosis domains of Self-Understanding and Well-being highlight the important roles of the diagnosing clinician and service providers in improving adults' post-diagnosis experiences. Low-to-moderate scores on Service Access indicate inadequate access to suitable post-diagnosis support, consistent with previous studies of autistic adults.[8,11] Our preliminary findings on the association between impact of diagnosis domains and demographic characteristics suggest possible inequalities in autism knowledge and quality of services, which require further confirmation.

The correlation between Clinician Support and Service Access suggests that the diagnosing clinician may be a key facilitator of support services, with highly skilled and knowledgeable clinicians providing greater guidance on accessing support. Our findings emphasize the need for a range of services addressing autistic adults' needs and clearer pathways between diagnosis and support to improve adults' self-understanding and well-being after diagnosis.

Age at diagnosis was not correlated with internalized stigma or overall impact of diagnosis. While it is possible that age at diagnosis has no underlying relationship with these constructs, sample characteristics may have influenced our findings. As few participants in our sample were diagnosed at very young ages, we may be unable to detect differences specific to diagnosis in early childhood. Past research has also suggested that adults diagnosed at different ages may differ in demographic and clinical characteristics such as gender and intellectual disability.[58,59] Thus, it is possible that these characteristics may have third-variable effects that prevented detection of underlying relationships. Additionally, our qualitative findings on how age-related maturity and life experiences contributed to participants' self-understanding suggest the need for further exploration of the relationship between age and impact of diagnosis constructs.

Better Clinician Support at diagnosis was associated with older age at diagnosis and absence of intellectual disability. As older age at diagnosis was correlated with more recent diagnosis, it is possible that improvements in autism understanding and doctor–patient communication in recent years[60] have led to more positive interactions. Another explanation is differences in clinicians' communication with clients of different age groups and abilities. Research suggested that children and adolescents were less involved in health care communication and decision-making than they desired.[61]

As autism diagnosis in young children may be communicated to parents only,[62] it may have led to poorer diagnostic experiences for participants diagnosed at younger ages. Similarly, research into people with intellectual disability reported inadequate explanations from clinicians and a tendency to mainly communicate with carers.[63] Our findings emphasize the need for effective communication and support from clinicians during autism diagnosis. It is especially important for clinicians to develop skills to engage with autistic people with specific communication needs including children and people with intellectual disability.

Qualitative findings showed that participants viewed autism diagnosis as a continuation of their pre-existing selves and an explanation for past and present experiences. The experience of autism diagnosis, although often viewed more positively than physical health diagnoses, is closer aligned with the biographic continuity of long-term conditions[17] than the biographic disruption of sudden life-changing illness.[15] While the effects of diagnosis on self-understanding were in line with Tan's concept of biographical illumination,[10] the explanatory power of diagnosis did not always lead to development of a positive autistic identity. Instead, some participants reported self-stereotyping and self-prejudice following diagnosis. As a neurodevelopmental condition with great individual variation, existing theories of health and illness often do not fully encompass the varied experiences of autistic people.

In the qualitative data, some participants maintained positive self-image by attributing negative autism-related experiences to societal factors. Our findings lend credence to Crocker and Major's theory that attributing negative feedback to societal prejudice helps protect stigmatized individuals from low self-esteem and enables them to resist societal stigma.[64] Research in the general population also found that external attribution of negative outcomes helps maintain high self-esteem.[65,66] Considering the numerous inequalities experienced by autistic adults[67,68] and not discounting the need for social change, this attribution style is likely to be valuable for helping autistic people resist stigma and maintain a positive autistic identity in the face of these challenges. Further quantitative research may help to clarify the mechanism in which attributional style influences self-esteem and internalization of stigma in autistic people, with possible clinical applications for autistic people undergoing negative experiences.

The *Late diagnosis as regret and freedom* theme appeared contradictory in that participants viewed early diagnosis as both enabling and limiting opportunities in adulthood. This contrasts with previous studies where autistic adults viewed early diagnosis favorably.[9,69] While early support is beneficial to development,[70] support that is stigmatizing, restrictive, or excessive may result in negative outcomes such as internalized stigma and overreliance.[71,72] Studies found that parents of children with disabilities were more likely to overprotect[73] and have lower academic expectations.[74] Another study showed that autistic adolescents perceived themselves as more capable than their caregivers and teachers' ratings.[75] Our findings and past research emphasize that interventions and supports need to recognize strengths and promote independence in autistic people to maximize the positive impact of diagnosis.

Limitations and Future Directions

Our convenience sample has several limitations regarding representativeness. The high proportion of women is unusual considering the past literature on higher autism prevalence in males.[76] One contributing factor is the high average age of autism diagnosis in our participants, as past studies suggested that females tend to be diagnosed later than males.[58,59] Research in non-autistic populations also suggested that women may be more willing to participate in survey-based research.[77,78] Female-dominated samples are common in autism studies using social media recruitment and online survey tools,[79] suggesting that gender differences in internet behavior may play a role.

The low prevalence of intellectual disability in our sample may be due to association with younger age at diagnosis[58,59] and barriers to completing the survey. There may also be reporting inaccuracies as participants may be unaware of the definition of intellectual disability or their disability status. Limited diversity in ethnicity and language spoken at home may be due to a combination of barriers to autism diagnosis, recruitment strategy limitations, and English language requirements for completing the survey. Future researchers should expand recruitment strategies and improve accessibility of survey instruments to ensure coverage of underrepresented groups.

As a tool developed for people with mental illness, the ISMI-9 has limitations when used in an autistic sample. External attribution of negative experiences means a person may endorse items such as "I feel out of place in the world because of _____" without having a negative view of their diagnosis. The ISMI-9 also cannot measure negative beliefs specific to autism or developmental disabilities. Validation of general internalized stigma measures in autistic samples and development of autism-specific tools would benefit further research in this area. Comparison with scales measuring

related constructs such as experience of societal stigma[80] and positive autistic identity[81] would help establish convergent and discriminant validity.

Some items in the prepublication version of the IODS-R may have problems with content validity. Despite its high internal consistency, the Self-Understanding domain contained items related to other psychological constructs. For example, Item 9 ''gave me less self-confidence'' relates to self-esteem. While the domains of Self-Understanding and Well-being are theoretically related, their high correlation suggests that the domains may not be sufficiently distinct. Replication using the final version of the IODS-R when available would help clarify our findings.

As a cross-sectional study, we were unable to capture changes in people's emotions and beliefs about the diagnosis over time. Longitudinal research examining multiple time points after diagnosis would help address this gap. Future researchers exploring impact of diagnosis may benefit from collaboration with diagnostic service providers so that data can be collected immediately after diagnosis. Due to the length and format of our survey, we were only able to include a few open-ended questions for qualitative data collection. Further research using in-depth interviews would help expand and enrich our findings.

Conclusions

This study is an exploratory investigation of relationships between internalized stigma and impact of diagnosis in autistic adults. The findings identified potential mechanisms underlying internalized stigma, psychological impact of diagnosis, and experience of services, which helped extend past research in mental health to an autistic population and identify potential areas for further study. Qualitative findings also helped illustrate the pervasive impact of societal stigma and individuals' resistance against internalization. These findings highlighted the important role of diagnosing clinicians and service providers in fostering positive self-understanding and stigma resistance via psychoeducation and support. We hope our research will lead to deeper understanding of internalized stigma and related processes in autism, and development of supports that empower autistic people without limiting their opportunities.

Acknowledgments

Authors' Contributions

All authors contributed to the study conception and design. Y.H. completed questionnaire design, data collection, and analysis with guidance from all authors. Y.H. wrote the first draft of the article. All authors commented on previous versions of the article. All authors read and approved the final article.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

Supplementary Material

Supplementary Material

References

1. Arnold SRC, Huang Y, Hwang YI, Trollor JN, Richdale AL, Lawson LP. ''The single most important thing that has happened to me in my life'': Development of the Impact of Diagnosis Scale—Preliminary Revision. *Autism Adulthood*. 2020;2(1):34–41. https://doi.org/10.1089/aut.2019.0059.

2. Punshon C, Skirrow P, Murphy G. The not guilty verdict: Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*. 2009;13(3):265–283. https://doi.org/10.1177/1362361309103795.

3. Lai M-C, Baron-Cohen S. Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry*. 2015;2(11):1013–1027. https://doi.org/10.1016/S2215-0366(15)00277-1.

4. Hickey A, Crabtree J, Stott J. 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism*. 2018;22(3):357–367. https://doi.org/10.1177/1362361316680914.

5. Griffith GM, Totsika V, Nash S, Hastings RP. 'I just don't fit anywhere': Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*. 2012;16(5):532–546. https://doi.org/10.1177/1362361311405223.

6. Happé FG, Mansour H, Barrett P, Brown T, Abbott P, Charlton RA. Demographic and cognitive profile of individuals seeking a diagnosis of autism spectrum disorder in adulthood. *J Autism Dev Disord*. 2016;46(11):3469–3480. https://doi.org/10.1007/s10803-016-2886-2.

7. Cassidy S, Bradley P, Robinson J, Allison C, McHugh M, Baron-Cohen S. Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: A clinical cohort study. *Lancet Psychiatry*. 2014;1(2):142–147. https://doi.org/10.1016/S2215-0366(14)70248-2.

8. Lewis LF. Realizing a diagnosis of autism spectrum disorder as an adult. *Int J Ment Health Nurs*. 2016;25(4):346–354. https://doi.org/10.1111/inm.12200.

9. Powell T, Acker L. Adults' experience of an Asperger syndrome diagnosis: Analysis of its emotional meaning and effect on participants' lives. *Focus Autism Other Dev Disabil*. 2016;31(1):72–80. https://doi.org/10.1177/1088357615588516.

10. Tan CD. ''I'm a normal autistic person, not an abnormal neurotypical'': Autism Spectrum Disorder diagnosis as biographical illumination. *Soc Sci Med*. 2018;197:161–167. https://doi.org/10.1016/j.socscimed.2017.12.008.

11. Crane L, Batty R, Adeyinka H, Goddard L, Henry LA, Hill EL. Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *J Autism Dev Disord*. 2018;48(11):3761–3772. https://doi.org/10.1007/s10803-018-3639-1.

12. Jones L, Goddard L, Hill EL, Henry LA, Crane L. Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United kingdom. *J Autism Dev Disord*. 2014;44(12):3033–3044. https://doi.org/10.1007/s10803-014-2161-3.

13. Crane L, Hearst C, Ashworth M, Davies J, Hill EL. Supporting newly identified or diagnosed autistic adults: An initial evaluation of an autistic-led programme. *J Autism Dev Disord*. 2021;51(3):892–905. https://doi.org/10.1007/s10803-020-04486-4.

14. Southby K, Robinson O. Information, advocacy and signposting as a low-level support for adults with high-functioning autism spectrum disorder: An example from the UK. *J Autism Dev Disord*. 2018;48(2):511–519. https://doi.org/10.1007/s10803-017-3331-x.

15. Bury M. Chronic illness as biographical disruption. *Sociol Health Illn*. 1982;4(2):167–182. https://doi.org/10.1111/1467-9566.ep11339939.

16. Faircloth CA, Boylstein C, Rittman M, Young ME, Gubrium J. Sudden illness and biographical flow in narratives of stroke recovery. *Sociol Health Illn*. 2004;26(2):242–261. https://doi.org/10.1111/j.1467-9566.2004.00388.x.

17. Llewellyn H, Low J, Smith G, Hopkins K, Burns A, Jones L. Narratives of continuity among older people with late stage chronic kidney disease who decline dialysis. *Soc Sci Med*. 2014;114:49–56. https://doi.org/10.1016/j.socscimed.2014.05.037.

18. Carricaburu D, Pierret J. From biographical disruption to biographical reinforcement: The case of HIV-positive men. *Sociol Health Illn*. 1995;17(1):65–88. https://doi.org/10.1111/1467-9566.ep10934486.

19. Onken SJ, Slaten E. Disability identity formation and affirmation: The experiences of persons with severe mental illness. *Sociol Pract*. 2000;2(2):99–111.

20. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Dev Psychol*. 2013;49(1):59–71. https://doi.org/10.1037/a0028353.

21. Singer J. *Odd people in: The birth of community amongst people on the ''autistic spectrum'': A personal exploration of a new social movement based on neurological diversity*. Honours thesis. University of Technology Sydney; 1998.

22. Courtney DB, Makinen J. Impact of diagnosis disclosure on adolescents with borderline personality disorder. *J Can Acad Child Adolesc Psychiatry*. 2016;25(3):177–184.

23. Rüsch N, Angermeyer MC, Corrigan PW. Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *Eur Psychiatry*. 2005;20(8):529–539. https://doi.org/10.1016/j.eurpsy.2005.04.004.

24. Kinnear SH, Link BG, Ballan MS, Fischbach RL. Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *J Autism Dev Disord*. 2016;46(3):942–953. https://doi.org/10.1007/s10803-015-2637-9.

25. Kuzminski R, Netto J, Wilson J, Falkmer T, Chamberlain A, Falkmer M. Linking knowledge and attitudes: Determining neurotypical knowledge about and attitudes towards autism. *PLoS One*. 2019;14(7):e0220197. https://doi.org/10.1371/journal.pone.0220197.

26. Perry E, Mandy W, Hull L, Cage E. Understanding camouflaging as a response to autism-related stigma: A social identity theory approach. *J Autism Dev Disord*. 2022;52(2):800–810. https://doi.org/10.1007/s10803-021-04987-w.

27. Cox BE, Thompson K, Anderson A, et al. College experiences for students with autism spectrum disorder: Personal identity, public disclosure, and institutional support. *J Coll Stud Dev*. 2017;58(1):71–87. https://doi.org/10.1353/csd.2017.0004.

28. Hull L, Petrides KV, Allison C, et al. ''Putting on my best normal'': Social camouflaging in adults with autism spectrum conditions. *J Autism Dev Disord*. 2017;47(8):2519–2534. https://doi.org/10.1007/s10803-017-3166-5.

29. Corrigan PW, Watson AC. The paradox of self-stigma and mental illness. *Clin Psychol Sci Pract*. 2002;9(1):35–53. https://doi.org/10.1093/clipsy.9.1.35.

30. Han E, Scior K, Avramides K, Crane L. A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Res*. 2022;15(1):12–26. https://doi.org/10.1002/aur.2652.

31. Dubreucq J, Plasse J, Gabayet F, et al. Self-stigma in serious mental illness and autism spectrum disorder: Results from the REHABase national psychiatric rehabilitation cohort. *Eur Psychiatry*. 2020;63(1):e13. https://doi.org/10.1192/j.eurpsy.2019.12.

32. Bachmann CJ, Höfer J, Kamp-Becker I, et al. Internalised stigma in adults with autism: A German multi-center survey. *Psychiatry Res*. 2019;276:94–99. https://doi.org/10.1016/j.psychres.2019.04.023.

33. Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. *Soc Ment Health*. 2018;10(1):20–34. https://doi.org/10.1177/2156869318804297.

34. Singh A, Mattoo SK, Grover S. Stigma and its correlates in patients with schizophrenia attending a general hospital psychiatric unit. *Indian J Psychiatry*. 2016;58(3):291–300. https://doi.org/10.4103/0019-5545.192024.

35. Crowe A, Mullen PR, Littlewood K. Self-stigma, mental health literacy, and health outcomes in integrated care. *J Couns Dev*. 2018;96(3):267–277. https://doi.org/10.1002/jcad.12201.

36. Alonso M, Guillén AI, Muñoz M. Interventions to reduce internalized stigma in individuals with mental illness: A systematic review. *Span J Psychol*. 2019;22:E27. https://doi.org/10.1017/sjp.2019.9.

37. DePape A-M, Lindsay S. Parents' experiences of caring for a child with autism spectrum disorder. *Qual Health Res*. 2014;25(4):569–583. https://doi.org/10.1177/1049732314552455.

38. Werner S, Shulman C. Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *J Intellect Disabil Res*. 2015;59(3):272–283. https://doi.org/10.1111/jir.12136.

39. Mogensen L, Mason J. The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder. *Sociol Health Illn*. 2015;37(2):255–269. https://doi.org/10.1111/1467-9566.12208.

40. Oredipe T, Kofner B, Riccio A, et al. 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*. 2022. https://doi.org/10.1177/13623613221086700.

41. Creswell JW, Plano Clark VL. *Designing and conducting mixed method research*. Thousand Oaks: SAGE Publications; 2007.

42. Huang Y, Arnold SRC, Foley K-R, Trollor JN. Choose your own adventure: Pathways to adult autism diagnosis in Australia. *J Autism Dev Disord*. 2022;52(7):2984–2996. https://doi.org/10.1007/s10803-021-05169-4.

43. Hoekstra RA, Vinkhuyzen AAE, Wheelwright S, et al. The construction and validation of an abridged version of the Autism-Spectrum Quotient (AQ-Short). *J Autism Dev Disord*. 2011;41(5):589–596. https://doi.org/10.1007/s10803-010-1073-0.

44. Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *J Autism Dev Disord*. 2001;31(1):5–17. https://doi.org/10.1023/a:1005653411471.

45. Hammer JH, Toland MD. 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 Health*. 2017;2(3):159–174. https://doi.org/10.1037/sah0000049.

46. Ritsher JB, Otilingam PG, Grajales M. Internalized stigma of mental illness: Psychometric properties of a new measure. *Psychiatry Res*. 2003;121(1):31–49. https://doi.org/10.1016/j.psychres.2003.08.008.

47. Braun V, Clarke V, Boulton E, Davey L, McEvoy C. The online survey as a qualitative research tool. *Int J Soc Res Methodol*. 2021;24(6):641–654. https://doi.org/10.1080/13645579.2020.1805550.

48. Feise RJ. Do multiple outcome measures require p-value adjustment? *BMC Med Res Methodol*. 2002;2(1):8. https://doi.org/10.1186/1471-2288-2-8.

49. Rothman KJ. No adjustments are needed for multiple comparisons. *Epidemiology*. 1990;1(1):43–46.

50. Huber PJ. The behavior of maximum likelihood estimates under nonstandard conditions. In: *Proceedings of the Fifth Berkeley Symposium on Mathematical Statistics and Probability*. Berkeley and Los Angeles: University of California Press; 1967;221–233.

51. White H. A heteroskedasticity-consistent covariance matrix estimator and a direct test for heteroskedasticity. *Econometrica*. 1980;48(4):817–838. https://doi.org/10.2307/1912934.

52. Satorra A, Bentler PM. Corrections to test statistics and standard errors in covariance structure analysis. In: von Eye A, Clogg CC, eds. *Latent Variables Analysis: Applications for Developmental Research*. Thousand Oaks: SAGE Publications; 1994:399–419.

53. Hu Lt, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Struct Equ Model*. 1999;6(1):1–55. https://doi.org/10.1080/10705519909540118.

54. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589–597. https://doi.org/10.1080/2159676X.2019.1628806.

55. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101. https://doi.org/10.1191/1478088706qp063oa.

56. Bland JM, Altman DG. Statistics notes: Cronbach's alpha. *BMJ*. 1997;314(7080):572. https://doi.org/10.1136/bmj.314.7080.572.

57. Pérez-Garín D, Molero F, Bos AER. Internalized mental illness stigma and subjective well-being: The mediating role of psychological well-being. *Psychiatry Res*. 2015;228(3):325–331. https://doi.org/10.1016/j.psychres.2015.06.029.

58. Shattuck PT, Durkin M, Maenner M, et al. Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *J Am Acad Child Adolesc Psychiatry*. 2009;48(5):474–483. https://doi.org/10.1097/CHI.0b013e31819b3848.

59. Huang Y, Arnold SRC, Foley K-R, Lawson LP, Richdale AL, Trollor JN. Factors associated with age at autism diagnosis in a community sample of Australian adults. *Autism Res*. 2021;14(12):2677–2687. https://doi.org/10.1002/aur.2610.

60. Conti AA, Gensini GF. Doctor-patient communication: A historical overview. *Minerva Med*. 2008;99(4):411–415.

61. Coyne I, Gallagher P. Participation in communication and decision-making: Children and young people's experiences in a hospital setting. *J Clin Nurs*. 2011;20(15-16):2334–2343. https://doi.org/10.1111/j.1365-2702.2010.03582.x.

62. Abbott M, Bernard P, Forge J. Communicating a diagnosis of autism spectrum disorder—A qualitative study of parents' experiences. *Clin Child Psychol Psychiatry*. 2012;18(3):370–382. https://doi.org/10.1177/1359104512455813.

63. Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A. Discrimination and other barriers to accessing health care: Perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS One*. 2013;8(8):e0070855. https://doi.org/10.1371/journal.pone.0070855.

64. Crocker J, Major B. Social stigma and self-esteem: The self-protective properties of stigma. *Psychol Rev*. 1989;96(4):608–630. https://doi.org/10.1037/0033-295X.96.4.608.

65. Blaine B, Crocker J. Self-esteem and self-serving biases in reactions to positive and negative events: An integrative review. In: Baumeister RF, ed. *Self-Esteem: The Puzzle of Low Self-Regard*. USA: Springer US; 1993:55–85.

66. Fitch G. Effects of self-esteem, perceived performance, and choice on causal attributions. *J Pers Soc Psychol*. 1970;16(2):311–315. http://doi.org/10.1037/h0029847.

67. Calleja S, Islam FMA, Kingsley J, McDonald R. Healthcare access for autistic adults: A systematic review. *Medicine (Baltimore)*. 2020;99(29):e20899. https://doi.org/10.1097/MD.0000000000020899.

68. Chen JL, Leader G, Sung C, Leahy M. Trends in employment for individuals with autism spectrum disorder: A review of the research literature. *Rev J Autism Dev Disord*. 2015;2(2):115–127. https://doi.org/10.1007/s40489-014-0041-6.

69. Bargiela S, Steward R, Mandy W. The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *J Autism Dev Disord*. 2016;46(10):3281–3294. https://doi.org/10.1007/s10803-016-2872-8.

70. Lord C, Brugha TS, Charman T, et al. Autism spectrum disorder. *Nat Re Dis Primers*. 2020;6(1):5. https://doi.org/10.1038/s41572-019-0138-4.

71. Hume K, Loftin R, Lantz J. Increasing independence in autism spectrum disorders: A review of three focused interventions. *J Autism Dev Disord*. 2009;39(9):1329–1338. http://doi.org/10.1007/s10803-009-0751-2.

72. McGill O, Robinson A. ''Recalling hidden harms'': Autistic experiences of childhood applied behavioural analysis (ABA). *Adv Autism*. 2021;7(4):269–282. https://doi.org/10.1108/AIA-04-2020-0025.

73. Gagnon RJ, Garst BA, Kouros CD, Schiffrin HH, Cui M. When overparenting is normal parenting: Examining child disability and overparenting in early adolescence. *J Child*

Fam Stud. 2020;29(2):413–425. https://doi.org/10.1007/s10826-019-01623-1.

74. McCoy S, Maître B, Watson D, Banks J. The role of parental expectations in understanding social and academic well-being among children with disabilities in Ireland. *Eur J Spec Needs Educ*. 2016;31(4):535–552. https://doi.org/10.1080/08856257.2016.1199607.

75. Tomaszewski B, Kraemer B, Steinbrenner JR, et al. Student, educator, and parent perspectives of self-determination in high school students with autism spectrum dsorder. *Autism Res*. 2020;13(12):2164–2176. https://doi.org/10.1002/aur.2337.

76. Loomes R, Hull L, Mandy WPL. What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *J Am Acad Child Adolesc Psychiatry*. 2017;56(6):466–474. https://doi.org/10.1016/j.jaac.2017.03.013.

77. Glass DC, Kelsall HL, Slegers C, et al. A telephone survey of factors affecting willingness to participate in health research surveys. *BMC Public Health*. 2015;15(1):1017. https://doi.org/10.1186/s12889-015-2350-9.

78. Johnsen NF, Thomsen BL, Hansen JV, Christensen BS, Rugulies R, Schlünssen V. Job type and other socio-demographic factors associated with participation in a national, cross-sectional study of Danish employees. *BMJ Open*. 2019;9(8):27056. https://doi.org/10.1136/bmjopen-2018-027056.

79. Rødgaard E-M, Jensen K, Miskowiak KW, Mottron L. Representativeness of autistic samples in studies recruiting through social media. *Autism Res*. 2022;15(8):1447–1456. https://doi.org/10.1002/aur.2777.

80. King M, Dinos S, Shaw J, et al. The Stigma Scale: Development of a standardised measure of the stigma of mental illness. *Br J Psychiatry*. 2007;190(3):248–254. https://doi.org/10.1192/bjp.bp.106.024638.

81. McDonald TAM. Discriminative and criterion validity of the Autism Spectrum Identity Scale (ASIS). *J Autism Dev Disord*. 2017;47(10):3018–3028. https://doi.org/10.1007/s10803-017-3221-2.

82. Australian Bureau of Statistics. Postcode 2017 to remoteness area 2016, 'Table 3: Correspondence'. 2020. https://www.abs.gov.au/ausstats/abs@.nsf/mf/1270.0.55.005 Accessed February 7, 2020.

Address correspondence to:
Samuel R.C. Arnold, PhD
Department of Developmental Disability
Neuropsychiatry (3DN)
University of New South Wales Sydney
Sydney, NSW 2052
Australia

E-mail: samuel.arnold@unsw.edu.au