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TALKING ABOUT AUTISM AND EXPLORING AUTISTIC IDENTITIES

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Abstract

Talking About Autism and Exploring Autistic Identities

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Autism is often framed using a deficit lens with ableist beliefs and medical model perspectives promoting the curing, treatment, or camouflaging of autistic characteristics. This contributes to poor outcomes experienced by many within the autistic community, including but not limited to victimization at higher rates (Fisher & Lounds Taylor, 2016; Nansel et al., 2001), lower satisfaction with quality of life in work, education, and relationships (Barneveld et al., 2014), suicidal ideation at higher frequencies (Mayes et al., 2013), and low self-esteem and high depression and anxiety (Cooper et al., 2017). Increased efforts are necessary to better understand how to support positive autistic identity development. This dissertation is comprised of three papers outlined below, aimed at exploring autistic identity.

Paper 1 sought to analyze how autistic adults without a formal autism diagnosis construct autistic identities in the narratives they tell about disclosure or talking to other about being autistic. Through interviewing using participant-preferred modalities, narratives were elicited from 15 self-identified autistic adults. Narratives were thematically and then discursively examined using Bamberg's 3-level model of positioning (Bamberg, 1997). Analysis showed that positioning techniques like reported speech, double-voiced discourse, and juxtaposition of characters were used by participants to reveal doubt experienced in self-identifying, claim autistic membership, and assert autism expertise. For autistic adults without formal diagnosis,

discussing autism and sharing their autistic identification can be a challenging experience. Understanding how these exchanges are narrated can offer insight on how to better support and affirm self-identified autistic adults.

Paper 2 examined the experiences of autistic adolescents and their caregivers of engaging in talk about autism. Adopting a multiperspectival interpretative phenomenological analytic (IPA) approach, 3 parent-child dyads were recruited and individually interviewed. Parents and adolescents were treated as separate participant groups and analysis of individual interviews was followed by cross-case analysis to identify group experiential themes. Adolescents found that conversations with their mothers impacted their autistic identity by strengthening perceived areas of difficulty related to autism and helping them to better understand themselves and conceptualizing autism. Caregivers noted that conversations about autism with their child felt natural, were spaces to frame autism in particular ways, and were opportunities to guide them through challenging social situations and offer support. This IPA study contributes to autism research in describing the psychosocial experience of autism-related talk between parent and child, appreciating the multiple perspectives involved in these interactions.

Using hierarchical regression and mediation models, Paper 3 identified the relationships between (a) awareness and knowledge about autism, (b) orientation to neurodiversity perspectives, (c) level of outness, (d) autism-related stigma consciousness, (e) autistic identity, and (f) mental well-being of autistic adults. A sample of 169 participants completed an online survey comprised of measures indexing these constructs. Autism awareness and knowledge, alignment with neurodiversity perspectives, outness, and stigma consciousness were predictive of autistic identity when controlling for gender, sexuality, and number of years knowing about autistic status. When entered into the regression model together, only orientation to

neurodiversity perspectives uniquely predicted autistic identity. Additionally, results showed that autistic identity mediated the relationship between stigma-related consciousness and mental wellbeing. This work offers direction for promoting positive autistic identity development.

Keywords: autism, autistic identity, adulthood, adolescence

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I

INTRODUCTION

Talking About Autism and Exploring Autistic Identities

It feels like the smoothness of this pen against paper
It feels like the inability to sit still.
It feels physically comfortable
It feels like nowhere is just right
It feels like nowhere feels like home
It feels like the inability to string anything together, so all my thoughts are in fragments
It feels fast, it feels like constant noise and interference
It feels like the constant fear of the future
It feels uncomfortable being unable to predict where I might be in five years
It feels uncomfortable being unable to construct a vision for the next five years
It feels like I'm constantly reacting
It feels fragile
It feels like constant attention
It feels like noise, noise, noise, noise, noise
It feels like repetition and things and lists
It feels like the inability to read a map from point A to B
It feels like the constant need to use drugs to enjoy my mind as well as to escape it
It feels like revisiting the same places and ideas over and over
It feels like nothing is familiar
It feels like a constant pursuit for the familiar
It feels more complicated than nostalgia
It feels comfort in community
It feels impossible to create community
It feels like psychosis
It feels so, so, so fucking specific and it feels so, so, so fucking unattainable
It feels like a distance between my heart and my mind
It feels like falling in love over music
It feels like falling in love over feeling anything
It feels like numbness without feeling
It feels black and it feels white
It feels like a fucking alien
It's always felt different, it's always wanted out
It feels like it doesn't understand idioms
It feels like having to understand what people want to hear when they say, “What's up?”
It feels like it wants to answer that question honestly, every single time without exception
It feels so uncomfortable dating; it has no idea where to start
It feels like there's no vision
It feels like everything is bad
It feels like everything is good
It feels like constant contradictions.

Naomi is a genderqueer autistic adult who participated in the first study introduced in this manuscript, sharing stories of how they came to self-identify as autistic without a formal diagnosis. Having struggled to describe what autism feels like for their therapist, Naomi opted to journal their thoughts and create this list of feelings which they describe as a “stream of consciousness." This passage reflects the contradictions of their autistic reality: joy and challenge; order and erraticism; ease and discomfort; bad and good. Beginning with Naomi's prose appropriately leads into this manuscript aimed at centering autistic perspectives and poignantly describes the complexity of the autistic experience.

Feeling the need to "pass" as non-disabled and/or not autistic or camouflage some traits that are characteristic of being autistic, is part of the lived experience for many autistic youth and adults (Baines, 2012; Kanfiszer et al., 2017). Disability is considered a "historically contingent, socially constructed phenomenon" and most definitions of disability contain, "a social as well as a bodily component" (Grue, 2016, p. 958). The diagnosis of autism spectrum disorder (ASD) is marked by impairments in social interaction and communication, as well as restricted and repetitive behaviors and/or interests (American Psychiatric Association, 2013). For autistic individuals, harnessing stereotyped repetitive behaviors and adopting prescribed social behaviors imposed through social skills interventions can contribute to others in society not viewing them as disabled – as though this is the most desirable outcome or goal (Heilker & Yergeau, 2011; Grue, 2016). What contributes to autistic youth and adults adopting a perspective like this? Phenomenological studies interviewing autistic adolescents and adults reveal fears of stigmatization and discrimination, feelings of difference, and experiences of bullying and victimization (Jones, Gallus, Viering, & Oseland, 2015; Kanfiszer, Davies, & Collins, 2017; Lewis, 2016; Parsloe, 2015; Mogensen & Mason, 2015; Baines, 2012). Crane, Jones, Prosser, Taghrizi, and Pellicano (2019) suggest that when framed positively in conversations between caretaker and child, talking about autism can encourage an earlier, and more inviting approach to viewing autism as an inextricable and valuable part of one's identity.

There are clear connections to other marginalized identities in society (i.e. gender, sexual orientation, cultural, racial) which further cements the assertion that disability – and autism more specifically – is a cultural identity and social group (Clary-Lemon, 2010). Autism *in culture* carries associations with medical rhetoric which problematizes disability and frames autism as a disease to prevent, treat, and cure (Parsloe, 2015; Broderick & Ne'eman, 2008). In contrast, autism *as culture* adopts a more communal identity that embraces neurodiversity and celebrates/recognizes difference (Parsloe, 2015; Broderick & Ne'eman, 2008).

More work looking at the performance of an autistic identity remains necessary in the field. Lester and Paulus (2012) acknowledge how research tends to focus on examining the way autistic individuals organize their talk, but not on how the talk generated works to construct a conceptualization of "autism." Instead of analyzing the voices and perspectives of autistic youth and/or adults, Lester and Paulus (2012) looked at the performance of autism, as told by caretakers and service providers. Efforts in autism research are increasingly made to invite and prioritize the participation and expertise of autistic individuals themselves.

It is important to account for how autism is being framed in talk by stakeholders who engage often in discussions with autistic youth and adolescents regarding diagnosis and support services. Disclosing a diagnosis of autism to one's child is a difficult experience, leaving caregivers unsure of when (or if) to disclose and how to talk about autism effectively (Crane et al., 2019; Smith et al., 2018). We must examine what contributes to the cultivation of higher autistic identities and self-concept, and what this means for autistic individuals. Research suggests that identifying with autism promotes self-esteem, protects against poor mental health (Cooper, Smith, & Russell, 2017), and relates to more reported disclosure which links to fewer camouflaging behaviors (Cage & Troxwell-Whitman, 2020). Determining which variables influence and explain autistic identity and how autistic individuals account their autism discovery experiences can highlight areas for caregivers, service providers medical and therapeutic professionals, and others within the autistic community to further support autistic individuals.

Overview of the Dissertation

The threads that weave the three papers comprising this dissertation are that of *talk* and *identity*: Papers 1 and 2 view discourse and experience as vehicles for building and structuring identities, while Paper 3 viewed autistic identity as a more stable construct, influenced by other variables.

Paper 1 sought to answer the research question: When telling narratives about disclosure or talking about autism with others, how do autistic adults construct autistic identities? Communicated text and actual speech of participants was discursively analyzed to reveal how self-identified autistic adults construct their autistic identities. Through talk, identities related to autism were performed by participants as they recounted narratives about disclosing or talking to others about being autistic.

Paper 2 proposed that the way talk and conversation about autism is conducted with one's caregiver contributes to the development of an adolescent's autistic identity. This interactive discourse with caregivers marks an exchange of information about autism where autistic youth learn what it means to be autistic. The research questions answered are: (1) How do autistic youth describe the impact of conversations with caregivers about autism on identity? And (2) How do the caregivers of autistic youth think about the experience of talking to their child about autism?

Paper 3 offers a departure from a more discourse-driven and phenomenological approach to identity construction, and instead adopts a static lens aiming to capture autistic identification using measures that account for individual attributes and broader group subscriptions to disability and autism. The extent to which the variables of autism knowledge and awareness, alignment with neurodiversity perspectives, stigma consciousness, and outness explained the concept of autistic identity was explored, answering the question: Which of the following variables, including autism awareness, orientation to neurodiversity perspectives, stigma consciousness, and outness predict variance in autism identification when controlling for gender, sexuality, and number of years knowing about one's autism? Additionally, this study looked at if and how autistic identity mediates the relationship between autism-related stigma consciousness and mental wellbeing, answering the question: Does autism identification mediate the effect of stigma consciousness on mental well-being?

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II

SELF-IDENTIFICATION OF AUTISM THROUGH NARRATIVES

Self-Identification of Autism Through Narratives

With increased prevalence of the autism diagnosis in the US and other Western countries, there has also been increased debate amongst different stakeholders, researchers, and community members as to how to conceptualize, define, and approach autism (Hens, Robeyns, & Schaubroeck, 2019). One such argument is how to view autism and how, depending on the lens adopted, this accounts for individuals who self-diagnose and identify as autistic. To view autism as a “neurological reality” (Hens et al., 2019, p. 3) emphasizes the natural, physiological, and genetic origins of autism shared across the autistic community, further positing that medical professionals are solely capable of confirming autism in individuals and thereby rejecting the practice of self-diagnosis (Sarrett, 2016). Autism as a “psychiatric diagnosis” instead focuses on the phenotypic behaviors that arise from autism and acknowledges how social challenges experienced while navigating neurotypical contexts within society contributes to defining autism (Hens et al., 2019, p. 3). This view creates space for accepting self-diagnosis; it appreciates the experiences of autistic individuals and allows for them to serve as experts capable of defining what autism is rather than prioritizing the medical model practice of empowering clinicians to determine ingroup membership to the autistic community (Gillespie-Lynch et al., 2017; Sarrett, 2016).

Sarrett (2016) contributes the term, “biocertification” to the discourse regarding the contested practice and legitimacy of self-diagnosis. Biocertification is the process by which one’s social identity is influenced and verified by institutional practices including medical and psychiatric diagnosis (Samuels, 2014). Challenges to formal autism diagnosis have led to increases in self-diagnosis among autistic adults (Lewis, 2017). With a broadening of the diagnostic criteria, there is an increased prevalence of autism observed in the general population

(Fombonne, 2005), leaving adults who failed to be identified in their youth to navigate their childhood, adolescence, and young adulthood without proper supports and to be referred to as a “lost generation” (Lai & Baron-Cohen, 2015). Individuals without intellectual disability and autistic women tend to be overlooked in diagnosis because they may exhibit highly adaptive functioning skills (Lehnhardt et al., 2013; Mayes et al., 2014) and diagnostic criteria and assessment measures are insensitive to gender expressions other than boys and men (Lai et al., 2011). Members of the autistic community who dismiss self-diagnosis argue that people who suspect they may be autistic are too biased to accurately determine the presence of autism in the self and that a trained professional is better suited to objectively and properly diagnose (Sarrett, 2016). Further, autistic opponents of this practice suggest that while those who self-diagnose may recognize traces of autistic traits in themselves, they may fail to attain clinical diagnosis because they are not actually autistic (Sarrett, 2016). This claim highlights tension within the autistic community and leads to the question: Who can claim group membership to the autistic community? Never receiving a formal diagnosis can lead some within the autistic community to question whether that person experienced comparable levels of impairment or challenge, rendering them ill-fit to advocate or offer autism expertise (Sarrett, 2016), when absence of a formal diagnosis may signal poor access to adult assessment, an inability to cover diagnostic costs, and fear of being unable to articulate symptoms or doubted by a medical professional (Lewis, 2016; 2017; Zener 2019).

Criticism of the medical model can lead to suspicion of clinician ability to accurately diagnose autism and invites acceptance of self-diagnosis as a practice (Sarrett, 2016). While therapeutic and medical professionals are trained to detect symptoms outlined by diagnostic criteria, an autistic person knows and understands the complexity and variability of the lived autistic experience (Angulo-Jimenez & DeThorne, 2019; Sarrett, 2016). Therefore, autistic proponents of self-diagnosis trust that those who self-identify share in having expertise (Sarrett, 2016; Zener 2019).

Little autism research exists which specifically examines the experience of self-identification, or self-diagnosis. Lewis (2016) asked 37 adults to describe their experience of self-diagnosing autism through an open-ended survey. Participants identified feeling different pre-diagnosis and persistently suspected autism as an explanation for behavior/tendencies (Lewis, 2016). After self-diagnosis, they reported feeling like they belonged and that they were at home within autistic communities online offering support and guidance. Not only did participants note feeling accepted, but they indicated feeling like they understood themselves more and could better understand past experiences in light of the diagnosis. Some self-diagnosed autistic individuals emphasized how self-diagnosis leads to nothing "concrete" (Sarrett, 2016, p. 30) which complements participant responses from Lewis' (2016) study suggesting no meaningful benefits would come with a clinical designation in adulthood. Lastly, participants explained how a formal diagnosis felt less necessary and identified some fear in considering the pursuit of clinical validation. Self-diagnosed participants shared concerns that they may not be believed by medical professionals, may be told they are not autistic, and/or may be perceived as someone seeking special or unique status.

Autism researchers often emphasize the confirmation of a formal autism diagnosis within their participant samples, leaving those without formal diagnosis unable to contribute their views and highlight their unique perspectives (Weksler-Derri, Shwed, & Davidovitch, 2019). While Lewis (2016) has examined the experience of autistic self-diagnosis in adults using a phenomenological approach, more research is needed that discursively analyzes the talk of self-identified autistic adults as they share stories of their process to personal discovery and autistic identity. Such work can highlight the ways in which self-identified autistic individuals position themselves to or away from diagnostic criteria, associated and stereotypic traits, and broader societal discourses regarding autism. Understanding how self-identified autistic adults recount these narratives can help direct efforts in better affirming (Frost et al., 2019) and including their perspectives when considering support provisions and diagnostic processes.

Personal Narratives and the Performance of Identity

Narratives are personal experiences that retell past events and share information or knowledge through interpersonal exchanges like everyday dialogue, performance, or interviewing. These personal accounts or recounted stories feature particular qualities including a plot, linked and temporally sequenced events, and characters positioned within a setting, from the perspective of the narrator (Bamberg, 2012). In the telling of narratives, narrators express to an audience the significance of the past occasion (Bamberg, 1997) and the meaning that has been made from it (Bruner, 1991). Every retelling reveals a new narrative; narratives can take on a new form with narrators making appropriate adjustments for different audiences. While the qualities of a past event may be consistent, it is in the act or performance of narrating where narrators position and reposition the self in relation to others repeatedly in events of action, change, and/or conflict (Capps & Ochs, 1995; Georgakopoulou, 2006a; Ochs & Capps, 2001; Ochs, 2004; Riessman, 2003) to achieve particular representations of the self and construct identities (Bamberg, 1997; Bucholtz & Hall, 2005; Deppermann, 2015; Georgakopoulou, 2006b). Because narrative is an oral or written medium through which narrators can convey their human experience (Georgakopoulou, 2006a), it is an appropriate vehicle for analyzing how autistic adults come to self-identify or self-diagnose (De Fina & Georgakopoulou, 2012).

Positioning

Positioning is a discursive process where narrators construct identities through locating the self in stories told (Davies & Harré, 1990; De Fina & Georgakopoulou, 2012). Through orienting the self in relation to other characters in the story, to an audience, and to broader sociocultural discourses that extend beyond the local interaction, narrators can achieve particular goals (Bamberg, 1997; 2004; Davies & Harré, 1990). Within their stories, narrators can position other characters in ways that ascribe them the part of antagonist, while themselves claim a more positive protagonist role (Ochs & Capps, 2001). Narrators use various discursive strategies to position themselves and others within storied events and in doing so construct identities that are empowered, assert authority, and establish control (Riessman, 2000).

Using a three-level approach, Bamberg (1997) offers an analytic framework for discursively examining narratives and the ways that narrators use them to construct their identities (Bamberg & Georgakopoulou, 2008). At level 1, narratives are examined within the storied world and hone in on how narrators identify and assign roles to characters, describe actions, and place the self within the story (Bamberg 1997, 2004; Bamberg & Georgakopoulou, 2008). Level 2 looks at the storytelling world and how narrators position themselves in relation to their interaction partners, or audience, as they perform their narratives; how does the narrator engage their audience and represent the self accordingly? (Bamberg 1997, 2004; Bamberg & Georgakopoulou, 2008). Analysis across the levels becomes progressively less localized from storied events and the conversation with the audience. More broadly, analysis at Level 3 focuses on how narrators claim particular identities and position themselves in particular ways within larger sociocultural discourses (Bamberg, 2004; Bamberg & Georgakopoulou, 2008). This analytic approach at multiple levels accounts for the complexity of telling narratives as a social performance of constructing identities.

Purpose & Research Questions

Self-identified adults actively claim autistic identities, but what do they employ in their speech to further do so? Using narrative analysis with a sociolinguistic, discourse analytic perspective, this study analyzed the personal narratives elicited by self-identified autistic adults. The following question guided this study: When telling narratives about disclosure or talking about autism with others, how do autistic adults construct autistic identities?

Methods

This study takes a sociolinguistic perspective to focus on how participants construct their autistic identities through the experience of self-diagnosis and discovery. Adopting Bamberg's (1997; 2004) analytical model of positioning, narratives told by autistic participants within interviews inquiring of their process and journey to self-identification were analyzed at three distinct levels. Positioning analysis has been selected for its multifaceted approach that examines how narrators present context-dependent versions of the self in interaction (Depperman, 2013). Using this approach allows researchers to study how a narrator locates the self and biographical orientations within a story, places themselves in relation to their audience while telling that story, and connects themselves to larger social positions or discourses (Bamberg, 2004; Depperman, 2013).

Participants

Non-probability purposive sampling was adopted to procure a participant group of 15 self-diagnosed autistic adults. Inclusion criteria for participants required that they (1) have never received a formal diagnosis of ASD and have elected to self-identify, and (2) are adults, ages 18 years and older. Recruitment was conducted primarily through Facebook and Twitter advertisement and email solicitation of community groups that access autistic communities and/or provide services for families with autistic members. Participants ranged in age from 24 to 59 years of age. Nine participants identified as female, 3 as male, 2 as genderqueer or agender, and one who preferred not to say. Additional demographic information can be found in Table 1.

Table 1

Participant Demographics

Participant	Age (years)	Gender Identity	Sexuality	Transgender	Race	Latinx	Level of Education	Employment Status	Level of Speaking Words
Bessie	35	Female	Asexual	No	Caucasian / White	No	Professional or doctorate degree	Employed full-time	Mostly speaking
Jae	34	Male	Bisexual or pansexual	Yes	Caucasian / White	No	Bachelor's degree	Employed full-time	Mostly speaking
Abel	48	Prefer not to say	Prefer not to say	Prefer not to say	Mixed race	Yes	Professional or doctorate degree	Employed full-time	Mostly speaking
Muriel	31	Female	Heterosexual or straight	No	African American/ Black	No	Bachelor's degree	Unemployed & looking for work	Mostly speaking
Neil	59	Male	Heterosexual or straight	No	Caucasian / White	No	Professional or doctorate degree	Employed part-time	Mostly speaking
Ann	40	Female	Heterosexual or straight	No	Caucasian / White	No	Bachelor's degree	Employed part-time	Mostly speaking

Participant	Age (years)	Gender Identity	Sexuality	Transgender	Race	Latinx	Level of Education	Employment Status	Level of Speaking Words
Desiree	32	Female	Heterosexual or straight	No	African American/ Black	No	Some college	Unemployed & not looking for work	Semi-speaking
Tracey	33	Female	Heterosexual or straight	No	African American/ Black	No	High school degree or equivalent	Unemployed & looking for work	Semi-speaking
Regina	34	Female	Heterosexual or straight	Yes	*Did not answer*	No	High school degree or equivalent	Unemployed & looking for work	Semi-speaking
Naomi	31	Genderqueer	Bisexual or pansexual	No	Caucasian / White	No	Bachelor's degree	Employed part-time	Mostly speaking
Weston	35	Male	Bisexual or pansexual	No	African American/ Black	Yes	Master's degree	Employed full-time	Mostly speaking
Kelli	28	Female	Heterosexual or straight	No	Caucasian / White	No	Associate's degree	Homemaker	Mostly speaking
Lora	24	Female	Bisexual or pansexual	No	Caucasian / White	No	Some college	Employed part-time	Mostly speaking
Freida	36	Female	Heterosexual or straight	No	Caucasian / White	No	Master's degree	Employed full-time	Mostly speaking

Participant	Age (years)	Gender Identity	Sexuality	Transgender	Race	Latinx	Level of Education	Employment Status	Level of Speaking Words
Jeri	35	Agender	Asexual	Yes	Caucasian / White	No	Master's degree	Student	Mostly speaking

Interview Schedule

Stories about participant experiences of becoming aware they were autistic were evoked through the process of *narrative interviewing* (Riessman, 2008). Narrative interviewing is an ethnographic approach to data collection in that its goal is to elicit extended participant accounts. To encourage expansion, questions were structured to ask participants to "tell" about what happened in a given moment, rather than ask a more closed question of "what happened" (Riessman, 2008, p. 25). Interviews were conducted through a video conference (n=6), an audio-only call (n=4), and by way of an online instant messaging or chat platform (n=5). Participants chose their preferred modality, and the interview schedule was given to them in advance allowing for review and familiarity. See Appendix B for the semi-structured interview protocol.

Data Analysis

Interviews were transcribed verbatim and reviewed for evidence of narrative episodes. A narrative episode was operationalized as an interview segment that: (1) may or may not stretch across multiple answering turns, (2) identifies a protagonist, (3) establishes temporality with a progression of events in a past setting, and (4) involves action, change, and/or conflict (Georgakopoulou, 2006a; Ochs et al., 2004; Ochs & Capps, 2001). Participants in this study were explicitly asked to, "Tell what happened when you first became aware of your autism," in an effort to encourage "extended accounts" and lengthy storytelling (Riessman, 2008, p. 25). Across all participants, a total of 172 narrative episodes were identified. Participant narrative counts are provided in Table 2.

Table 2

Participant Demographics (cont.) & Narrative Episode Count

Participant	Description of Interest/Status in Formal Diagnosis	# Years Knowing Autistic Identity	# Narrative Episodes
Bessie	Currently awaiting formal diagnosis.	19	16
Jae	Other: “Undecided. Finances, no one in my area diagnoses adults, and unsure if I will lose any rights with a diagnosis.”	1	5
Abel	Plans to seek a formal diagnosis.	2	16
Muriel	Does not want a formal diagnosis.	7	7
Neil	Plans to seek a formal diagnosis.	15	14
Ann	Other: “I’m open to a formal diagnosis if offered, but don’t necessarily seek one.”	1	15
Desiree	Does not want a formal diagnosis.	10	1
Tracey	Does not want a formal diagnosis.	12	2
Regina	Does not want a formal diagnosis.	13	2
Naomi	Plans to seek a formal diagnosis.	2	13
Weston	Plans to seek a formal diagnosis.	32	9
Kelli	Does not want a formal diagnosis.	1	18
Lora	Plans to seek a formal diagnosis.	1	19
Freida	Other: “I haven’t decided.”	1.5	14
Jeri	Other: “Undecided whether I will ever seek a formal autism diagnosis.”	13	21

Following the identification of narratives, the corpus was first analyzed thematically and then discursively (e.g. Solomon & Lawlor, 2013) using Bamberg's model of positioning (Bamberg, 1997). When asked to share their process of self-identification with autism, participants recounted stories that explored a wide range of topics like the experience of adaptive morphing (also referred to as "masking" or "camouflaging"), meltdowns, and mistreatment from others. Thematic analysis of narrative episodes identified content patterning across participants and revealed ideas or themes that were most representative of the sample. For 13 of 15 participants, narratives recounting disclosure and/or what it was like to talk with others about their autism were evident. These narratives were then analyzed according to the three different levels of positioning which comprise Bamberg's analytical model (Bamberg 1997; Bamberg 2004). Using a discourse analytic approach, I used guiding questions derived from Bamberg (2004) and Bamberg and Georgakoppoulou (2008) that are provided in Table 3. Participants' use of positioning strategies in the telling of their narratives were located and examined to highlight how they place themselves as narrators within the storied context (level 1), in the story-telling world (level 2), and more largely within master discourses of autism (level 3) (Bamberg, 1997; Bamberg & Georgakopoulou, 2008). Positioning techniques were inductively identified at each level of analysis. The most relevant positioning techniques include constructed dialogue (Tannen, 1989), double-voiced discourse (Bakhtin, 1994), and juxtaposition of multiple characters' responses to narrator disclosure and talk about autism.

Constructed dialogue, or reported speech, is the recounted spoken discourse or interaction from a past event (Holt, 2009). Repeated past dialogue can be "direct," recalling utterances verbatim, or "indirect," offering a paraphrasing of speech (Tannen, 1989). Using constructed discourse as an evaluative device allowed narrators to situate characters within the narrative, grant particular characters a voice, and create a self-image demonstrative of moral beliefs and/or agency at positioning level 1 (De Fina & Georgakopoulou, 2012).

Double-voiced discourse refers to “two voices, two meanings and two expressions” that are interrelated within a single interaction (Bakhtin, 1981, p. 324). It has been described as a type of “reflexive talk” (Baxter, 2011, p. 235) where a speaker is acutely aware of their audience and supplements or adjusts their talk to reflect “two consciousnesses” (Bakhtin, 1994, p. 102). An example of this in research includes examining how children read a book aloud while simultaneously commenting on elements of the story (Sterponi, 2007). In the current study, employing double-voiced discourse as a strategy at positioning level 2 enabled narrators to share their inner dialogue and thinking to gain understanding from their audience, resolve, in present time, tensions experienced in the storied world, and to (re)claim power in what may have felt like a difficult past exchange (Baxter, 2014).

Juxtaposition in narrative is the portrayal of two characters, scenarios or contexts with opposing stances, and often from different temporal periods (Bakhtin, 1929/1973; Hermans, 1996; Wortham & Rhodes, 2015), to create one single story (Mertz, 1996). To position the self in cultural discourses at positioning level 3, narrators juxtaposed and compared other characters’ responses to disclosure and discussion of autism to reveal the range of responses that narrators have had to navigate in their self-identification process, highlighting their experienced struggle/support and rejection/validation, and social categorization of the self and others.

Table 3

Guiding questions for micro-analysis with examples per positioning level

Positioning Level	Questions Guiding Micro-Analysis (Adapted from Bamberg, 2004; Bamberg & Georgakoppoulou, 2008)	Examples (Bamberg, 2004, p. 9-10)
1	● Who are the characters within the episode? ● What actions are performed by the characters? ● How does the narrator situate others in the episode? ● How does the narrator situate him/herself in relation to others in the episode? ● How does the narrator describe him/herself in the episode? ● How does the narrator describe others in the episode?	- Categorical names given to characters within the story: "a *kid,* another *child* in our class" - Descriptors to characterize others: "I think she is *worthless*… she's *horrible."*
2	● What does the narrator achieve in telling this particular episode to his/her/their audience? ● What representation of self does this positioning achieve for the narrator in the storytelling context?	- Hedges to qualify or limit statements told to audience: "*I know it may sound mean to say this* but we couldn't really care less about her anyway."
3	● How does the narrator want to be understood by his/her/their audience? ● What sense of self does the narrator create for his/her/their audience, as it relates to autism? ● How does the narrator position him/herself to larger cultural discourses regarding autism?	- Establishing and affirming a broader culture: "It was like so shocking that Ted didn't even believe it." *In this example, male narrators establish what is morally acceptable ("it was like so shocking") and position themselves as responsible and virtuous in comparison ("Ted didn't even believe it").*

Findings

In accordance with other research employing Bamberg’s analytical model of positioning, (Blix, Hamran, & Normann, 2015; Miller, 2013) analysis focused on a subset of the dataset to allow for microanalysis. Kelli and Abel’s narratives about disclosing and talking about being autistic with others were strong examples of the most relevant positioning strategies of constructed dialogue, double-voiced discourse, and character juxtaposition which were evident in most participant narratives telling stories with this theme. The following narrative episodes from Kelli and Abel were elicited in response to prompts aimed at learning more about their self-identification process and experience. Narratives will be presented by participant, and will be analyzed at each positioning level, expanding on the discursive strategy associated with that level.

Kelli’s Psychological Evaluation

At the onset of the interview, Kelli was invited to share stories associated with her autistic self-identification. The following narrative recounts discussions with her husband and a psychiatrist or psychologist capable of diagnosing ADHD.

Table 4

Transcript of Kelli's Psychological Evaluation

The interview began with Kelli being invited to share her experiences at what felt like a "natural starting point" for her. She shared the following narrative.

1 For the past few years, I've wondered,
2 “Maybe I'm autistic. Maybe that's what's going on.”
3 But I honestly wouldn't even let myself say that out loud. Like
4 I think I brought it up to my husband once a few years ago,

and he was kind of like, “Well, maybe.”
But he's also autistic, so,
I couldn't really read like, “Is this making him uncomfortable?" Like,
"Does he disagree? Does he feel like I'm invalidating his struggles,
because I'm claiming that I have the same ones?”
So I kind of just set that aside.
I was in college at the time
when I needed a psych eval to receive accommodations for my ADHD.
So I went and had the psych eval,
which was just like over the course of an hour and a half or two hours.
It was really rushed.
We had suspected that I might have a learning disability,
and so he tested for learning disabilities.
He tested my IQ and he did some like, testing for like surveys and stuff about ADHD.
And kind of towards the end I said,
“So, I am wondering, do you think I could be autistic? And here's why...”
And I kind of like had that list of,
kind of points in my head of,
“Here are the things that affected me the most.”
"Surely, if I tell him these things,
he will at least see where I'm coming from!"
And he said, “Oh, no.
You're not autistic.
You came in here.
You looked me in the eye.
You shook my hand.
You introduced yourself.

32 You did fine when we were having conversation.
33 If you had autism,
34 you'd be like looking at your feet.
35 You would not want to look at my face,”
36 and all of this.
37 And I felt so invalidated because he never even did a screener.
38 He didn't ask me any questions – nothing.
39 And so I walked away from that and thought,
40 “Okay, I'm just being ridiculous”. Like,
41 "I am claiming to have struggles that apparently I do not have
42 or they can be attributed to my other diagnoses,
43 and I just need to stop being so dramatic."
44 You know?
45 And I kind of felt bad about myself that…
46 I don't know that I just, and even now,
47 I really try hard.
48 I don't want to invalidate my husband’s struggles
49 because he is diagnosed. It's like,
50 if someone has a migraine,
51 and you come in, and you're like,
52 “Oh, yeah, my head hurts so bad too. My head is just awful.”
53 And it's like,
54 drawing away from what they're dealing with.
55 And I don't want to do that to my husband.

Level 1: Positioning of Characters in the Storied World (Bamberg, 1997)

Within this narrative, there are three central characters: Kelli, her husband, and the medical professional leading her psychological evaluation. Kelli situates her narrative and orients her audience, establishing temporality and telling her psychological stance in the opening, "For the past few years, I've wondered, 'Maybe I'm autistic'" (lines 1-2). Her first example of reported speech follows the introduction of her husband as a character in this narrative. After suggesting to her husband that she may be autistic, he replies with, "Well, maybe" (line 5), giving a response that is neither validating nor dismissive. She goes on to explain to her audience, "But he's also autistic" (line 6) and achieves a few things discursively in the process: Kelli identified her husband as autistic, assigning with certainty his membership to this social categorization, and in sharing that he's "*also* autistic," Kelli indicates her own social categorization and membership within the autistic community. The neutrality of her husband's response causes Kelli to engage in the inner dialogue featured in lines 7 to 9 questioning her husband's level of agreement and comfort with the idea that she too may be autistic. This establishes some of her own reticence in fully claiming an autistic identity and foregrounds her subsequent interaction with the medical professional.

The next example of constructed dialogue is directed to the medical professional performing a psychological evaluation through Kelli's question, "So, I am wondering, do you think I could be autistic? And here's why" (line 20). Asking the medical professional if he thinks she could be autistic is a deferral of judgment, recognizing his expertise and ability to diagnose patients. When immediately followed by "And here's why," Kelli exhibits initiative in revealing her own knowledge of what might diagnostically qualify her to receive an autism diagnosis and how this coincides with her lived experience. This dichotomy of yielding to a professional's perspective and illustrating one's agency within a clinical space highlights how she perceives there to be a tenuous power dynamic between her and the doctor.

As Kelli reports the setting for the psychological evaluation, she notes that it "was just over the course of an hour and a half or two hours," (line 14) followed by "It was really rushed" (line 15). In providing this temporal context with an evaluative judgment that it was "really rushed," Kelli positions this doctor as one who worked in haste indexing suspicion of the quality, and thereby accuracy, of this visit. Lines 26 through 35 contain the reported speech given by the doctor in reply to her question about being autistic. In his dialogue, the doctor rejects the possibility of Kelli being autistic by telling her all of the actions she performed upon entry into the appointment and suggesting that an autistic person would be unable to behave in this way. Through describing how she felt "invalidated" (line 37) by the doctor's assertion that she is "not autistic" (line 27), Kelli continues to position the doctor as the antagonist. Further, stating that "he never even did a screener" (line 37) and that he didn't ask her "any questions – nothing" (line 38) strengthens her claim that this doctor is remiss in his practice and that her health concerns were overlooked.

Level 2: Positioning of Interaction Partners in Storytelling World (Bamberg, 1997)

Shifting often from articulating her inner thoughts to the reported speech uttered within the storied world, Kelli engages in double-voiced discourse throughout her narrative as her characters interact (Bakhtin, 1981). Kelli employs this strategy to be understood by and construct particular self-images for her audience. After the doctor rejects the suggestion that she could be autistic, Kelli tells her audience that she "walked away" (line 39) from the appointment and offers insight into what she was thinking at the time. She reports these inner thoughts as speech in lines 40 through 43. When Kelli articulates her thinking of, "Okay, I'm just being ridiculous" and “I am claiming to have struggles that apparently I do not have,” she presents a humbled self to her audience in the storytelling world. With her use of the word, “Okay,” (line 40) and “apparently” (line 41) she voices a capitulation to the doctor’s perspective and emphatic rejection of a possible autism diagnosis. In her voiced inner dialogue, she states that the characteristics she has identified as tied to autism might very well be attributed to her “other diagnoses” (line 42) and that she needs to “stop being so dramatic” (line 43) presenting to her audience her attempts to adopt the doctor’s perspective and consider alternative rationale for what she perceived to be her autistic traits; Kelli does not create a self-image that is defiant of the doctor’s evaluation, instead she double-voices to show her audience how she engaged in self-doubt when it comes to identifying as autistic.

Throughout her narrative, Kelli uses double-voiced discourse to present herself as someone plagued by self-doubt as it relates to identifying as autistic. At the onset of the narrative when Kelli mentions the possibility of being autistic with her husband, again Kelli reports her internal dialogue as speech in her storytelling. She poses the questions, “Is this making him feel uncomfortable?,” “Does he disagree?,” and “Does he feel like I’m invalidating his struggles because I’m claiming that I have the same ones?” (lines 7-10). Explaining to her audience in the storytelling world (present) what her psychological stance was within the storied world of the narrative, works to position Kelli as an empathetic wife; she is mindful of how her claiming membership to the autistic community might make her autistic husband feel minimized. For Kelli to continue considering an autistic identity even after being told by a medical professional that she is not autistic, she jeopardizes her role as an empathetic wife. Recognizing this tension, Kelli discursively tries to resolve the dissonance and preserve this role by explicitly telling her audience at the closing of her narrative, “I don’t want to invalidate my husband’s struggles” (line 48).

Level 3: Positioning in Relation to Cultural/Societal Discourses (Level 3; Bamberg, 2004)

Kelli juxtaposes the experiences from her past with her husband and with the doctor to contextualize her struggle in fully claiming autistic membership. Her narrative touches on larger social discourses about autism expertise and diagnosis (Gillespie-Lynch et al., 2017; Pellicano et al., 2020; Zener, 2019). Kelli sought out the stance and perspective of her husband and doctor on the plausibility of her being autistic. Identifying her husband as autistic and aware of the doctor’s role as a diagnostician, Kelli marks these two characters as having particular autism expertise (Gillespie-Lynch et al., 2017). When given a lukewarm response of “Well, maybe” (line 5) from her husband, and a definitive “Oh, no” (line 26) from the doctor, Kelli is not readily granted membership to the autistic community and, as in the exchange shared with her doctor, she is denied. These two recounted episodes told within the same narrative work in tandem to elicit a single message of feeling “invalidated” by others who hold expertise and power; power in being able to claim a formal autism diagnosis and power to diagnose others.

In the broader autistic community, debate regarding the legitimacy of self-identification as a practice pits biocertification against self-knowledge and lived experience (Sarrett, 2016). Though she is not granted access to an autism diagnosis from a medical professional nor afforded firm validation from her autistic spouse, Kelli prioritizes her own self-knowledge and proceeds with identifying as autistic, claiming some autism expertise herself. This tension between her self-determination of autism and the doctor’s insistence that she behaves in ways that deem her non-autistic underscores larger discourse within the autism community about how autistic identification in women and girls is infrequent, delayed, or missed (Whitlock et al., 2020;

Zener, 2019). Gender differences in autistic identification are credited only to diagnostic criteria being ill-fit for autistic girls and women, but also to diagnosticians' familiarity with autistic behavioral criteria as it is expressed in boys and men (Suckle, 2021). Because autistic women and girls are more likely to exhibit adaptive morphing behaviors (Lawson, 2020) in social relational situations (Lai et al., 2017) and be misdiagnosed or first diagnosed with other conditions, presentation of autism is often ignored or overlooked (Suckle, 2021). Kelli's narrative is demonstrative of this in how her doctor itemized a list of social behaviors she successfully enacted (lines 29-32), denied her suspicions of autism without further inquiry, and proceeded to consider only a diagnosis of ADHD. As she positions herself against the characters of her husband and doctor, Kelli constructs herself as an invisibly autistic woman, capable of drawing from her lived experiences to claim expertise and membership within the autistic community.

Abel and His Band at an Autistic Support Group Benefit

During their interview, Abel shared how they diagnosed themself with autism using available tools online and after investigating diagnostic criteria. When asked to describe this process and when it started, Abel shared the following account of being told that they are autistic by the organizer of a benefit event for an autistic support group and in tandem, what it was like telling friends or colleagues about their autistic identity.

Table 5

Transcript of Abel and His Band at an Autistic Support Group Benefit

Abel shared the following narrative when asked to describe his process of self-diagnosis.

1	Abel	I was playing music in a band,

and I was asked to participate in a benefit for an autistic… an autistic support group.
And then, so I was like,
“Oh, yeah, I'm happy to like, you know, contribute.
And, you know, we're happy to perform as a band.”
So we performed, and then only afterwards, did it come out
that they actually thought that I was autistic,
and they kind of just assumed that I was autistic.
And I was like, “No, I have not been diagnosed as autistic
and I’m not aware that I am autistic.”
And one of the people who helped organize the event was like,
somebody who does have like training in the diagnosis of autism,
was like, “No, you are, you are very autistic.”
But it wasn't part of like a formal meeting,
or me like sort of compensating them or seeing them as a diagnostician.
So they were like, “Yes, you are definitely autistic.”
And then I didn't really think that I was,
but over a period of the next month, a few months to like, a year after that,
I sort of started looking into it, and I was like,
“I guess I really am autistic.”
And gradually, as that diagnosis has been with me for a longer time,
I've sort of identified more and more features of my past.
“Oh, yeah, that was because I'm autistic.”
And now I sort of embrace the diagnosis.

Interviewer What was that like? You know,
what was that experience like after hearing this from someone
and then sort of looking further online?

Abel Well, I guess I didn't know a lot about
whatever form of autism was appropriate to ascribe to my symptomatology.
So I had the reaction that -
So I'm a radiologist.
So I'm a professional, sort of medical diagnostician based on, you know
very sort of black and white literally, like imaging stuff.
I've noticed that like, I've told other doctors,
“Hey, I'm actually autistic”
who are like, just people who are friends of mine,
and they're like, “You can't be autistic.
You're not..." you know, "you're not, you're not a small child.
You would have been diagnosed in childhood.”
And that's from people who are not working in the field of autism,
but people who are also mostly professional diagnosticians

42 radiologists that I'm surrounded with, so I kind of had a similar reaction.
43 I was very surprised because I was like,
44 "I feel like if I were autistic, I would have known by now.
45 Somebody would have said something.
46 I feel like I would have, you know, received medical treatment for it.
47 I feel like somebody would have pointed it out to me."
48 So I was also incredulous the first time it was pointed out to me.

Level 1: Positioning of Characters in the Storied World (Bamberg, 1997)

Within their full narrative and using reported speech, Abel identifies three main characters: Abel, the event organizer, and Abel's doctor friends as a one collective entity. Abel launches into the narrative by offering their audience background for their involvement with an autistic support group benefit. To contextualize the exchange Abel has with the event organizer, Abel establishes first that they were part of a band that was approached to participate and play the event because "they," the autistic support group as a whole, "thought" and "assumed" (lines 7-8) Abel is autistic. Abel constructs dialogue of "No, I have not been diagnosed" (line 9) and "I'm not aware that I'm autistic" (line 10) as a counter to the event organizer's presupposition regarding their autistic identification. While rejecting this assumption and stating later how they were "incredulous" (line 48) at first suggestion, Abel's use of passive language within their reply reveals a degree of receptiveness to actually being autistic. Through admitting that they had not been diagnosed and that they are "not aware" of being autistic (line 10), Abel leaves open the possibility of missing out on a potential diagnosis in their past and simply needing to be made aware of their autistic identification. The reported speech of the event organizer in response to Abel's negation of being autistic, argues first, "No, you are, you are very autistic" (line 13) and later is more confirmatory with, "Yes, you are definitely autistic" (line 16). This rejection of Abel's denial and affirmation of their initial supposition serves to characterize the event organizer as unyielding and firm in their belief of Abel's autistic status. This obstinance serves to position the event organizer as a domineering figure within the interaction who imposes a particular social identity upon a more passive recipient, Abel.

Alternatively, when Abel discloses to their doctor friends, “I’m actually autistic” (line 35), their colleagues are skeptical stating, “You can’t be autistic” (line 37). While Abel is careful to qualify the capability of the event organizer and their doctor friends to serve as diagnosticians, they simultaneously categorize themself as “a radiologist” (line 31), “a professional,” and “medical diagnostician” (line 32) asserting their own credentials and familiarity with criteria-based decision making. In offering this social categorization of the self, Abel positions themself as competent in evaluating the conflicting autism identifications received from the event organizer and from their medical colleagues. Within this narrative, Abel positions themself as flexible, receptive, and ultimately qualified to discern and determine their own autistic identification.

Level 2: Positioning of Interaction Partners in Storytelling World (Bamberg, 1997)

In addition to the reported speech that Abel constructs for the characters within their narrative, Abel uses double-voiced discourse. Like Kelli, Abel employs this strategy throughout their narrative to garner understanding from their audience of their perspective within the storytelling world. Abel anticipates the curiosity of their audience/interviewer, and offers, in the form of inner dialogue, their thinking and impressions of these storied interactions with the event organizer and colleagues while those parties casted their perceptions of Abel’s autistic identification. After being told they were autistic by the event organizer, Abel tells his audience that they began “looking into it” (line 19). Through this informational biocitizenship process where they sought more data about autism to determine how appropriate a diagnosis it was for them (Sarrett, 2016), Abel states that “more and more features” (line 22) of their past seemed to fit with an autism diagnosis. Abel signals to their audience their impression of its fit by saying, “I guess I really am autistic” (line 20). While Abel was receptive to being identified as autistic by the event organizer, they reveal how they allowed the label and diagnosis to “gradually” stay with them. When “a longer time” passes (line 21), Abel began to accept identifying as autistic. Abel shares their inner dialogue that takes the form of an internalized commentary (Sterponi, 2007) and reaction to his research into autism following their exchange with the event organizer. They present to their audience the self-image of a person who trusts in themself to evaluate information about autism and its relevance to their own experience, ultimately coming to an informed decision regarding their self-identification.

Abel’s first use of double voicing is to give their audience insight into their process of self-evaluation and research. Following their recounting of the “incredulous” (line 48) response their doctor friends had to their disclosure of autism, Abel double-voices again within the narrative. Here, they offer their audience an insider glimpse into their emotional response to the interaction with the event organizer. Aligned in stance with their medical colleagues, Abel notes that they “kind of had a similar reaction” (line 42) and was “very surprised” (line 43). They provide their inner dialogue of, “I feel like if I were autistic, I would have known by now” (line 44) representing themselves as skeptical and disbelieving, likely prompting their process of information gathering and application to self-determine autistic identification.

Level 3: Positioning in Relation to Cultural/Societal Discourses (Bamberg, 2004)

Juxtaposing their discussion of autism with the event organizer and with their medical colleagues in a single narrative serves to ground Abel’s reticence in affirming autistic membership. Like Kelli, Abel’s narrative reflects upon a larger social discourse surrounding autism expertise. Because Abel establishes the credibility of the event organizer as someone who has “training in the diagnosis of autism” (line 12) and their medical friends as “professional diagnosticians” (line 41), the two parties’ differing perspectives on Abel’s autistic identification provides further nuance in determining who is best suited to appropriately diagnose autistic individuals. Abel notes that these radiologist friends are not “working in the field of autism” (line 40), implying that despite being medical professionals, these doctors are less competent than other diagnosticians more familiar with how variably diagnostic autism criteria can be expressed.

Additionally, within Abel’s narrative, they state how their doctor friends were insistent that if Abel was actually autistic, they “would have been diagnosed in childhood” (line 39). Abel even admits that their incredulous response after emphatically being told they were autistic by the event organizer was because they felt they “would have known by now” (line 44) and that “somebody would have said something” (line 45). Here, Abel voices trust in medical professionals’ abilities to identify and diagnose autistic individuals in their youth, though their particular lived experience proves otherwise – Abel was never diagnosed in their youth. Like the argument made for why there are gender discrepancies in autism identification, under-identification of autism in autistic youth more generally can be attributed to observable autistic characteristics and traits presenting more subtly and going undetected (Mandell et al., 2005). By positioning themself in this narrative with the event organizer and their doctor colleagues, Abel represents themself as a self-aware autistic adult, more adept at critically analyzing diagnostic criteria and applying it to their own personal experience accurately than other medical professionals who lack a more complex understanding of autism.

Discussion

Self-identified autistic adults without a formal diagnosis constructed their autistic identities through narrative storytelling in this study. Through the act of telling their narratives, participants positioned themselves and others in ways that presented particular self-images and ultimately claimed autistic membership. There is a growing body of qualitative research examining accounts and perspectives of self-identified autistic adults and those formally diagnosed in adulthood (Leedham et al., 2020; Lewis, 2016, 2017; Lilley et al., 2021, Lilley et al., 2022) but none discursively analyze the ways that autistic adults tell their stories.

Findings echo previous work that looked at autistic individuals who had received a formal autism diagnosis in mid-adulthood and reported their experiences of others rejecting their autism diagnosis and questioning their own diagnosis due to self-doubt (Lilley et al., 2022). This study reveals how disclosing and talking about autism with others are challenging activities for autistic adults. In Kelli's narrative, she shares her suspicions and inclinations of being autistic with others, while Abel is first emphatically told that they are suspected of being autistic in a non-clinical context and later discloses this identification with others. These interactive exchanges are opportunities for autistic adults to be questioned, doubted, and "corrected" as it relates to their autistic self-identification. As characters within their recounted events, both participants illustrate disempowerment to some degree, however in being able to tell an audience of these experiences, they reclaim power while asserting their self-identification as autistic individuals.

Reported speech afforded narrators the opportunity to present themselves as agentic figures in and outside of the stories told. Through approximating direct dialogue in their narratives, Kelli and Abel highlighted characters of significance and signaled to their audience which voices were most salient (De Fina & Georgakopoulou, 2012). The level of constructed dialogue assigned to each character is a way that Kelli and Abel were able to reclaim power and assert themselves as protagonists while telling narratives reflecting self-doubt. For example, Kelli reports very little speech from her herself and husband but animates the doctor considerably to illustrate his role in invalidating her suspicions of being autistic and keeping her from formal diagnosis. Abel demonstrates their agency by granting a single voice to a collection of colleagues who insisted Abel is not autistic. Through merging these colleagues into one voice, Abel diminishes their perspective which challenges Abel's claims of being autistic (De Fina & Georgakopoulou, 2012).

Through double-voicing, Kelli and Abel revealed their internal conflict of claiming membership to the autistic community. They created images of the self that are reflective and contemplative of the messages and opinions of others, but ultimately authoritative in more firmly identifying as autistic. Kelli's expressed inner thoughts and dialogue tell her audience about her worries of diminishing her husband's autistic experience and dissatisfaction with the exchange she had with her doctor. Despite feeling conflicted, Kelli moves past the responses she received that were void of affirmation to assert her autistic status. Abel's internal dialogue walked their audience through how they engaged in research and investigation into what it means to be autistic after the interaction with the event organizer. It also reflected Abel's ability to empathize with their doubting friends to show that self-identification has been a conflicting process. The use of double-voiced discourse can index insecurity in that it evokes an acute awareness of and need to be understood by an audience (Baxter, 2014). Instead, through double-voicing, participants convey a trust in themselves to determine and confirm their autistic identification, following a process of rumination reflected through their double-voiced discourse.

For Kelli and Abel, there is purpose in offering two temporally distant interactions with others in a single narrative (Wortham & Rhodes, 2015). Juxtaposing two vignettes worked to contextualize external factors hindering their autistic membership and touch upon larger discourses in the field of autism that are salient for them, like adult diagnosis. The absence of evaluation or evaluations which fail to identify autism in youth explains the delayed and misdiagnoses experienced by the greater autistic adult community. Autistic adults have reported medical professionals who are unwilling to formally diagnose as a barrier (Lewis, 2016; 2017). Diagnosticians refuse because they claim screening tools to identify autism in adulthood are less reliable than diagnostic procedures used to identify autism in childhood (Lewis, 2017). They also claim that scant or nonexistent supports available to the autistic adult community render a formal diagnosis unhelpful (Lewis, 2016).

Kelli and Abel both identify how their past experiences resonate with diagnostic autistic characteristics. In emphasizing this, they articulate how it is their experience that renders them better qualified to determine an autistic identification (Gillespie-Lynch et al., 2017); Kelli is more knowledgeable about autism in women than her husband, and of the variability in presentation of autism than her psychiatrist, while Abel is more capable than his other radiologist colleagues in identifying characteristics aligned with diagnostic criteria. While the interactive achievement of disclosure and discussion of autism can be laden with negativity, it is paramount that they are investigated for how they contribute to autistic identity construction and how autistic adults affirm their membership to the autistic community (Bamberg, 2004).

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Appendix A

Interview Schedule for Self-Identified Autistic Participants

Question	**Probes**	**Source for Adaptation**
What is your language preference when talking about autism (e.g., identity-first vs. person-first language)?	*What language do you find you use most when talking about it (i.e. "autistic," "have autism," "on the spectrum")?* *Can you tell me why you may prefer this way?*	
Would you call yourself "self-diagnosed," or do you prefer another term?*	*What does it mean to you?**	
Tell me what it has been like without an acquired or suspected diagnosis.	*Tell me about a particular time in your…* • *Youth* • *Adolescence* • *Adulthood* • *(Some things to think about: school, social activities, sports/hobbies, friendships, family, romantic relationships, jobs/work, travel, living situations)* *During that particular time, how would you describe your experience? How would you describe yourself or your identity?** -- *Can you remember a particular time or moment before your self-diagnosis when you felt "different"?* *Tell me why that particular time or moment stands out for you.*	Riessman (2008) Lewis (2016) Pellicano et al., (2020)
Tell me what happened when you became aware of being autistic.*	*Was there **one** particular time or moment when you became aware, or was there an **accumulation** of moments?**	Riessman (2008) Hickey et al. (2018)

	*Tell me about that moment or some of those moments. How would you describe that experience/those experiences?** *Can you remember a particular time or moment when knowing about autism felt validating, revelatory, and/or like "life made sense"?* *Tell me more about what has helped you first become aware.*	Lilley et al. (2021)
How do you know you are autistic?	*Can you tell me more about that?* *What does it mean to you to "be autistic" [or use participant-preferred language]?*	Jones et al. (2015)
Tell me about how your self-diagnosis has impacted you.	*How would you describe your experience after self-diagnosis?** • *Has anything changed for you?* • *What have you learned about yourself? Are there strategies you've learned or developed as a result?* • *What have you learned about others?* *Can you think of a particular time or series of moments after self-diagnosis when you felt…* • *Understood,* • *At peace, or* • *[Participant language used to answer question describing experience after self-diagnosis]* *Tell me why that particular time or series of moments stand out for you.* *Tell me how self-diagnosis/self-identification helps shape what you envision for your future.*	
Have any of your relationships changed or evolved since identifying as autistic?	*Do you talk about being autistic with others?* *Have you engaged with the autistic community? What have your interactions been like with the autistic community?**	Pellicano et al., (2020)

	 • *To what extent do you feel you belong to the autistic community?** • *How does this community perceive or treat you?* *What have your interactions been like with non-autistic people in your life?* • *To what extent do you feel similar to or different from these people?* • *How do the non-autistic people in your life perceive or treat you?* *What, or who, have been the biggest sources of support for you in this process of self-identification?* *Do you think that you will one day seek out a formal diagnosis? Why or why not?*	

*Questions or prompts recommended by autistic colleagues

III

THE EXPERIENCE OF TALKING ABOUT AUTISM

Paper 2. The Experience of Talking About Autism

Parental decisions to disclose a diagnosis to their child can be fraught with emotion and uncertainty about how to best deliver information. Disclosure conversations between a caregiver and child mark a type of social interaction that involves awareness of identity; both parties enter an awareness context where only one interaction partner (caregiver) fully knows the diagnostic identity of the other (child) (Glaser & Strauss, 1964). Glaser and Strauss (1964) applied awareness contexts to the dynamics of hospital social interactions between a dying patient, loved ones, and medical professionals. While the situations are not analogous, this awareness paradigm can be applied to the disclosure of a child's diagnosis or condition from the caregiver to the child. For example, in a *closed* awareness context, the parent possesses knowledge of the child's diagnosis and the child does not, while in a *suspicion* awareness context the child may suspect they have a diagnosis or condition but are uncertain. The process of disclosure would then transform these awareness contexts thereby becoming *open* where both the parent and child are aware of diagnosis. Alternatively, contexts can operate under *pretense* where both parties are fully aware but may avoid acknowledging diagnosis and pretend to not be informed or aware (Glaser & Strauss, 1964).

Caregivers must decide whether to initiate this transformation and shift in their child's awareness. When the potential for social stigma surrounds the diagnosis or condition, parents may be inclined to withhold this information as a protective measure (Goffman, 1963; Todd & Shearn, 1997). Various concerns influence parent decisions to disclose to their children. Generally, there is the overall discomfort of engaging in conversation that illuminates the child's difference (Dennis et al., 2015; Cunningham et al., 2000; Todd & Shearn, 1997). In studies interviewing and surveying the parents of children with genetic conditions and/or disabilities, caregivers explain being fearful of conversations of disclosure because they did not want their child's sense of self or self-esteem to become compromised upon learning of their diagnosis (Cunningham et al., 2000; Dennis et al., 2015). Additionally, these caregivers noted feeling uncertain of how to deliver the news in ways that were age-appropriate and in a manner that would prevent the child from reacting negatively (Cunningham et al., 2000; Dennis et al, 2015). In fact, some caregivers admitted choosing not to disclose to and remain in a closed awareness context with their child because they felt their child would not understand (Cunningham et al., 2000; Todd & Shearn, 1997). Other parents reveal that they were reactive in their disclosure because their child exhibited some suspicion or awareness and explicitly asked (Cunningham et al., 2000; Todd & Shearn, 1997).

Caregiver experience of disclosing autism

Little research specific to the experience of disclosing autism to one's child exists in the field. Quantitative studies from Crane, Jones, Prosser, Taghrizi and Pellicano (2019) and Kiely, Adesman, Rapoport, and Gutman (2020) conducted online surveys each reaching over 550 caregivers of autistic youth aimed at identifying, on a large scale, contextual factors influencing the decision to disclose and general sentiments surrounding the experience. Kiely et al. (2020) reported that over 80% of caregivers had explicitly disclosed to their child his/her autism. Most caregivers (approximately 68%) participating in the study by Crane et al. (2019) revealed that their child knew their autism diagnosis and, of this group of caregivers, 84% felt satisfied in how their child learned of this and 63% expressed being confident in delivering and explaining autism to their child. These findings pertaining to caregiver confidence contrast somewhat with other parent experiences of disclosing disability or genetic conditions (Cunningham et al., 2000; Dennis et al., 2015; Todd & Shearn, 1997). Like these other studies though, parents voiced some uncertainty as to whether their child fully understood what the autism diagnosis more broadly entails, but this was mostly observed among parents with autistic children who are nonspeaking or exhibit limited language ability (Crane et al., 2019).

Prominent concerns about disclosure that were identified by most parents include fear of their child not understanding the diagnosis, fear of harming their child's self-esteem, and further causing their child to feel different from their peers (Crane et al., 2019; Kiely et al., 2020). The most important motivators for disclosure include feeling that it is their child's right to know their diagnosis, wanting their child to be aware of why their behavior is different from peers, feeling that disclosure would help their child to become better aware of specific strategies that can help in everyday functioning, and that knowing their diagnosis would prepare them for becoming better self-advocates (Crane et al., 2019; Kiely, 2020).

In stark contrast to the concerns of negatively impacting their child's self-esteem with making them know of their disability or condition (Cunningham et al., 2000; Dennis et al., 2015), caregivers of autistic youth mark these conversations as empowering, suggesting that increased awareness can be revelatory for a child once unable to understand their challenges (Crane et al., 2019; Kiely et al., 2020). In a similar study looking at the autistic caregiver perspective of disclosure, Crane et al. (2021) found that autistic parents were able to draw from their own expertise and experience when talking to their autistic child and exhibited less concern regarding potential distress or negative impact of disclosure for their child.

Qualitative research designs have also been used to examine the disclosure experiences of parents of autistic youth from much smaller sample sizes. A sample of seven caregivers from a study by Finnegan, Trimble, and Egan (2014) voiced having/having had more trepidation in sharing the diagnosis with their child than did the parents surveyed in Crane et al. (2019). Two of the seven caregivers had not yet disclosed to their child and justified withholding information because they did not think their child would understand the information, or they thought the news would be emotionally detrimental for the child (Finnegan et al., 2014). Much like the improved sense of self identified by caregivers in Crane et al. (2019), parents who did disclose in the Finnegan et al. (2014) study marked disclosure as a source of comfort and were careful to frame autism as an explanation and not an excuse for the social challenges experienced by their child. In a study by Riccio et al. (2021), from a sample of 11 caregivers of autistic adolescents, some reported uncertainty as to whether or not their child fully understood the information about autism and 9 shared how they opted to voluntarily disclose to their child his/her autism. Given that their study also interviewed caregivers' autistic teens, Riccio et al. (2021) found that the children of those caregivers who voluntarily disclosed identified more social-communicative strengths in their descriptions of self. This suggests a link between open discourse about autism and developing more positive autistic identities (Riccio et al., 2021).

Autistic experience of being disclosed to

The autistic experience of learning about their autism from caregivers has been explored far less than the parent experience. Huws and Jones (2008) and Mogensen and Mason (2015) broadly sought to learn from small samples of autistic adolescents and young adults what it is like to have autism. Emerging from the data were stories about what it was like to learn of their diagnosis and how this impacted their constructions of identity. Delays between diagnosis and learning about their diagnosis caused disappointment in some participants (Huws & Jones, 2008). Becoming aware of one's autism offered control and a chance to reframe challenges in a way that offered explanations for difficulties experienced in school (Huws & Jones, 2008) and improved understanding of the self (Mogensen & Mason, 2015). Others marked the experience of learning the diagnosis as limiting in how the label conceptually and socially categorizes and separates the autistic person from others. This very separation was perceived by some participants as a positive difference that enhanced personal identity (Mogensen & Mason, 2015).

Research by Riccio et al. (2021) was unique in how it examined the autistic adolescent perspective in conjunction with that of caregivers to determine overlap in the way adolescents and caregivers define autism. Content analysis of definitions given revealed a greater number of shared themes between parent and child pairs who had experienced disclosure conversations when compared to the responses given from parents and children who had not disclosed/learned of their autism (Riccio et al., 2021). Such a finding supports the proposition that caregiver perspectives and the messages they impart in conversations about autism influence the way their child forms their own perspectives.

Purpose & Research Questions

Pellicano et al. (2018) have called for a shift in approaching autism research. Instead of perpetuating medical perspectives, research efforts should prioritize the "everyday realities of autism" to better support autistic people and allies and invite stakeholders to have more active participation in the research process (Pellicano et al., 2018, p. 82). The use of interpretative phenomenological analysis (IPA) in autism research has increased considerably in recent years as a response to this proposed shift (Howard, Katsos, & Gibson, 2019). With its aim to capture the experiences of participants, IPA is a useful approach for analyzing the lived, personal accounts of autistic individuals and/or their families to develop authentic insights surrounding autism (Pellicano et al., 2018). Using IPA, this study aims to retrospectively investigate experiences of autistic youth and their caregivers in regard to disclosure conversations. The following research questions guided this work:

1. How do autistic youth describe the impact of conversations with caregivers about autism on their identity?
2. How do the caregivers of autistic youth think about the experience of talking to their child about autism?

Method

This paper examined data collected from interviews with autistic adolescents and their caregivers and used IPA as an analytic approach. The use of IPA is intentional for its emphasis on the lived and perceived human experience, its utility in understanding multiple and layered interpretations of experience, and its focus on personal accounts (Smith et al., 2009). There are three main principles or theoretical approaches to knowledge acquisition that underpin IPA. First, phenomenology gives weight to everyday subjective experiences (Smith et al., 2009). Experience is more dynamic than just its observable elements; It encompasses the individual's processes of conscious perception and reflection (Husserl, 1970). Second, hermeneutic theory informs the interpretative nature of IPA and acknowledges the presuppositions and preconceptions researchers possess and inadvertently apply when analyzing participant experience (Heidegger, 1962; Smith et al., 2009). Employing a multiple hermeneutic where more than one party is making sense of a given interaction, IPA relies on interpretation at many levels. Participants not only report on a given experience and their personal interpretations of its significance, but the researcher then must make meaning of this interpretation (Smith et al., 2009). To better access the lived experience of the participant, the researcher is encouraged to engage on both an empathetic and critical level (Shinebourne, 2011). With empathy and awareness of one's own preconceptions, the researcher can partially attain the insider perspective that only the participant can fully access (Shinebourne, 2011; Smith et al., 2009). Critical questioning allows a researcher to extrapolate more of the experience than what the participant originally recounted or shared, offering a fuller description (Eatough & Smith, 2008). A third tenet of IPA is its idiographic focus highlighting the particular and aiming to capture nuance through detail from small sample sizes of data (Smith et al., 2009). As participants offer storied experiences of poignant moments and/or significant transitions in life, links to a developing sense of self often emerge, making IPA an apt approach and method for examining identity (Smith et al., 2009).

Researchers employing IPA seek to access the insider perspective of the participant (Smith et al., 2009). Though it is improving, autism research is saturated with studies that situate the perspectives of caregivers and other stakeholders as the proxy informants of the autistic experience, bypassing the voices of autistic people (Milton & Bracher, 2013). This study melds the perspectives of autistic youth and their caregivers as I examined, in parallel, the experiences of disclosure and talk of autism between these two groups. The experience of disclosing a diagnosis of autism to a child or learning of one's autism from a caregiver is not necessarily a singular event, instead it can be a more episodic experience where parties navigate conversations about autism intermittently over time, thereby influencing autistic identity formation (Dennis et al., 2015). I used a multiperspectival group design, recognizing that this phenomenon of discussing autism is a complex interaction involving the caregiver and child (Larkin, Shaw, & Flowers, 2019).

Participants

Purposive homogeneous sampling allows for gaining access to in-depth representation of autistic perspectives, in addition to mitigating variation in a broader sample (Smith et al., 2009). Studies using IPA intentionally utilize small sample sizes to garner detailed and specific understandings about particular groups. This small sample need not be representative of the population, but instead participants should exhibit relative similarity allowing for researchers to draw specific observations and conclusions about the group (Smith & Osborn, 2012). Inclusion criteria for autistic individuals in this study are that participants must: (1) have a diagnosis of ASD, (2) are young adults between the ages of 14 and 25, and (3) have engaged in explicit conversations with their caregiver telling them of their diagnosis, and about autism more generally. Criteria for participation in this study as a caregiver of an autistic individual includes: (1) has a child with a diagnosis of ASD, and (2) has communicated to their child their ASD diagnosis, and about autism more generally within the last 10 years. Parameters on the ages of autistic participants and time in which caregivers have disclosed their child's diagnosis is purposeful to allow participants to recollect their insider experience more readily (Huws & Jones, 2008).

Participants were recruited through Facebook advertisement, word of mouth, and email solicitation of community groups that access autistic communities and/or provide services for families with autistic children. Three mother-child dyads signed up to participate and their names have been changed for anonymity: Nancy and Aaron, Janice and Derek, and Corinne and Shane. The three autistic youth were enrolled in high school at the time of the study and between the ages of 15 and 17 years. Two identified as male and one as genderqueer; This participant indicated no preference for particular pronouns and so the use of "they/them/theirs" will be used when appropriate throughout this study. The three mothers ranged in age from 41 to 52 years. All dyads noted residency in or around New York City. Additional demographic information is located in Table 1.

Interview Schedule

Prior to interviewing participants in this study, autistic colleagues were asked to review the interview schedules and suggest revisions to encourage descriptive and episodic replies (Smith et al., 2009). Questions were kept broad and were written to welcome open-ended responses to elicit stories and life experiences from participants. They were specifically sequenced to gradually work toward answering the research questions with rapport-building and issues of sensitivity in mind (Smith et al., 2009). Adopting some of the same data collection strategies applied from other autism research using IPA, participants were offered choice in how they were interviewed (MacLeod et al., 2018) and were given the interview schedule in advance of the interview (Cridland et al., 2014; Griffith et al., 2012; Huws & Jones, 2015; MacLeod et al., 2018). Interview questions elicited stories related to diagnosis, schooling, and relationships. Average interview length for autistic participants and their caregivers was approximately 46 minutes and 62 minutes, respectively. See Appendix A for preliminary interview schedules developed for autistic participants and their caregivers.

Analytic Procedure

Immediately following interviews, field notes were generated to document initial impressions and key points articulated by participants (Huws & Jones, 2008). This log served as

Table 1

Participant Demographics

Autistic Youth

Participant	Age (years)	Gender Identity	Sexuality	Transgender	Race	Latinx	Year in High School	Level of Speaking Words	Years Knowing of Autism Diagnosis
Aaron (Nathan)	16	Male	Heterosexual or straight	No	Caucasian/ White	No	Grade 10	Mostly speaking	10
Derek (James)	16	Male	Heterosexual or straight	No	Caucasian/ White	No	Grade 11	Mostly speaking	“About as long as I can remember.”
Shane[a] (Charles)	17.7	Genderqueer	Bisexual or pansexual	Yes	Caucasian/ White	No	Grade 12	Mostly speaking	15

Caregivers of Autistic Youth

Participant	Age (years)	Gender Identity	Sexuality	Transgender	Race	Latinx	Level of Education	Employment Status	Years Knowing Autism Diagnosis
Nancy (Amy)	49	Female	Heterosexual or straight	No	Caucasian/ White	No	Master’s degree	Homemaker	12
Janice (Deb)	52	Female	Heterosexual or straight	No	Caucasian/ White	No	Master’s degree	Employed full-time	15
Corrine (Anne)	41	Female	Queer	No	Caucasian/ White	No	Bachelor’s degree	Employed part-time	15

Note. [a] Participant indicated an openness to the use of any pronouns. They/them/theirs is used throughout the manuscript.

a source for reviewing data for credibility in theme generation (Elliott, Fischer, & Rennie, 1999). Audio from virtual and phone interviews was transcribed to include participants' words, and other features or talk like false starts, pauses, and laughter (Smith & Osborn, 2012).

For analysis, each participant group was viewed as a "micro-system": Individual analyses of autistic youth interviews were collectively examined to address RQ1, and likewise, individual analyses of caregiver interviews were compared to answer RQ2 (Larkin et al., 2019, p. 190). Due to the idiographic nature of IPA, a single transcript from each participant group was first analyzed thoroughly before examining other participant accounts, allowing for full immersion into the perspectives and "world" of the individual (Smith et al., 2009, p. 82). First, a single transcript from the group was selected, read, and re-read while listening to available audio of the interview. Second, exploratory noting followed where detailed annotations were made to describe content, highlight specific language used by the participant and its meaning, and engage in reflection regarding concepts evident within transcripts. Third, experiential statements were documented to align with the relevant portions of the transcript to best capture the experience of the participant. Fourth, experiential statements were clustered to identify connections and potential superordinate experiential themes in the data for this singular participant, ultimately leading to the creation of a personal table of experiential themes. This full analysis process was then applied to other participant transcripts within the same group. Tables of the personal experiential themes for participants within each group allowed for the examination of convergence and discrepancy. Shared patterns across cases were then identified and group experiential themes were generated (Smith & Nizza, 2022).

Analysis

Group experiential themes are reported separately for the autistic adolescents and their caregivers to best attend to each research question and reflect each group perspective.

Table 2

Group Experiential Themes

Autistic Youth	Caregivers of Autistic Youth
Describe the impact of conversations with caregivers about autism on their identity as…	Think of the experience of talking to their child about autism as…
Strengthening their perceived areas of difficulty ● Mom as a liaison and partner in sharing information about autism ● Strategies for navigating social situations	Natural, due to creating an autism-friendly home ● Autism literature made available ● Language related to difference and disability readily used ● Acts of self-advocacy are supported
Insightful in better understanding self and conceptualizing autism ● Appreciation for being made aware early ● Autism as a way of being ● Adopting more positive/neutral framing of autism	An opportunity to coach them through challenges related to autism ● Modeling language for how to navigate difficult social situations ● Careful scaffolding and delivery of supports
	A chance to frame autism in particular ways ● Highlighting shared conditions as a way to connect to others ● Destigmatizing autism

Adolescents

Derek, Shane, and Aaron are three autistic adolescents who were attending high school at the time of data collection. Two of the adolescents attended a public high school and one was a boarder at a private school. In their interviews, all were asked to recall and describe conversations they have had with their caregivers about autism and each autistic youth explicitly mentioned and centered their responses around experiences with their mother. All three teens highlighted the significance of conversations with their mothers about autism and emphasized a level of transparency experienced in talk with their caregiver. After collectively analyzing the interviews, two group experiential themes were generated. Autistic youth describe the impact of conversations with their mothers about autism on their identity development as (1) strengthening their perceived areas of difficulty, and (2) insightful in better understanding self and conceptualizing autism.

Insightful in Better Understanding Self and Conceptualizing Autism

Adolescents could not recall a specific exchange where it had been disclosed to them that they are autistic. Being unable to recount a particular moment supported claims made by each adolescent that they have known about their autism since early youth. Each teen expressed appreciation for their caregivers making them aware of being autistic early, recognizing how this is not how all families approach the topic and noting how this enabled the adolescents to put their experience into context and better understand themselves and what it means to be autistic. In the following, Shane lauds their parents for being direct with them about their diagnosis early.

> I've known that I was autistic since I can remember because I was diagnosed at a very early age, and my parents were extremely transparent with me about it. And yeah, I see a difference: It didn't mean that I was any less capable or limited in terms of opportunities. It was that I had some accommodations that my parents thought were useful. And I was like, “Alright, that's fine.” (Shane, Autistic Youth)

Shane credits this honesty and openness with a “difference” they perceive between themselves and other autistic peers who, alternatively, may not have had such early awareness; the difference being that having greater awareness and insight into autism and what it entails has enabled Shane to have access to appropriate supports and develop an understanding of their utility and benefit. Aaron expounded on this concept of being made aware early of his autism:

> It's important to know because it could help you understand… Like, if there are things that affect you that you might not get what is happening, knowing about autism can help you understand that. (Aaron, Autistic Youth)

Here, Aaron suggests that knowing about an autism diagnosis is enlightening and that without knowing, an autistic individual may feel out of touch with the self or confused about perceived differences that one can experience. Autistic youth placed great value on learning about autism early from a caregiver because it has shaped their understanding of the diagnosis and offered a pathway to better knowing the self.

Through engaging in talk about autism or autism-related topics with their caregivers, these youth have adopted ways of conceptualizing autism that are more neutral and/or positive in tone, accepting and embracing difference. When asked to recall any specific autism-related conversations, Derek shared the following:

> I never really had to have the "just because you're autistic, doesn't mean you're bad" talk because… I've kind of sort of known for as long as I can remember that there was something… not *wrong*, not *different* just… or maybe it *is* different, but just different about how I interact with the world and other people. And that there were certain advantages and challenges I'd have because of that. […] I don't even really view it as a set of challenges. Because again, it's hard for me to think of myself as autistic because I haven't been raised to think, "Oh, I'm autistic, this is something that's going to be harder for me." I just think that something is harder for me and I need help with that. And I think a lot of the times I don't even think

> about something being harder because of autism, because I don't know anything different. (Derek, Autistic Youth)

Derek discussed how autism was framed for him in conversations with his mother. While he acknowledged being acutely aware of differences between himself and others from an early age, Derek noted how this "something" was not "wrong." Marking this distinction highlights further his rejection of negative associations with autism. This difference does not carry only difficult experiences or adversity, but for Derek it also means possessing valuable skills and qualities. He emphasizes how being autistic is all he has ever known and experienced, so hardships or difficulties that he encounters are not immediately tied to or viewed as caused by autism. In having not "been raised to think" that autism is limiting, Derek has cultivated a spirit of resolve, intent to problem solve and seek help when necessary.

The adolescents all reflected on difficulties they experience which they feel may be autism-related but were also careful to emphasize that autism does not indicate inferiority or damage. Shane expanded on this when recounting the reticence exhibited by peers on campus to joining a school group intended to provide a supportive space for students with disabilities:

> It [autism] was framed as a difference in the way my brain works, and that has both positives and negatives. I still think that that's sort of the way that I see it today. [...] It's been a part of my identity that I've celebrated and the fact that there are people who can't or don't celebrate it, it's just a sad thing to me. (Shane, Autistic Youth)

Shane began by explaining how their caregivers defined autism as a neurological difference. For Shane, being autistic is something they embrace positively; they are proud of the difference it affords them and find it disheartening that others with disabilities do not appreciate this difference as invaluable variation. Though not explicit about celebrating autism, Derek firmly advised against treating autism "as a bad thing, ever" while Aaron wants it to be more widely understood that "there aren't things wrong with us." These messages and ways of viewing autism are ones that have been communicated to these teens by their caregivers, and have been readily adopted, shaping how the adolescents themselves think about being autistic.

Strengthening Their Perceived Areas of Difficulty

When asked about what topics related to autism they discuss with their mothers, the teens primarily named difficult experiences in which they require support. Adolescents voiced being able to vulnerably talk about struggles with their mothers and identified them as helpful in strengthening their abilities to manage needs and successfully navigate social situations. Aaron stated plainly how conversations with his mom helped him:

> Interviewer: What topics do you find helpful to talk about with your parents? What parts of autism have your parents helped you to understand more?
>
> Aaron: General things I might have trouble with [...] My mom helps me with a lot of things. One of the main things is the energy level. I'd say that I can get tired of stuff easily. I can need more time to rest and recharge as someone who's autistic. Also, with noise sensitivity [...] When it's a somewhat enclosed area and there's three conversations happening at once, that can overwhelm me. I usually try to leave the room.

Aaron identified limited energy levels and high noise sensitivity as two self-regulatory challenges he experiences that are autism related. In addition to naming these topics as helpful to discuss with his mom, he outlined specific strategies that he employs for managing overstimulating circumstances. Explaining these strategies after articulating how his mom helps him with “a lot” suggests that it is with her help that he has incorporated these acts of self-management into his repertoire. Their mothers are interaction partners to whom they can identify and describe challenges they experience and determine appropriate solutions to ease discomfort or difficulty.

Caregivers are also described as sources of guidance and strategy for how to best approach particularly taxing or confounding social circumstances. Derek noted how he discussed “social anxiety and talking to people” heavily with his mother. He shared the following:

> One piece of advice was that if someone sits next to you, it doesn't mean that they like you a lot and want to be your best friend. But it also doesn't mean… but it also does mean that they don't *not* like you and that they, at the very least, tolerate you. And I think that's helped me through a lot of social anxiety. (Derek, Autistic Youth)

Earlier in the interview, Derek expressed how socializing is more of a challenge for him than it is for peers. Advice from his mother has helped to mitigate the anxiety he experiences surrounding social interactions with peers. In this excerpt, advice given to Derek helped him to decipher meaning and interpret social cues from others and better recognize reciprocity in exchanges and relationships with peers. Relatedly for Shane, talk with caregivers emphasized the importance of engaging in particular social behaviors that Shane finds challenging. Shane voiced:

> They’ve kind of pushed me to be more comfortable with making eye contact, which I appreciate because now it's the case where it's not impossible for me, it's just very hard. And also if I'm doing it then I'm probably not paying attention to what the other person is saying, but I'm capable of doing it. (Shane, Autistic Youth)

Shane exhibited an appreciation for this parental advice: Though difficult, they recognize that being capable of making eye contact is generally a more advantageous skill to possess within typical social interactions. Interestingly, they are highlighting how in society it is somehow more valuable to appear engaged with a person by making eye contact, than it is to accurately process what that person communicates within the interaction. The three autistic adolescents all marked their caregivers as confidants whose support and willingness to engage in honest communication have helped the teens to better learn more about themselves and how to tackle experienced difficulties with greater confidence and agency.

Caregivers

Nancy, Janice, and Corrine are the mothers of Aaron, Derek, and Shane, respectively. At the onset of the interviews, caregivers launched into a chronological retelling of their child's upbringing and developmental milestones to give context for their autism diagnosis. These mothers talked about their high schooler's difficulties and triumphs, as well as articulating goals for their adolescent and advice for other caregivers to autistic children. During her interview, Janice revealed how, after reading and learning more about autism due to Derek's diagnosis, she suspects that both she and her husband are "definitely spectrum." While the mothers share some demographic characteristics, it is important to note this distinction and how this particular parent/child dyad of Janice and Derek identifies as neurodivergent. From analysis of their interviews, three group experiential themes were developed to highlight how caregivers think about the experience of talking to their child about autism. Mothers viewed these exchanges as (1) an opportunity to coach their child through challenges related to autism, (2) a chance to frame autism in particular ways, and (3) natural, due to their creation of an autism-friendly home.

Natural, due to creating an autism-friendly home

Each mother noted how conversations about or related to autism were so ingrained in the culture of their home environment, that while autism may not have always been explicitly discussed, it was an undercurrent in many of their exchanges. This theme illustrates how the caregivers cultivated an approach within their homes that allowed for conversation related to autism to flow more naturally and with ease. Helping to achieve this was how readily the language and literature of autism, disability, and difference was used in the home and creating a context that was open. In the following, Nancy recounted a moment where Aaron inquired about autism-related language he spotted in school:

> At some point in kindergarten he saw "ASD" somewhere and asked me what that was. I explained, "Autism spectrum disorder. It's like the Asperger book." So, it's kind of always been part of the nomenclature and part of the thinking. (Janice, Caregiver)

Earlier in the interview, Nancy explained how Aaron was a part of their school districts' autism-specific program offering inclusive classroom settings and that signage featuring "ASD" was often used throughout the school and in affiliated paperwork, inspiring the query from Aaron. Nancy expanded on the meaning of "ASD" for Aaron and further made the connection to the term "Asperger" which was familiar to him through texts in the home. Caregivers helped their child to develop a lexicon surrounding autism. Each mother acknowledged that while they operated with transparency surrounding language related to autism and disability and fostered their child's understanding of autism-related terms, not all families in their child's school or classroom did so. Corinne told the anecdote below emphasizing how this level of transparency contrasted some other parent approaches:

> One day [Shane] asked me, "Is my friend, so-and-so, is he autistic too?" Because I knew this kid's mom pretty well, I knew that they had absolutely avoided that conversation. I

> knew she felt very strongly about not ever telling him about his diagnosis. […] I thought, “I can't answer this question honestly.” But I also can't say, ‘Well, it's not appropriate to ask,’ because that's gonna feel very shaming and I don't want to give Shane the sense that this is something to be embarrassed about. (Corinne, Caregiver)

Like Corinne demonstrates in this quote, these caregivers reject a culture of secrecy and concealment when it comes to discussing autism and being forthright about their child’s autism diagnosis with their child. To shroud autism from their child was described as “heartbreaking” (Janice) and harmful in how it can keep a child from developing a better sense of self or understanding their feelings of difference (Mogensen & Mason, 2015).

Just as Nancy referenced a book about Asperger’s that she made available to Aaron in their home, the other caregivers also prioritized making autism literature and autistic-authored materials readily accessible:

> When I see authors and people who say things that I think are powerful for kids…Autistic voices, you know? I… I sent him all that stuff about Greta Thunberg. I want him to find places where he sees autistic people, not as “other.” (Janice, Caregiver)

Janice insisted that sharing meaningful literature and media featuring autistic perspectives was not an exercise in “normalizing” autism, but instead it was an effort to provide more “relatable” material that would allow Derek to feel better represented.

In addition to providing access to informative and representative materials about autism and from autistic authors in the home, caregivers also highlighted moments where they celebrated and encouraged their child to exercise self-regulatory strategies in and out of the home. Both Corinne and Janice shared recent accounts of when, in their presence, their child took action in enacting a coping strategy without prompting:

> Thanksgiving, there were a lot of people. At one point, I realized Shane was not in the room, [they were] not on the same floor as anybody else. I went downstairs and [they were] laying on the couch with [their] arms over [their] head. And I said, “You okay?” And Shane said, “I needed to go. This is too much for me.” I said, “Okay.” (Corinne, Caregiver)

> We were in a restaurant the other day, and it was too much for Derek. And he said, “Can I put my headphones in?” And we were both like, “Hell yeah, sure!” (Janice, Caregiver)

The mothers retold these moments with pride, pleased to witness their child exhibit self-awareness, but also show a level of security in enacting coping strategies readily with them. Familiarity with autism-related language, ensuring representation through autism and autistic-authored literature made available in the home, and their child’s level of comfort to initiate self-regulatory behaviors signal how caregivers view conversations with their child about autism as naturally occurring.

An opportunity to coach them through challenges related to autism

Caregivers identified conversations about autism as spaces where they could guide and support their child through experienced struggles or difficulties related to autism. Particularly, caregivers highlighted the strategies and styles of delivering their guidance that proved to be effective. The following quote illustrates how one mother modeled talk for their child’s use in specific social scenarios:

> He made plans with some kids. Two girls were meeting up and got in touch with him after he made plans. […] He didn't want to blow off the dudes but he *really* wanted to see the girls. So, we talked about how he could meet up with them beforehand and how he

> could say “I have plans at 5, but I can hang out til here.” And then at 4:30 when he goes to the next plan, he could casually say [to the girls], “You’re welcome to come.” (Janice, Caregiver)

> He’s learning more about advocacy and I tried to explain to him what advocacy is. “Most people don’t care if you need to get up and walk around because you like to move your body. It just helps them to know you like to get up and walk around because you need to move your body.” It’s a matter of saying, “This is what works for me. This is what I need. Is this ok? Can we figure out a way to make this work? Is this possible?” (Nancy, Caregiver)

In both situations, the caregivers offered their child language to use within a social interaction perceived as challenging to achieve a desired outcome or goal.

Repeatedly within their interviews, Nancy and Janice implicitly and explicitly shared how they must carefully approach how they scaffold and present their support to their child. Nancy explained how when breaking down a task for and giving feedback to Aaron, she needs to be delicate in her delivery and mindful not to “make it sound like a character defect” to gain his receptiveness. Similarly, Janice stated the following about approaching Derek:

> I'm pretty good about asking him things in sort of a light enough way where there's an open door. Where it doesn't have to be, [[in a deep voice]] “So let's talk about the autism,” but more like, “Who did you have lunch with today? How'd that work?” Letting him control it once I've thrown out my gambit, so to speak. (Janice, Caregiver)

Through her more subtle probing, Janice has found greater success in Derek opening up and sharing daily occurrences and dilemmas on his own volition. Knowing that successfully imparting support and guidance to their autistic adolescents would benefit them, caregivers are conscientious in the ways they broach the exchange to garner their child's receptiveness and engagement.

A chance to frame autism in particular ways

Throughout their interviews, each caregiver often described how they defined, explained, or framed autism for their child, revealing how they viewed conversations as opportunities to convey particular messaging about autism. This theme illustrates how mothers used conversations as a medium to destigmatize autism and highlight the conditions and diagnoses of others to make connections. Caregivers sought to outwardly reject negative perceptions and misconceptions about autism by celebrating positive traits associated with autism and by use of humor. Corinne and Nancy both made mention of being able to joke around and enjoy comedy surrounding autism. Referencing an episode of an animated television series that she watched with her son, Nancy expanded on this use of humor:

> The genesis [of the episode] is one kid has Asperger's for real and then the other person is jealous because he's getting special treatment. So he puts a burger between his ass and says he has "Ass-burgers." And I definitely shared this with my 6-year-old. It's completely inappropriate – but it made him laugh! It just made it not so dire. Because he's not going to die of autism. It's not fatal. It's not going to ruin his life. It just shapes how he sees the world and that is what it is. (Nancy, Caregiver)

Nancy described this experience of shared comedy as an opportunity to lighten negative perspectives or tones associated with autism, allowing her son to view it more positively and to laugh at those who hold misconceptions and fail to understand what it means to be autistic.

Janice voiced a potential conflict in how she had been framing autism with Derek. While explaining how Derek is resistant to join disability-related groups within school or look at applying to colleges specifically aimed at supporting students with disability, she wondered if her messaging about autism was an influence:

> I've explained it to him as autism isn't a disability because it gives you strength in some ways, even as it makes other things harder. So I don't think that… He may not see it as a disability and it may bother him when it is portrayed as such. And maybe I don't make enough of a distinction because we don't see this as a disability, right? I mean, it is a disability in that it impacts his living in some ways, and there are things he needs to do. But the things that come with an autistic brain are so amazing that it's hard for me to say it's a disability, but maybe we don't distinguish that enough or maybe he objects being sort of "lumped in," for lack of a better word. (Janice, Caregiver)

In her efforts to celebrate autism and emphasize strengths that come from being autistic, Janice refrained from associating autism with disability, despite autism impacting "his living in some ways." While she wants Derek to find strength and pride in being autistic, she does not want him to reject avenues and spaces of support aimed at broader communities of disability.

Similar to how caregivers made use of autism-related literature and media to let their child feel represented, they also highlighted familial diagnoses to allow their adolescent to feel more connected:

> We had always been very open with [them] about [their] diagnosis. We had always just share it as, you know, "Mommy has diabetes. Daddy has ADHD. You have autism. Everybody has something." (Corinne, Caregiver)

> We try to acknowledge our own things, my husband and I. Not that I think that Derek looks at us and is like, “Boy, when I grew up, I want to be them,” but… when he looks at my husband, I think he *does* admire my husband and want to be like him. So, I think we try to highlight those things about ourselves that we see as being “spectrum,” and how we've navigated, managed, and made them into strengths when we can. (Janice, Caregiver)

Each caregiver shared stories of how they made a point to reveal and disclose to their adolescent other conditions family members have so that their child would not feel alone in being autistic. Both excerpts above achieve this, but Corinne and Janice do this in different ways. For Corinne, it is paramount that Shane understands that having a label or having a condition that one lives with is part of the human experience. Janice’s excerpt comes after her revealing within the interview that she and her husband both suspect they are autistic after learning more about the diagnosis through Derek’s journey. Sharing autistic characteristics with Derek, Janice and her husband make sure to outline their strategies and ways of leveraging these traits and finding success in their respective paths.

Discussion

The purpose of this multiperspectival study was to explore how autistic adolescents and their caregivers perceive autism-related conversations shared: How caregivers think about talk of this nature and how this talk shapes adolescents’ formation of autistic identities. Discussing autism was not recounted or described by caregivers or autistic adolescents as a ceremonious or discrete experience. Instead, adolescents and mothers in this study often required time to recall interactions when they explicitly discussed autism. Autism was part of the fabric of many conversations between parent and child because autism was viewed as “a way of being,” inextricable from the youths’ lived experience. Caregivers and adolescents described contexts of being openly aware of autism, devoid of pretense or suspicion (Glaser & Strauss, 1964).

Parent-child interactions are a dynamic exchange where there is risk that interlocutors' goals, messages, and underlying intentions be misinterpreted by their conversation partner. For caregivers of autistic youth, some perceived risks of autism-related talk include fear of exacerbating any feelings of difference that their child may feel and negatively influencing their self-esteem (Kiely et al., 2020). Mothers in this study sought to mitigate this and described their efforts to actively identify the diagnoses of others within the family and share information tied to autistic authors and figures so that their adolescent could feel more connected and like others navigating autism or other conditions (Lilley et al., 2022). Caregivers also reflected an assuredness in how they explained autism to their adolescent and confidence in having delivered these messages from the onset of learning about their child’s autism, extending the findings of Crane et al. (2019).

Reports from both groups demonstrated a streamlined effect of messages delivered from caregiver to adolescent. As caregivers described conversations where they intentionally highlighted strengths and promoted strategies for working through experienced challenges associated with autism, autistic youth also framed autism more positively, abandoning negative societal stereotypes of autism (Wood & Freeth, 2016) and other common misconceptions (Gillespie-Lynch et al., 2015; Gillespie-Lynch et al., 2021). These findings further support work from Riccio et al. (2021) which also examined parent/child dyads and found that autistic adolescents whose parents voluntarily disclosed to them their autistic diagnosis described autism in neutral and/or strengths-based ways and themselves more generally positive.

Adolescents were also receptive to messages from their mothers promoting self-awareness and suggested approaches for difficult social interactions. Just as autistic caregivers reported having a particular insight into what it means to live and manage autistic characteristics in daily life (Crane et al., 2021), Janice explained how she and her husband, who both suspected being autistic after learning more about autism, were able to offer Derek anecdotes of how they leverage autism as a strength when they can. Though they do not identify themselves as autistic, Nancy and Corinne's style of approaching autism-related talk with their child also expounded on findings in Crane et al. (2021). Like the autistic caregiver participants, mothers in this study, regardless of autistic status, would support their child with the struggles that were relevant for them at a given developmental by offering them language and strategies for navigating situations with teachers and peers (Crane et al., 2021). Findings further support results from a subset of adolescent participants from the study by Mogensen and Mason (2015) who found that knowing their autism diagnosis was an advantage, contributing to their self-understanding.

Adolescents claimed learning about the self through these exchanges with caregivers and identified their mothers as influential liaisons in their process of strengthening their abilities to self-regulate and navigate social challenges. Caregivers described these conversations as contexts where they allowed their child to exercise greater autonomy. For both groups, these interactions were founded on mutual trust: while caregivers exhibited great confidence in their child to be a partner in knowing the meaning of their evaluation reports or make appropriate educational decisions for themselves, autistic youth entrusted their mothers with knowing their struggles and supporting them in determining how to best problem solve. Creating conversational spaces and home environments where adolescents felt safe to take risks and enact initiative was an intentional objective for caregivers, and autistic youth acted upon these opportunities accordingly, showing themselves to be receptive collaborators and partners to their parents in devising ways to navigate experiences related to being autistic.

Limitations

Because the orientation of IPA is to analyze particular perspectives from small, purposive homogeneous samples (Smith et al., 2009), results found cannot be appropriately generalized to broader communities. While three caregiver-child dyads is an appropriate, though modest sample size, additional pairings could have made within-group cross analysis more robust. This study aimed at recruiting parent/child dyads, so it is possible that this reduced sample size was due to caregivers being interested in participation but their child being unwilling, and/or vice-versa. Conversely, a study of this nature may attract the participation of dyads that are confident and comfortable with their autism discourse in the home, revealing more positively charged experiences. Familial connection between groups in this study may explain the strong connections of themes generated between groups. Future IPA research in this area could analyze the experiences of autistic youth and unrelated caregivers to autistic youth to observe any distinctions in identified themes. More research that repeats this design using a relatively homogenous sample that is different in racial, ethnic, gender of parent/child, and/or geographical location would offer further nuance to the phenomenon of autism-related talk between caregiver and child. While this phenomenon was analyzed at the group level within this study to examine autistic perspectives collectively and in isolation from their caregivers, future considerations may analyze at the dyadic level to better capture interactions and relationships within families (Larkin et al., 2019).

Recommendations

Riccio et al. (2021) suggest early discussion of autism between caregiver and child so that autistic youth cultivate perspectives about autism that are aligned with the neurodiversity movement. This study reflects this in how transparent conversations about autism very early in childhood contributed to autistic youth themselves talking about autism in ways that acknowledged associated challenges and traits, while neutrally noting that autism is a condition that leads to experienced differences; one condition of many others. To impact autistic identity development in positive ways, recommendations for caregivers from this study include engaging in talk about autism at early developmental stages, framing autism in neutral and positive ways, and adopting collaborative, problem-solving approaches to guiding autistic youth in tackling challenges experienced.

Conclusion

Adding to a growing collection of multiperspectival IPA studies, this research effectively described the shared psychosocial experience of talking about autism through outlining caregiver and child perspectives (Larkin et al., 2019). By looking at these caregiver/child dyads in groups, it allowed for autistic adolescent voices to be analyzed independently from caregivers - continuing an important shift in autism research (Milton & Bracher, 2013) - while still joining these group perspectives to better contextualize the larger experience of autism-related conversation in the home. From this joint exploration, talk about autism between the caregiver and autistic child should be conducted early, with perpetuity, transparency, intentions for growth, and trust between parties.

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Appendix A

Semi-structured Interview Schedules

Interview Schedule for Autistic Participants.

Question	**Probes**	**Source for Adaptation**
How do you tend to refer to your autism?	*What language do you find you use most when talking about it (i.e. "autistic," "have autism," "on the spectrum")?* *Can you tell me why you may prefer this way?* *Tell me what it means to you to* <u>*[preferred terminology here]*</u>*.* **Has your language changed or evolved over time? How so?*	
How do you know you have autism?	*Can you tell me more about that?* *How would you describe your relationship to autism?* *Tell me what happened when you first became aware of your autism.*	Jones et al. (2015)
Can you remember a particular time when you talked about your autism/being autistic with a caregiver? OR How would you describe conversations that you had with caregivers about your autism?	*Tell me why that particular time or moment stands out for you.* *Who initiated the talk, and what may have been the purpose for it?* **What does/did your caretaker say about autism in your conversations(s)?* *What do you wish was communicated during these conversations?* *How did you feel during/after?* *What did you value most/least from these conversations?*	Riessman (2008)
What autism-related topics did/do you discuss with your parent(s)/caregiver(s)?	*What topics, if any, were particularly helpful or challenging to discuss?*	Crane et al., (2019)

Have the conversations that you had with caregivers about autism changed the way you feel about your autism/being autistic?	*Do you see yourself differently now than you did when you had those conversations?* **Tell me about your involvement with neurodiversity and/or autism communities.* **How does the weight of your caregivers' perspectives compare with the weight you may give to the perspectives and opinions of peers?* *How do you feel about your autism/being autistic?*	Shinebourne & Smith (2009)
What advice would you give to parents of autistic children who might be debating if, when, and how to discuss autism with their child?	*What factors should parent(s)/caregiver(s) of autistic children consider before informing their child of his/her/their autism?*	Crane et al. (2019)
What advice would you give to autistic individuals who receive this news for the first time from a caregiver?	*What advice* ***do you wish you received*** *before having these conversations?*	Crane et al. (2019)
Has your understanding of autism changed over time?	*How so?*	

*Questions or prompts recommended by autistic colleagues

Interview Schedule for Caregivers of Autistic Individuals.

Question	**Probes**	**Source for Adaptation**
Tell me about your child.	*Can you tell me about your journey and relationship with your child from beginning to present?*	
How did you come to find out about your child's autism?	*Tell me what happened when you first became aware of your child's autism.* *What did you know about autism before?* *What were some of the messages you received about autism after or while learning your child's diagnosis?* *How would you describe your relationship to autism?*	Jones et al. (2015)
How do you tend to refer to your child's autism?	*What language do you find you use most when talking about it (i.e. "autistic," "have autism," "on the spectrum")?* *Can you tell me why you may prefer this way?* *What language does your child use when referring to autism?*	
Can you remember a particular time when you talked to your child about their autism/them being autistic? OR How would you describe conversations that you had with your child about their autism?	*Tell me why that particular time or moment stands out for you.* *Who initiated the talk, and what may have been the purpose for it?* *What were some things you considered before talking to your child?* *What messages were articulated?* *What did you try to communicate during these conversations?* *How did you feel during/after?* *What do you wish was communicated during these conversations?* *What did you value most/least from these conversations?*	Finnegan et al., (2014)

What autism-related topics did/do you discuss with your child?	*What topics, if any, were particularly helpful or challenging to discuss?*	Crane et al., (2019)
Have the conversations that you have had with your child about autism changed over time?	*If so, tell me what you think accounts for this change.* *Do you see yourself differently now than you did when you first had those conversations?* *Do you think these conversations have had an influence on the way your child feels about autism?* *How do you think your child feels about their autism/being autistic?*	Shinebourne & Smith (2009)
What advice would you give to other parents of autistic children who might be debating if, when, and how to discuss autism with their child?	*What factors should parent(s)/caregiver(s) of autistic children consider before informing their child of his/her/their autism?* *What advice* ***did you receive*** *before having these conversations? Who were sources for you?* *What advice* ***do you wish you received*** *before having these conversations?*	Crane et al. (2019)
Has your understanding of autism changed over time?	*How so?*	

IV

EXPLAINING AUTISTIC IDENTITY

Explaining Autistic Identity

Social identity research examines the ways individuals seek to define their self-concept in part through membership to different social groups (Turner, 1982). Self-concept is an aspect of identity that is viewed as a more stable, “cognitive structure” (Oyserman, 2001, p. 504). This set of schemas that one transports and applies across contexts to create a variety of self-images is influenced by the various social identifications, or group memberships one claims (Turner, 1982). In this study, autism is viewed as a social identity (Cooper et al., 2017); a group to which individuals know they belong due to shared characteristics between members, and may feel emotionally connected to (Turner, 1982).

As a social identity, autistic identity is composed of one’s intergroup and intragroup perspectives of autism. Intergroup perspectives of autism can include one’s subscription to views and attitudes held by the larger group and enactment of group-specific behaviors when interacting with nonautistic communities (Sherif, 1966). Intragroup perspectives capture how much the individual perceives uniformity, mutuality, and similarity with others belonging to the autistic community group (Turner, 1982). Accuracy of knowledge about autism (Markus, Smith, & Moreland, 1985; Tekin, 2011), alignment with the neurodiversity paradigm (Kapp et al., 2013), level of outness (Gill, 1997, Hull et al., 2017), and consciousness of autism-related stigma (Botha et al., 2020; Moses, 2009; Tajfel & Turner, 1979) are constructs that influence intergroup and intragroup perspectives, and therefore, autistic identity. This study aims to determine associations between autistic identity and: (a) orientation to neurodiversity perspectives, (b) autism awareness, (c) stigma consciousness, (d) outness, and (e) mental health and wellbeing of autistic adults. Each of these constructs will be described in detail below. Because identity is not consistently defined across literature, research is reviewed that highlights relationships between proposed predictors and identity-related constructs, including self-concept.

Autism Awareness and Knowledge

When navigating social environments, the self-schemas one develops are employed to help make meaning of interactions with others, inform behavior, and further refine and define identity (Markus, 1977). Self-schemas are crafted through knowledge acquisition and information gathering (Markus, Smith, & Moreland, 1985) thereby suggesting that learning more about the characteristics of a given disability can shape identity (Tekin, 2011). The receipt of a psychiatric diagnosis has both benefits and risks for young people's self-identification (O'Connor et al., 2018; Tekin, 2011). For some, learning about their condition or diagnosis can feel incongruous to one's sense of self, leading to unfavorable, devalued self-images (O'Connor et al., 2018). Attributing negatively perceived aspects or events of one's life to an unchangeable condition can contribute to poorer self-identification (Tekin, 2011). Others mark a diagnosis as insightful and confirmatory (Sarrett, 2016) as diagnostic information allows for a better understanding of the self, a legitimization of the difficult experiences that can stem from disability, and optimism regarding more informed pathways to self-regulation and management (O'Connor et al., 2018; Punshon et al., 2009; Tekin, 2011).

Research looking specifically at autistic identification further highlights how learning about autism led to higher self-compassion (Hickey et al., 2018), greater self-acceptance (Lewis, 2016), and heightened feelings of control and agency (Mogensen & Mason, 2015). Though research has shown that autistic adults exhibit increased autism awareness and hold fewer stigmatizing views of autism (Gillespie-Lynch et al., 2017), no studies have been conducted to determine relationships between accurate conceptions of autism and identity.

The Neurodiversity Movement

While self-schemas can be created using factual knowledge about autism, beliefs and attitudes can also inform their composition (Markus et al., 1985). Alignment with neurodiversity perspectives signifies belief that variations in neurological development are examples of natural human diversity, are not disorders that warrant curing, and yield socially valuable contributions (Hughes, 2020). Autism should be viewed as a naturally occurring neurodivergent condition – not something to be stigmatized (Kapp, 2020). Social models of disability such as the neurodiversity paradigm, place responsibility on societal and political structures for the disadvantages and inequity experienced by people with disabilities (Darling & Heckert, 2010; Nario-Redmond et al., 2013). This contrasts with medical orientations to disability which situate disabilities exclusively within the autistic person, calling for rehabilitation or treatment to better adjust to societal norms (Darling & Heckert, 2010).

The neurodiversity paradigm is more closely linked to the social model, though autistic self-advocates emphasize that there are biological underpinnings of autism that can be disabling and/or influence the social experience (den Houting, 2019; Gillespie-Lynch et al., 2017; Kapp, 2020). While there is pride in this way of being (Kapp et al., 2013), societal ableism creates unsupportive environments (den Houting, 2019). Support for and belief in neurodiversity has been operationalized as "autism acceptance," and it has been found that externally sourced autism acceptance predicts depression and personal autism acceptance predicts lower depressive symptoms in autistic adults (Cage et al., 2018). While, to the best of my knowledge, connections between alignment with neurodiversity perspectives have not been explicitly made with cultivating autistic identification, increased awareness of the neurodiversity movement is associated with more positive emotional descriptors of autism and preference for identity-first language when referring to one's autism (Kapp et al., 2013).

Outness and Disclosure

Reasons to conceal one's autism diagnosis or autistic status include fear of being negatively viewed or stereotyped by others and/or treated poorly in discriminatory ways (Frost et al., 2019; Johnson & Joshi, 2014; Romualdez et al., 2021). Feeling the impetus to adaptively morph behavior (also referred to as "masking" or "camouflaging") to socially hide autistic features can impact willingness to disclose autistic status and levels of "outness" to others (Lawson, 2020). Disclosing and consciously or unconsciously modifying behavior are interactional decisions made based on self-schemas created to best navigate different social contexts (Frost et al., 2019; Hull et al., 2017; Pearson & Rose, 2021). While research has shown that autistic adults report avoiding talk of personal or sensitive topics, including the disclosure of autism, to safely cope with and participate in social situations (Cook, Hull, Crane, & Mandy, 2021; Romualdez et al., 2021), autistic students in college (Frost et al., 2019) and adults in the workplace (Romualdez et al., 2021) offered several reasons for why they would disclose: Openness about being autistic can foster understanding from peers, faculty, and colleagues, aid in attaining necessary supports, and potentially mitigate judgment.

Disclosure of being autistic has been referred to as "coming out," adopting language widely used in LGBTQIA communities when opening up about sexuality (Botha & Frost, 2020; Davidson & Henderson, 2010; Gill, 1997). When reviewing disability identity development, Gill (1997) argued that the "coming out" stage reflects an integration of the personal or private self with how an individual then wants to be perceived and seen by others in society. Further, Gill (1997) expanded that this outness is an accomplishment given that disability identities are marginalized and stigmatized. In autistic research, connections have been made between outness and disclosure with autistic identification. Cage and Troxwell-Whitman (2020) identified a significant pathway between autistic identity and disclosure when exploring how disclosure mediated the effect of autistic identity on adaptive morphing behaviors. Qualitative data has also revealed a relationship between outness and autistic identity. Though Frost et al. (2019) found that most of their sample of autistic college students came out rarely to others, one participant explained in an interview how his autism is an integral part of his self-concept and so disclosure allows for others to better understand who he is. Participants surveyed in Hull et al. (2017) acknowledged how the continued practice of adaptive morphing and concealment of autistic characteristics can feel like a “betrayal” to the autistic community (p. 2529) revealing guilt and questioning the imperviousness of their pride and level of positive autistic identification.

Stigma Consciousness

While the neurodiversity movement positively frames autism and advocates for its acceptance within society, autism as a social group remains marginalized with greater negative stereotypic traits attributed to its members than positive ones (Wood & Freeth, 2016). Inferior and superior statuses between different social groups and categories (Caddick, 1982) renders groups’ stereotypic characteristics as either high or low in value. This creates bias and invites discriminatory behavior between groups (Tajfel & Turner, 1979). Asserting the stigmatization experienced by autistic groups, nonautistic youth and adults report poorer perceptions of autistic peers when compared to impressions given of nonautistic peers (Sasson et al., 2017). Nonautistic individuals report less likelihood to pursue friendships with autistic peers who are viewed as more awkward, less approachable, less likable, and less attractive (Sasson et al., 2017).

How does awareness of one’s stigmatized status relate to identity? Because individuals are driven to maintain a positive self-concept or identity (Caddick, 1982; Hornsey, 2008), consciousness of group-related stigma may influence perceived significance of identifying as part of a particular social group. Research has studied constructs related to identity including self-esteem and self-clarity, which are considered more distillate components of self-identification (Hasson-Ohayon et al., 2014; Moses, 2009; Noyman-Veksler et al., 2013; Reyes et al., 2015). Self-esteem measures aim to quantify how individuals value themselves (Moses, 2009) and constructs measuring self-clarity indicate how “clearly and confidently” (Reyes et al., 2015, p. 339) individuals articulate and define components of their identity (Campbell et al., 1996). In people with schizophrenia, awareness of stigma is negatively associated with self-clarity (Hasson-Ohayon et al., 2014). Noyman-Veksler et al. (2013) noted that an increase in self-clarity predicted a decrease in stigma, while Moses (2009) identified perceived social exclusion and mistreatment by others as a significant predictor of self-esteem in a group of youth receiving treatment for mental health conditions. In Filipino transgender youth and adults, decreased self-stigma was found to significantly explain increases in self-concept clarity (Reyes et al., 2015).

Relationships between stigma and identity have also been explored in autism research. Botha, Dibb, and Frost (2020) interviewed a group of autistic adults to examine participant experiences of “diagnosis, identity, and community” (p. 7). Discussion of stigma was ubiquitous across participant accounts revealing how stereotypic views within society make members of the autistic community feel “dismissed” (p. 12), villainized and labeled as violent, and infantilized. In a population of autistic adolescents and adults, Cooper et al. (2021) found that more positive perceptions of autism correlated with higher reported measures of identifying with autism and with more positive views of how autism is viewed in society and by the individual (Cooper et al., 2017; Cooper et al., 2021). Autistic individuals who identify with more negatively charged attributes of autism likely internalize more stigma associated with autism. This leads to lower levels of membership to autism as a social identity and less pride in being autistic (Cooper et al., 2021).

Autistic Identification and Mental Well-being

Meaningful identification with a social group(s) has been found to have an impact on health and well-being (Adarves-Yorno et al., 2020; Begeny & Huo, 2018; Bobowik et al., 2017; Bowe et al., 2020; Cooper et al., 2017; Crabtree et al., 2010; Kyprianides et al., 2019; Maitland et al., 2021). It is important to note that mere identification with a social group does not ensure greater, more positive outcomes related to mental health well-being; perceived value or worth of a social group by society and support or connectedness experienced within the in-group can affect variance observed in self-esteem and well-being (Begeny & Huo, 2019; Bobwik et al. 2017; Crabtree et al., 2010). In their work determining the impact of immigrant identification on health, Bobowik and colleagues (2017) found that social and psychological well-being was higher for those who identified strongly with their country of origin. Similarly, Begeny and Huo (2019) examined how centrality of identification with, and status within a marginalized in-group influenced mental health. With greater centrality of identification with racial and ethnic groups of color, participants exhibited decreased measures of mental health (Begeny & Huo, 2019). Findings suggest that the greater a marginalized social identity is central to one's self-concept, societal discrimination is that much more damaging to mental health (Begeny & Huo, 2019).

Looking at Bobowik et al. (2017) and Begeny and Huo (2019) is particularly relevant when thinking about autistic identification because their work centers around social identification with in-groups known to be marginalized. Outcomes for autistic adults have been deemed relatively poor with low levels of social integration, independent living, and smaller proportions of employment within skilled positions stemming from ableist beliefs held within society (Howlin, Moss, Savage, & Rutter, 2013; Waldron et al., 2022). Research looking at autistic populations has shown that robust autistic identification can help protect against poor mental health (Cooper et al., 2017). Relatedly, Maitland et al. (2021) found lower scores for depressive symptoms and higher measures for positive mental health were observed in autistic adults who more strongly identified with autism as a social identity. The current study focuses specifically on what can promote positive autistic identity and wellbeing in autistic adults (Hedley, Uljarevic, Bury, & Dissanayake, 2019). Knowing that health and wellbeing is negatively influenced by perceived stigma (Perry et al., 2022), it is important to examine how autistic identification mediates the relationship between stigma and mental wellbeing.

Research Questions

The research questions that guided this work include:

RQ 1

Which of the following variables, including autism awareness, orientation to neurodiversity perspectives, stigma consciousness, and outness predict variance in autism identification when controlling for gender, sexuality, and number of years knowing about one's autism?

Rationale and Hypothesis for RQ 1

No research has looked at these four predictor variables collectively to determine their influence on autistic identification. Doing so is important in that it allows us to look beyond direct relationships between these constructs and instead observe the extent to which these predictors explain autistic identity. I hypothesized that all four predictors would statistically significantly explain autistic identification: Increased autism awareness and knowledge, orientation to neurodiversity perspectives, and outness will predict higher measures of autistic identity, while increased stigma consciousness of autism will predict lower measures of autism identification. Table 1 offers a list of predictors with citations of studies that used these variables to find associations with related identity constructs (i.e., self-clarity, self-esteem, views of self).

RQ 2

Does autism identification mediate the effect of stigma consciousness on mental well-being?

Rationale & Hypotheses for RQ 2

Stigma has been directly and negatively associated with the mental well-being of autistic adults (Perry et al., 2020) and autistic identity (Cooper et al., 2021). Cooper et al. (2017) has found that higher collective self-esteem, or positive perception of one's autistic identity, was a protective mechanism against depression. Because extant research has determined direct associations of stigma with wellbeing and autistic identity, and between autistic identity and wellbeing, this study sought to examine the mediating effect of autistic identity on the relationship between autism-related stigma consciousness and mental well-being. If we can better understand the relationship between stigma consciousness and mental well-being, and to what extent autistic identity mediates this relationship, targeted efforts aimed at strengthening autism identification can be considered. This question will determine not only *if* high levels of stigma consciousness of autism lead to lower measures of well-being, but *how*: How might this relationship be impacted when we consider autistic identity as a mediator? I hypothesized that autistic identity mediates the relationship between stigma consciousness and mental wellbeing. Further, the indirect effect of stigma consciousness on wellbeing through autistic identity is less negative than the direct negative effect of stigma consciousness on wellbeing, suggesting that positive associations between autistic identity and wellbeing attenuate the negative effect of stigma consciousness on wellbeing. Figure 1 illustrates these hypothesized relationship paths.

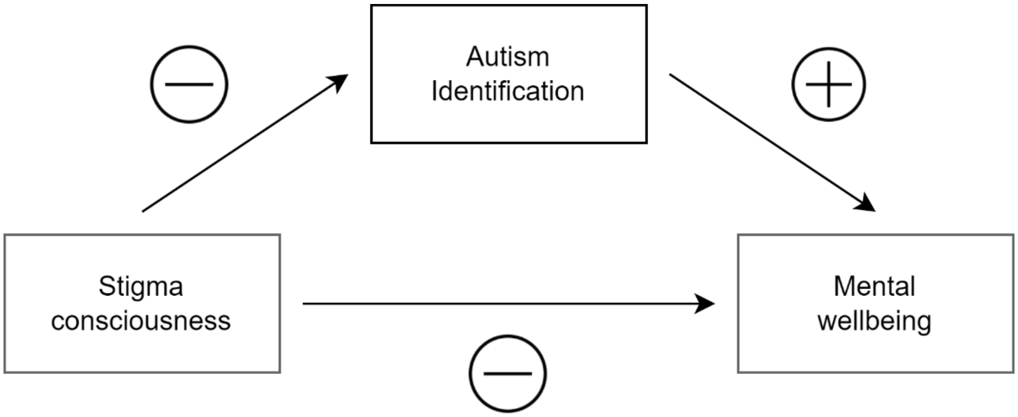

Fig. 1. Hypothesized relationships in mediation model with proposed valence of pathways.

Table 1. *Predictors of identity or self-concept with their empirical and/or theoretical support*

Predictor	Empirical studies finding associations with identity/self-concept	Studies proposing an explanation for influences on identity /self-concept
Awareness and knowledge about diagnosis	Hickey, Crabtree, & Stott (2018) Lewis (2016)	O'Connor, Kadianaki, Maunder, & McNicholas (2018) Sarrett (2016)
Orientation to neurodiversity	Kapp, Gillespie-Lynch, Sherman, & Hutman (2013)	
Stigma consciousness	Hasson-Ohayon, Mashiach-Eizenberg, Elhasid, Yanos, Lysaker, & Roe (2014) Moses (2009) Reyes, Alcantara, Reyes, Yulo, & Santos (2015) Botha, Dibb, & Frost (2020)	
Outness	Cage & Troxwell-Whitman (2020) Frost et al. (2019) Hull et al. (2017)	Gill (1997)

Methods

Participants

Criteria for participation in this study included: (1) having a diagnosis of autism and/or identifying as autistic, and (2) being an adult aged 18 or older. Recruitment relied primarily on non-probability sampling through posting advertisements on Facebook, Twitter, and Reddit platforms, word of mouth, and email solicitation of community groups that support autistic people and/or provide services for families with autistic children. The final sample consisted of 169 participants ranging in age from 18 to 61 years (*M* = 29.92 years; *SD* = 9.12 years). When asked approximately how many years they have known they are autistic, 166 participants gave responses ranging from 0 to 26 years (*M* = 6.26 years; *SD* = 5.96 years). Sample demographics including gender identity, sexuality, race, educational level, employment status, and more are presented in Table 2.

Table 2. *Participant demographics*

Characteristics	**%**	**n**
Gender identity (n = 167)		
Man	30.2	51
Woman	46.7	79
Non-binary (neither, both) / third gender	21.9	37
Sexuality (n = 165)		
Straight	43.8	74
Not straight	53.9	91
Member of LGBTQIA+ community (n = 163)		
Yes	51.5	87
No	45.0	76
Identify as transgender (n = 161)		
Yes	29.0	49
No	66.3	112
Geographical place of residence* (n = 168)		
North America	72.2	122
South America	4.7	8
Europe	16.6	28

Africa	0.6	1
Asia	1.8	3
Australia	3.6	6
Racial identity* (n = 169)		
African American / Black	7.1	12
Native American Indian / Alaskan Native	4.1	7
Asian - Eastern	1.8	3
Caucasian / White	78.1	132
Mixed race	5.9	10
Other	3.0	5
Hispanic or Latinx (n = 168)		
Yes	10.1	17
No	89.3	151
Educational level (n = 168)		
Less than a high school diploma	2.4	4
High school degree or equivalent	11.8	20
Some college	23.7	40
Associate degree	8.3	14
Bachelor's degree	30.8	52
Master's degree	16.6	28
Professional or doctorate degree	4.7	8
Other	1.2	2
Employment status (n = 169)		
Employed full-time	30.2	51
Employed part-time	16.6	28
Unemployed and currently looking for work	7.7	13
Unemployed and not currently looking for work	7.7	13
Student	20.1	34
Homemaker	2.4	4
Self-employed	5.3	9
Unable to work	3.6	6
Other	6.5	11
Description of autism status (n = 169)		
Received a formal diagnosis	66.9	113
Self-diagnosed	30.8	52
Prefer to self-describe	2.4	4
Description of level/degree of speaking words, currently (n = 169)		
Mostly speaking	82.2	139
Semi-speaking	17.2	29
Mostly nonspeaking	0.6	1
Description of level/degree of speaking words, as a child (n = 169)		
Mostly speaking	72.2	122
Semi-speaking	23.7	40
Mostly nonspeaking	4.1	7

Note. *Table lists only categories representative of sample responses and is not exhaustive of all answer response options presented within the survey.

Measures

Measures were compiled into a Qualtrics survey disseminated online. Each measure in the survey is described below, and. Table 3 presents the descriptive statistics of scores on each measure.

Dependent Variables

Autism Social Identification Scale (ASIS). Leach et al. (2008) developed the In-Group Identification scale to measure how individuals identify with a particular social group in different ways. This scale measured autistic identity as the outcome variable for the hierarchical regressions performed in this study. Capable of being adapted to examine participant membership to any social in-group of interest, Cooper et al. (2017) and Maitland et al. (2021) modified question items from the measure first created by Leach et al. (2008) to gauge autism identification in a sample of autistic participants. The 14-item scale breaks down social identification into a total of five components organized within the dimensions of self-investment and self-definition. Self-investment reflects the degree to which individuals feel positively about their in-group membership and is comprised of three components: *Solidarity*, *satisfaction*, and *centrality* (Leach et al., 2008). The dimension of self-definition consists of the components *individual self-stereotyping* and *in-group homogeneity* which capture the extent that individuals perceive similarities with others belonging to the focal social in-group (Leach et al., 2008). As in Maitland et al. (2021), questions were adapted to reflect identify-first language when discussing autism as the in-group (Botha et al., 2021; Bury et al., 2020). Examples of some items include, “I am glad to be autistic,” “I think that autistic people have a lot to be proud of,” and “Being autistic is an important part of how I see myself." Responses are measured using a 7-point scale: strongly disagree (1), mostly disagree (2), somewhat disagree (3), neither agree or disagree (4), somewhat agree (5), mostly agree (6), and strongly agree (7). In both Cooper et al. (2017) and Maitland et al., (2021) internal reliability was good with calculated Cronbach's αs at 0.87 and 0.91, respectively. In the current study, internal consistency was $\alpha = 0.878$.

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). Developed by Tennant et al. (2007), this scale measures positive mental health and wellbeing, including positive affect, positive functioning, and satisfaction with interpersonal relationships. This measured mental wellbeing as the outcome variable for the mediation analysis conducted. Using a 5-point Likert scale, participants were given 14 statements, and were asked to consider their experience within the last two weeks indicate how often they had those presented thoughts or feelings: none of the time (1), rarely (2), some of the time (3), often (4), and all of the time (5). Scores can range between 14 and 70, with a higher level of positive mental health and wellbeing indicated by a higher score on this measure. When used with a student sample and a representative population sample, internal consistency was $\alpha = 0.89$ and $\alpha = 0.91$, respectively (Tennant et al., 2007). This measure has been used with autistic populations with acceptable to strong internal consistency. Cai et al. (2019) made use of the WEMWBS with a sample of adults with and without ASD (collective $\alpha = 0.95$), and Hedley et al. (2019) distributed the WEMWBS to autistic adults at baseline ($\alpha = 0.85$) and follow-up ($\alpha = 0.92$) from supported employment programming. Additionally, this measure has been used with autistic students between the ages of 15 and 22 years, with an internal consistency of $\alpha > 0.70$ (Lei & Russell, 2020). Internal consistency in this study was acceptable/good/very good with $\alpha = 0.892$.

Independent Variables

Participatory Autism Knowledge-Measure (PAK-M). The first iteration of this measure was developed by Stone (1987) and its 13-items measure the accuracy of knowledge, and perceptions about autism. Originally designed for a sample of professionals who work with autistic populations (Stone, 1987) and later used for assessing neurotypical college community members' knowledge of autism (Gillespie-Lynch et al., 2015; Tipton & Blacher, 2014), this study aims to contribute further to research looking at the knowledge and beliefs about autism, by autistic individuals (Gillespie-Lynch et al., 2017). Since its development, the survey has undergone adaptations to better account for shifts in what is considered "accurate" information surrounding autism (Gillespie-Lynch et al., 2015; Gillespie-Lynch et al., 2021). This study used the latest version adapted by Gillespie-Lynch et al. (2021) which includes additional items reflecting misconceptions of autism, outcomes for autistic adults, and masking. Each of the 29 items was scored using a 5-point scale: strongly disagree (-2), disagree (-1), neither agree or disagree (0), agree (1), or strongly agree (2). Select items require reverse coding, and a higher overall score indicates a higher accuracy of autism knowledge. Internal consistency of this measure was $\alpha = 0.944$.

Questionnaire on Disability Identity and Opportunity: Social Model Subscale (QDIO). Darling and Heckert (2010) used the social model subscale of the Questionnaire on Disability Identity and Opportunity to measure the orientation of people with disabilities to a social model of disability. In this study, an adapted version of this subscale indexed orientation and alignment with neurodiversity perspectives. Responses use a 5-point Likert scale: strongly disagree (1), disagree (2), neither agree or disagree (3), agree (4), and strongly agree (5). Higher scores indicate a higher adherence to a social model of disability which adopts the perspective that societal systems and structures should accommodate people with disabilities (Darling &

Heckert, 2010). The social model further asserts that established ableist norms contribute to discriminating against, and limiting populations with disabilities (Hughes, 2020; Shakespeare, 2017). Because neurodiversity as a movement and paradigm is rooted in some of the ideals of the social model of disability, an adapted Social Model Subscale of the QDIO is used in the current study to measure participants' orientation to neurodiversity perspectives (Hughes, 2020). Items focusing on physical accessibility and assessing familiarity with disability legislation specific to the U.S. were omitted for relevance (to neurodiversity) and inclusivity (of participants outside of the U.S.). Remaining items were modified to use the terms, "autistic" and "non-autistic" in place of "disabled" and "non-disabled," respectively. In one item, the phrase, "lack of accessibility" is replaced with "lack of acceptance," to better represent tenets of the neurodiversity paradigm that emphasize conditions like autism as "natural and normal" (Hughes, 2020, p. 5). The internal consistency of this 7-item scale was $\alpha = 0.665$.

Stigma Consciousness Scale. This 5-item scale was developed by Link and Phelan (2014) to measure the level of awareness that individuals with mental health conditions have of their "stigmatized status" (p. 28) and of how the treatment of others may be contingent on their status as a person with a mental health diagnosis ($\alpha = 0.64$). Perry et al. (2020) have adapted this scale for the purpose of measuring autistic participants' awareness of their stigmatized status ($\alpha = 0.65$). Items were modified to replace mention of "mental illness" with that of autism and are scored using a 4-point scale: strongly agree (0), agree (1), disagree (2), and strongly disagree (3). Scores can range between 0 and 15, with a higher score indicative of a higher awareness of stigmatized status due to autism. This scale demonstrated good reliability in the current sample ($\alpha = 0.871$).

Outness. Meyer et al. (2002) developed a 5-item measure of outness to measure the degree to which lesbian and bisexual participants had disclosed their sexuality to others. Using a 4-point scale, items ask respondents if they are out to none (1), some (2), most (3), or all (4) of their family, LGBTQIA+ friends, heterosexual friends, co-workers, and healthcare providers. Because the language of "outness" is commonly used within the autistic community when discussing disclosure of being on the spectrum to others (Gill, 1997; Smith & Jones, 2020), Botha and Frost (2018) have adapted question items specifically mentioning sexuality to better address outness for autistic respondents. In alignment with their adaptation, this study asked participants, "Are you out as autistic to none, some, most, or all of your *autistic peers/non-autistic friends*?" A sum of all items created a total score of disclosure, with high scores denoting a higher degree of being out to others as autistic. In this sample, reliability for the scale was $\alpha = 0.825$.

Additional Measures

Ritvo Autism and Asperger Diagnostic Scale (RAADS-14). RAADS-14 is a screening tool that was used to help identify autism in the participant sample (Eriksson et al., 2013). The 80-item RAADS-R diagnostic scale was reduced to 14-items addressing three domains of "sensory reactivity," "social anxiety," and "mentalizing deficits," which correspond to the diagnostic criteria of autism (American Psychiatric Association, 2013; Eriksson et al., 2013). Items within the domain of "sensory reactivity" correspond to the DSM-5 criterion of restricted and repetitive patterns of behavior, while items within the domains of "mentalizing deficits" and "social anxiety" align more with the social communicative impairments outlined in the diagnostic criteria (American Psychiatric Association, 2013). To further illustrate the distinction between a question item within the "mentalizing deficits" domain and that of "social anxiety," an example of the former focuses more on the internal challenge or tendency of an autistic individual: "It's difficult to figure out what other people expect of me" (Eriksson et al., 2013, p. 5). An item reflecting "social anxiety" instead focuses on the challenge of the interpersonal experience: "I often don't know how to act in social situations" (Eriksson et al., 2013, p. 5).

This particular screening tool is useful in its brevity and in that it aims to identify autism even in the instance of other co-occurring psychiatric conditions (Eriksson et al., 2013). While helping to confirm that the participant sample of the current study is autistic, the use of RAADS-14 additionally allowed for those without a formal autism diagnosis to be included within the current study. Autism was confirmed in participants who scored 14 or above on the measure, which uses a 4-point Likert scale ranging in 0 to 3 for each of its items: "This is true or describes me *now and when I was young*" (3 points); "This was true or describes me *only now*" (2 points); "This was true *only when I was younger than 16*" (1 point); and "This was *never true and never described me*" (0 points). The internal consistency of this scale for autistic participants was α = 0.781. Three participants scored slightly below the cutoff of 14 due to missing question items. Repeating analyses with these participants excluded from the sample determined that results and statistical significance remained the same, so they remain in the total sample.

Demographics. Participants were asked to report their age, number of years knowing about their autism, gender, sexuality, level of education, race, ethnicity, employment/school enrollment, level of speaking words, and location of residence (in or outside of the U.S.).

Table 3. Descriptive statistics for measures used

Measure	**M**	**SD**	**Range**	
			Minimum	*Maximum*
RAADS-14	30.43	7.53	10	42

ASIS, composite		71.15	13.14	33	97
	Self-investment	52.75	10.56	29	70
	Self-definition	18.40	4.91	4	28
PAK-M		34.53	17.19	-13	56
QDIO		20.56	2.64	12	25
Stigma		1.99	0.72	0	3
Outness		12.78	3.98	5	20
WEMWBS		42.67	8.55	19	70

Note. M = mean; SD = standard deviation; RAADS-14 = Ritvo Autism and Asperger Diagnostic Scale; ASIS = Autism Social Identification Scale; PAK-M = Participatory Autism Knowledge-Measure; QDIO = Questionnaire on Disability Identity and Opportunity, Social Model Subscale; Stigma = Stigma Consciousness Scale; WEMWBS = Warwick-Edinburgh Mental Wellbeing Scale.

Cleaning & Handling Data

While online survey dissemination allows for expediency in data collection and wide distribution for a broader sample, it is also vulnerable to bot attacks which can compromise data integrity. Within the first 18 hours of recruitment, the quota limit of 152 responses had been reached. Storozuk et al. (2020) note that incurring high inflow within a short period of time warrants closer inspection of data. Following recommendations outlined by Griffin et al. (2021) and Storozuk et al. (2020), responses were eliminated that had repeated IP addresses (n=111), repeated/similar email addresses (n=3), emails with strings of illegible letters or strings of more than four numbers at the end (n=3), and duplicate, incomprehensible, and/or irrelevant answers to open-ended questions (n=7).

The incentive structure of the survey in this first wave of recruitment offered participants $10 for survey completion. Griffin et al. (2021) argue that this incentive design enhances the vulnerability of online surveys to bot infiltration. To reduce the number of bots and with IRB approval, an amendment was made to the incentive design of the online survey offering instead a raffle structure: Upon completion, participants would be entered into a raffle for the chance to win one of ten available $20 gift cards. With increased efforts for broader recruitment, a total of 488 survey responses were collected. Due to an influx of 237 responses within a 48-hour period, survey collection was closed for further cleaning. Following the same procedure described after the initial recruitment wave, 280 responses were removed (IP addresses: n=29; Repeated/similar email addresses: n=8; Emails with strings of letters/numbers: n=27; Answers to open-ended questions: n=216). Additionally, responses completed in less than one standard deviation from the mean (sessions lasting less than 302 seconds) were removed from the data set (n=23). It is important to acknowledge that while these measures taken were to ensure data integrity against bots and fraudulent behavior, I cannot be certain that I have not also eliminated legitimate participant data in the process. Withdrawal from the study was determined by completion of less than 75% of the survey, which qualified as unusable data and resulted in the removal of 16 responses, leaving a total of 169 responses.

Data Analyses

IBM SPSS Statistics (Version 27) was used for all data analyses. Little's test (Little, 1988) determined that data was not missing completely at random ($p = 0.034$). An overall summary of missing values indicated that there was complete data from 76.92% of the participant sample and between 0 and 4.7% missing data at an item level for each variable used in analyses. Multiple imputation with a recommended setting of 40 imputations was used to address missing data from the sample (Graham, 2012). Pooled statistics are reported across all analyses, unless otherwise noted.

For all analyses, assumptions of linearity, normality, homoscedasticity, and absence of significant outliers were met as determined through the review of frequency distributions, P-P plots, and plots of standardized residuals against predicted values. Bivariate correlations were calculated (Table 4) to determine the relationships between the continuous dependent and independent variables. Review of correlations identified a significant, strongly positive correlation ($r = 0.739$) between stigma consciousness and autism awareness and knowledge, suggesting the possibility of multicollinearity, though cutoff values of 0.8 or 0.9 are often used (Mason & Perreault, 1991). After performing a linear regression model testing for multicollinearity, variance inflation factors all under the value of 2.5 and tolerance levels greater than 0.4 suggested no issue (Kim, 2019). However, further investigation revealing some eigenvalues under 0.05 and accompanying condition indices between 12 and 29 suggest that multicollinearity could be present, though not seriously harmful to analysis with no two predictor variables' variance decomposition proportions exceeding 80% when corresponding to a condition index greater than 10 (Kim, 2019).

Hierarchical regressions were conducted to determine the degree to which the four variables of interest (autism awareness and knowledge, orientation to neurodiversity perspectives, stigma consciousness, and level of outness about being autistic) are associated with autistic identification. Research has identified the number of years knowing about one's autism, gender, and sexuality as predictors of autistic identity. Given that disclosure delays can inspire disappointment and disbelief in autistic youth (Huws & Jones, 2008), greater elapsed time since diagnosis leads to improved feelings about autism (Oredipe et al., 2022) and greater autistic identity satisfaction (Corden et al., 2021), years of knowing about being autistic must be accounted for when controlling for covarying variables impacting autistic identification. Additionally, heterosexuality was found to be positively related to autistic self-esteem (Cooper et al., 2017) and not being male predicted more positive perspectives of autism (Oredipe et al., 2022), necessitating the inclusion of these variables within the regression model. Gender was dummy coded to best represent the groups of women, men, and non-binary individuals, with women being the reference group. Sexuality was treated as a dichotomous variable with participants either identifying as straight (reference group) or not straight. Because this work is exploratory, multiple hierarchical regression models with various iterations of variable step two are examined. In all models, gender, sexuality, and number of years knowing about autism were entered into the first step or block as control variables. For models 2-5, each predictor variable was entered in block two (Autism awareness for Model 2; Neurodiversity perspectives for Model 3; Stigma consciousness for Model 4; Outness for Model 5). Finally, in Model 6, all four predictor variables were simultaneously entered into block two to determine which variable(s) uniquely explain autistic identity while controlling for the other variables.

To determine whether autistic identification mediates the relationship between stigma consciousness and mental health and wellbeing, a simple mediation analysis was performed using version 4.0 of the PROCESS macro for SPSS (Model 4; Hayes, 2018). The bootstrapping method was employed with 5000 bootstrap samples and 95% confidence intervals. Because PROCESS requires complete datasets (Hayes, 2018), analysis from one randomly selected imputed dataset is featured in Figure 2.

Table 4. *Bivariate correlations of continuous independent and dependent variables*

		1	2	3	4	5	6	7
1	Autism knowledge and awareness (PAK-M)	1						
2	Orientation to neurodiversity perspectives (QDIO)	0.475 ***	1					
3	Stigma consciousness	0.739 ***	0.547 ***	1				
4	Outness	0.249 **	0.209 **	0.213 **	1			
5	Autistic identity (ASIS)	0.405 ***	0.511 ***	0.440 ***	0.184 *	1		
6	Wellbeing (WEMWBS)	0.052	0.020	-0.079	0.228 **	0.170 *	1	
7	Number of years knowing about autistic status	-0.053	-0.035	-0.028	0.208 *	-0.050	0.098	1

*p < 0.05. **p < 0.01. ***p < 0.001

Table 5. *Hierarchical regressions with variables predicting autistic identity (ASIS, full composite)*

		Model 1			**Model 2**			**Model 3**		
		β (SE (β))	***p***	**ΔR²**	**β (SE (β))**	***p***	**ΔR²**	**β (SE (β))**	***p***	**ΔR²**
Block 1				0.093*			0.093*			0.093*
	Women vs. Men	0.395 (2.323)	0.865		2.664 (2.254)	0.237		2.965 (2.067)	0.152	
	Women vs. Non-binary	4.868 (2.667)	0.068		3.104 (2.547)	0.223		4.236 (2.331)	0.069	
	Sexuality	5.648 (2.168)	0.009*		3.427 (2.111)	0.104		3.528 (1.924)	0.067	
	Number of years knowing about autism	-0.112 (0.155)	0.472		-0.082 (0.155)	0.581		-0.089 (0.139)	0.525	
Block 2							0.101**			0.211**
	PAK-M				0.273 (0.060)	<0.001**				
	QDIO							2.521 (0.360)	<0.001**	
	Stigma Consciousness									
	Outness									
					Only *autism awareness and knowledge (PAK-M)* is put into Block 2 within the model			Only *alignment with neurodiversity perspectives (QDIO adapted social model subscale)* is put into Block 2 within the model		

		Model 4			**Model 5**			**Model 6**		
		β (SE (β))	***p***	**ΔR²**	**β (SE (β))**	***p***	**ΔR²**	**β (SE (β))**	***p***	**ΔR²**
Block 1				0.093*			0.093*			0.093*
	Women vs. Men	2.488 (2.208)	0.260		0.594 (2.302)	0.796		3.774 (2.075)	0.069	
	Women vs. Non-binary	3.440 (2.500)	0.169		4.343 (2.653)	0.102		3.265 (2.336)	0.162	
	Sexuality	1.800 (2.168)	0.406		5.374 (2.151)	0.012*		2.126 (2.019)	0.292	
	Number of years knowing about autism	-0.095 (0.147)	0.516		-0.182 (0.160)	0.254		-0.102 (0.144)	0.479	
Block 2				0.121**			0.024*			0.239**
	PAK-M							0.083 (0.076)	0.276	
	QDIO							1.999 (0.411)	<0.001**	
	Stigma Consciousness	7.331 (1.475)	<0.001**					2.065 (1.952)	0.29	
	Outness				0.534 (0.254)	0.036*		0.167 (0.231)	0.469	
		Only *level of stigma consciousness* is put into Block 2 within the model			Only *level of outness* is put into Block 2 within the model			*All conceptual predictor variables* are put into Block 2 within the model		

Note. $*p < 0.05$, $**p \leq 0.001$; PAK-M = Participatory Autism Knowledge-Measure (autism knowledge and awareness); QDIO = Questionnaire on Disability Identity and Opportunity, Social Model Subscale (alignment with neurodiversity perspectives).

Results

Aim 1. Explaining Autistic Identification

The six hierarchical regressions conducted in this study are summarized in Table 5. In model 1, control variables accounted for approximately 9.3% of variance in autistic identity and only sexuality was shown to be a significant predictor ($\beta = 5.648$, $p = 0.009$), with participants who were not straight identifying more positively than straight participants. For models 2-5, each predictor of interest was significantly associated with autistic identity when entered into block 2 in isolation (autism awareness and knowledge: $\beta = 0.273$, $p < 0.001$; alignment with neurodiversity perspectives: $\beta = 2.521$, $p < 0.001$; stigma consciousness: $\beta = 7.331$, $p = 0.001$; level of outness: $\beta = 0.534$, $p = 0.036$). Of the covariates entered into block 1 in these models, only sexuality uniquely predicted autistic identity in Model 5 when level of outness was entered in block 2. In model 6, when the four predictor variables were simultaneously entered into block 2 of the model, they explained approximately 23.9% of the variability in autistic identity. Only orientation to neurodiversity perspectives ($\beta = 1.871$, $p < 0.001$) significantly predicted autistic identity when controlling for the block 1 control variables.

Aim 2. Stigma Consciousness, Autistic Identity, and Wellbeing

The path between stigma consciousness and autistic identity was significant and positive ($b = 7.992$, $t(169) = 6.310$, $p < 0.001$) with stigma consciousness explaining approximately 19.25% of variability observed in autistic identity. The path between autistic identity and wellbeing was also significant and positive ($b = 0.164$, $t(169) = 3.019$, $p = 0.003$). In the presence of autistic identity, the direct effect of stigma consciousness on wellbeing was negative and significant ($b = -2.215$, $t(169) = -2.243$, $p = 0.026$), while the total effect of stigma consciousness on wellbeing was negative and not significant ($b = -0.907$, $t(169) = -0.998$, $p =$

0.320). The mediating influence of autistic identity on the indirect effect of stigma consciousness on wellbeing (a*b = 1.309) was positive and significant, with confidence intervals not including zero (CI = [0.407 – 2.340]). The significance of both the indirect and direct effect suggests partial mediation, whereby stigma consciousness exerts some of its influence directly on wellbeing, and some via autistic identity. The opposing signs of the direct and indirect path counteract each other and indicate competitive mediation, rendering the total effect as non-significant (Jiang et al., 2020). This model accounted for approximately 5.77% of variability observed in wellbeing. Appendix A presents the mediation analyses of five other randomly selected imputed datasets which are aligned with the results presented.

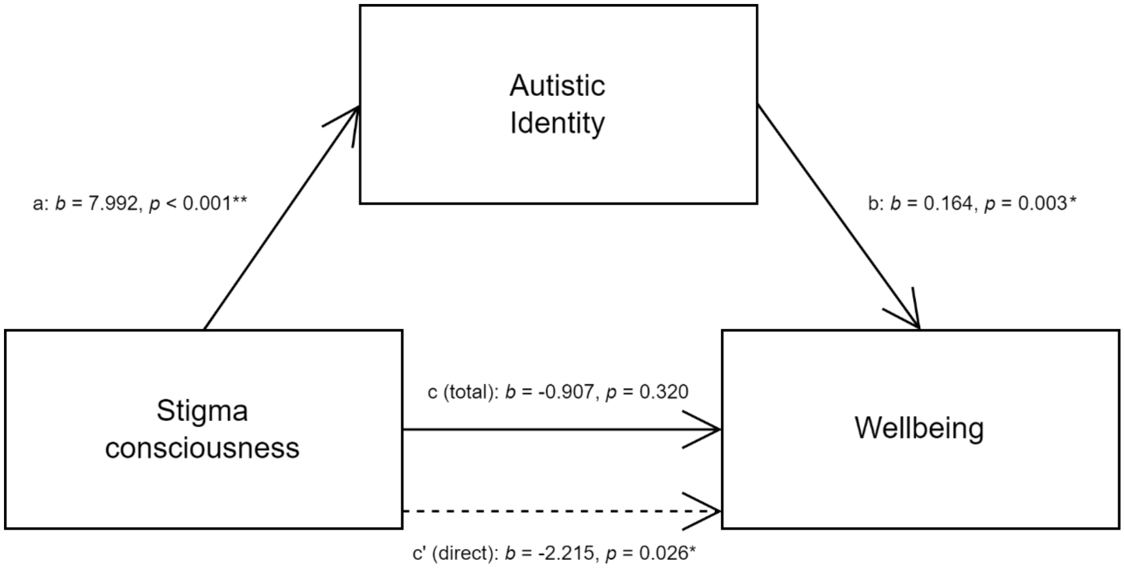

Fig. 2. The mediating effect of autistic identity on the relationship between stigma consciousness and wellbeing. *$p < 0.05$, **$p < 0.001$

Discussion

This study sought to: (1) determine whether autism awareness and knowledge, orientation to neurodiversity perspectives, stigma consciousness, and level of outness influence autistic identity after controlling for the effects of relevant covariates, and (2) analyze the indirect effect of stigma consciousness on mental wellbeing through autistic identity.

Explaining Autistic Identification

Findings show that autistic identification is associated with perceptions and accuracy of autism knowledge, level of alignment to perspectives of the neurodiversity movement, consciousness of autism-related stigma, and degree of autism disclosure when controlling for gender, sexuality, and number of years knowing about autistic status.

With greater autism awareness and knowledge, autistic adults are likely better able to self-define and self-invest within the autistic community (Cooper et al., 2017; Leach et al., 2008). When autistic adults ascribe accurate conceptions of what it means to be autistic to their personal presentation and experience, findings suggest they more readily embrace autistic identity.

Counter to my hypothesis, stigma consciousness was *positively* associated with autistic identity. While unexpected, this finding offers an important consideration: Being acutely aware of autism-related stigma does not always mean that stigma is internalized. Instead, higher consciousness of autism-related stigma might suggest that autistic adults actively cultivate positive autistic identities as a way to combat marginalization and ableism. Societal stigma and stereotyping of a social group are considered intergroup conflicts where the autistic community is afforded less social capital when compared to nonautistic groups (Tajfel & Turner, 1979; Turner, 1982). In response to said stigma, members of the marginalized group can opt to reject or make their membership less salient to preserve or attain power (Turner, 1982). Instead of minimizing the significance of autism as a social identity, autistic adults strengthen their autistic identities in the face of perceived stigma.

A greater level of outness was shown to be associated with higher autistic identification, meaning that those more readily disclosing their autistic status to others reflected more positive autistic identities. While previous research found that autistic identity had a positive direct effect on disclosure (Cage & Troxwell-Whitman, 2020), the current study suggests that there may be more of a reciprocal relationship between the two constructs. For example, not only are those with higher autistic identities more likely to disclose or be out in multiple social contexts about being autistic (Cage & Troxwell-Whitman, 2020), but those who selectively disclose being autistic in settings where it is relevant or necessary (Thompson-Hodgetts et al., 2020) and are met with affirmative attitudes and support from others (Frost et al., 2019), may exhibit more positive autistic identities.

Orientation to neurodiversity perspectives was the only variable uniquely predictive of autistic identification when all other conceptual variables were entered into block 2 of the regression model. Similar to related previous research connecting greater knowledge of the neurodiversity movement with positive, emotional descriptors of autism (Kapp et al., 2013), results from this study indicate that with greater alignment to the beliefs of the neurodiversity movement there is greater autistic identification. Much like being aware of autism-related stigma, those who strongly adopt the perspectives of the neurodiversity movement may embrace positive autistic identification as a reaction to what is perceived as an unsupportive and unaccommodating society (den Houting, 2019); strongly identifying as autistic may be an approach to celebrating natural human variation (Garcia, 2020; Walker, 2012) in ways society fails to.

When considering how to support positive autistic identification, findings imply equipping autistic individuals with accurate information and dispelling misconceptions about autism. Strategies and guides for how to navigate the process of disclosing autistic status in various contexts and with different audiences may also foster more positive autistic identification. Engagement or familiarity with the neurodiversity movement and discourse surrounding ableism might promote autistic identification through viewing autism more positively or as a neutral condition (Gillespie-Lynch et al., 2017) and society as having to make change, rather than the autistic individual (den Houting, 2019).

Stigma Consciousness, Autistic Identification, and Wellbeing

Results revealed a competitive mediation where autistic identity partially mediated the relationship between stigma consciousness and wellbeing. My hypotheses were supported in part; in the presence of autistic identity, stigma consciousness had a direct negative effect on wellbeing and the path between autistic identity and wellbeing was significant and positive. These findings support previous research demonstrating how greater awareness of autism-related stigma contributes to lower mental wellbeing (Perry et al., 2022). While Cooper et al. (2017) concluded that autistic identification was only linked to depression and anxiety through collective self-esteem, the current study detected a direct relationship between autistic identification and mental wellbeing, similar to the findings from Maitland et al. (2021). Rather than focusing on the evidence of poor wellbeing in autistic adults, like Maitland et al. (2021) this study suggests that greater autistic identification supports more positive aspects of mental health.

Initial hypotheses were unsupported in that findings indicate the indirect effect of stigma consciousness on wellbeing via autistic identity was *positive*. This suggests that the effect of positive autistic identity may outweigh the negative influence of higher stigma consciousness on wellbeing. Conversely, it is possible that with greater awareness of autism-related stigma, autistic individuals engage in stigma management or coping strategies that nurture personal wellbeing and/or foster more stalwart autistic identification (Botha et al., 2020). To counteract perceived societal stigma, autistic adults may enact protective or self-preservatory behaviors in the forms of attending to mental health concerns or bolstering their connectedness to the autistic community (Both et al., 2022). In sum, findings support autistic identity development and greater consciousness of stigma surrounding autism as a way to improve mental health and wellbeing in autistic adults.

Limitations

This survey was distributed on online social media platforms, and it is in these online spaces where autistic individuals create robust communities of support, information sharing, socialization, and advocacy (Abel et al., 2019; Lewis, 2022). Because of this, it is possible that the current sample of autistic adults exhibit stronger and more positive autistic identification than those who are not members of online autistic communities. Additionally, they may have greater access to fact-based information about autism and shared experiences from others who are autistic, more exposure to the neurodiversity movement and paradigm, familiarity with discourse surrounding ableism and societal perceptions of autistic people, and increased comfort in disclosing autistic status.

Distilling orientation to neurodiversity perspectives to alignment with the social model of disability as outlined through Darling and Heckert’s (2010) subscale of the Questionnaire on Disability Identity and Opportunity is imperfect. While the neurodiversity movement does recommend that environments become more inclusive and accommodating to mitigate impairment or barriers experienced by those with disabilities, it also acknowledges that there exists some biological impairment that societal adjustments and supports cannot alleviate (den Houting, 2019). The subscale first used by Darling and Heckert (2010) was validated with a sample of adults with disabilities, but never specifically with an autistic adult sample. The reliability of the adapted subscale in the current study was comparable (α = 0.665) to the reported internal consistency in Darling and Heckert's study (α = 0.72) but remains questionable. Though flawed, this approach to measuring orientation to neurodiversity perspectives was adopted due to the absence of a validated neurodiversity measure in the field of disability research which would have strengthened arguments made connecting level of belief in neurodiversity perspectives to autistic identification.

Attending to and representing intersectionality within research is imperative to understand the diversity of experience within the autistic community (Botha & Gillespie-Lynch, 2022). The participant sample of the current study has a high proportion of gender and sexual minority groups but fails to represent intersectional racial and ethnic identities, rendering the findings of the current study ungeneralizable to the broader autistic community. In the demographic categories of gender identity, sexuality, membership to the LGBTQIA+ community, and transgender identity, identifying as a woman or non-binary individual, not straight LGBTQIA+ community member, and transgender comprised a considerable percentage of participants. Because this sample is predominantly Caucasian/white and not Latinx, I was unable to include race and ethnicity as additional covariates controlled for in block 1 within the hierarchical regression models. Greater efforts must be made to recruit more racially and ethnically diverse participant samples in autism research, or to specifically narrow in on just these underrepresented populations when designing a study (Rodgaard et al., 2022). Autistic individuals who belong to racial and/or ethnic minority groups experience cumulative stress and marginalization (Botha & Gillespie-Lynch, 2022; Wright, 2021). Without accounting for race and ethnicity in this exploration of autistic identity, findings do not consider how the lived experience of multiple minoritized identities may impact the dependent variables like stigma consciousness, autism awareness, outness, and alignment with neurodiversity views.

Future Directions

This study does not account for what specifically contributes to and explains the positive relationship between stigma consciousness and autistic identity. Extensions of this work aimed at understanding this link can offer further insight into the conditions necessary for stigma consciousness to positively impact wellbeing. For example, moderation analyses shed light on the circumstances in which stigma consciousness positively influences autistic identity. If stigma consciousness can improve mental wellbeing via autistic identity, stakeholders aimed at supporting the wellbeing of those belonging to the autistic community would benefit from further exploration into the connection between stigma consciousness and autistic identity.

The competitive mediation observed in this study suggests that other mediators explain the relationship between stigma consciousness and wellbeing (Zhao et al., 2010). Some additional unmeasured variables that may impact the relationships observed in this model include fear or internalization of stigma, social withdrawal, and experienced discrimination, victimization, and/or bullying. Future research accounting for these omitted mediators can better explain the magnitude of the direct path between stigma consciousness and wellbeing.

Conclusion

For autistic adults in this study, alignment with neurodiversity perspectives predicted more positive autistic identification and greater consciousness of stigma related to autism had a positive relationship with mental wellbeing via autistic identity. As direction within autism research abandons deficit-driven perspectives and increasingly prioritizes the health, wellbeing, and improved outcomes for those belonging to the autistic community (Roche et al., 2021), this work expands our understanding of autistic identification and further highlights potential pathways for more positive autistic identity development.

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Appendix A

Included Measures

The following are the measures used in a Qualtrics survey distributed online. In order, the measures include: (1) Ritvo Autism and Asperger Diagnostic Scale, (2) Autism Social Identification Scale, (3) Participatory Autism Knowledge-Measure, (4) Additional Neurodiversity question items, (5) Adapted Social Model Subscale, (6) Stigma Consciousness Scale, (7) Outness, and the (8) Warwick-Edinburgh Mental Wellbeing Scale.

Ritvo Autism and Asperger Diagnosis Scale; RAADS-14 (Eriksson et al., 2013)

Responses are given on a 4-point Likert scale, ranging from 0 to 3. Please choose one of the following alternatives:

- (3 points) This is true or describes me *now and when I was young*. // True now and when I was young.
- (2 points) This is true or describes me *only now* (refers to skills acquired). // True only now.
- (1 point) This was true *only when I was young* (16 years or younger). // True only when I was younger than 16.
- (0 points) This was *never true and never described me*. // Never true.

Suggested cut-off score of 14 or greater, out of a maximum of 42 points.

Bold items are reversed.

Numbers in parentheses indicate question order when distributed.

Mentalizing deficits

- (13) I take things too literally, so I often miss what people are trying to say.
- (01) It is difficult for me to understand how other people are feeling when we are talking.
- (09) When talking to someone, I have a hard time telling when it is my turn to talk or to listen.
- (04) It is difficult to figure out what other people expect of me.
- (11) It can be very hard to read someone's face, hand, and body movements when we are talking.
- (12) I focus on details rather than the overall idea.
- (14) I get extremely upset when the way I like to do things is suddenly changed.

Social anxiety

- (03) It is very difficult for me to work and function in groups.
- (05) I often don't know how to act in social situations.
- **(06) I can chat**
- **and make small talk with people.**
- (08) How to make friends and socialize is a mystery to me.

Sensory reactivity

- (02) Some ordinary textures that do not bother others feel very offensive when they touch my skin.
- (07) When I feel overwhelmed by my senses, I have to isolate myself to shut them down.
- (10) Sometimes I have to cover my ears to block out painful noises (like vacuum cleaners or people talking too much or too loudly).

Autistic Social Identification Scale (Cooper et al., 2017; Leach et al., 2008)

For each item below, please indicate how strongly you agree or disagree with that statement (7-point Likert scale).

Adaptations are made to account for autistic identity and the autistic community as the in-group as evident in Cooper et al. (2017). Identity-first language has been adopted.

(Group-Level) Self-Investment

Solidarity

- I feel a bond with ***the autistic community***. 1
- I feel solidarity with ***the autistic community***. 2
- I feel committed to ***the autistic community***. 3

Satisfaction

- I am glad to be ***autistic***. 4
- I think that ***autistic people*** have a lot to be proud of. 5
- It is pleasant to be ***autistic***. 6
- Being ***autistic*** gives me a good feeling. 7

Centrality

- I often think about the fact that I am ***autistic***. 8
- The fact that I am ***autistic*** is an important part of my identity. 9
- Being ***autistic*** is an important part of how I see myself. 10

(Group-Level) Self-Definition

Individual Self-Stereotyping

- I have a lot in common with the average ***autistic person***. 11
- I am similar to the average ***autistic*** person. 12

In-Group Homogeneity

- ***Autistic*** people have a lot in common with each other. 13
- ***Autistic*** people are very similar to each other. 14

Participatory Autism Knowledge-Measure (Gillespie-Lynch et al., 2021)

Response choices included strongly disagree (-2), disagree (-1), neither agree nor disagree (0), agree (1), strongly agree (2).

Bolded items are reverse scored.

1. Autism is more frequently diagnosed in males than females.
2. Autistic children do not develop attachments, even to parents/caregivers.
3. Richer people are only more likely to be diagnosed with autism in countries where everyone does not have equal access to health care.
4. Autistic people are deliberately uncooperative/bad mannered.
5. Autistic children can grow up to go to college.
6. Autistic children can grow up to have successful romantic relationships.
7. Autistic people can grow up to be loving parents.
8. There is one intervention that works for all autistic people.
9. Autism can be diagnosed as early as 18 months of age.
10. With the proper intervention, most children diagnosed with autism eventually outgrow autism.
11. Autistic people show affection.
12. Most autistic people have low intelligence.
13. Autistic children grow up to be autistic adults.
14. Autistic people are generally disinterested in making friends.
15. Autistic people have empathy (feel for other people).
16. Autistic people tend to be good at recognizing patterns.
17. Many autistic people have trouble tolerating loud noises or certain types of touch.
18. Many autistic people show the need for routines and consistency (sameness).
19. The number of diagnosed cases of autism has increased over the past 10 years.
20. Autistic people tend to become particularly knowledgeable about topics they are interested in.
21. Autistic people often notice details that people without autism miss.
22. We now have treatments that can cure autism.
23. Vaccinations cause autism.
24. There is currently no brain scan or blood test to diagnose autism.
25. Autism is due to cold, rejecting parents.
26. Interventions for autistic people should build from their interests.
27. Autistic people can lead successful and satisfying lives.
28. Autistic girls and women tend to be diagnosed later than autistic boys and men are.
29. Autistic people who hide their autism symptoms are more likely to experience mental health challenges than those who are comfortable with their autism.

Additional Neurodiversity Question Items

Responses were made using 1 to 10 Likert scale.

1. On a scale of 1 to 10, **how aware** are you of the neurodiversity movement?

(Not aware; Very aware)
2. On a scale of 1 to 10, **how much do you agree** with the neurodiversity movement?
(Strongly disagree; Strongly agree)
3. On a scale of 1 to 10, **how involved** are you with the neurodiversity movement?
(Not involved; Very involved)

Adapted Social Model Subscale; QDIO (Darling & Heckert, 2010)

All responses were made using 1 (Strongly disagree) to 5 (Strongly agree) Likert scale.

Any language indicating “disabilities” and will be changed to “autistic.”

Strikethrough items are omitted because they focus primarily on accessibility and U.S. legislation.

1. Lack of ***acceptance*** and discrimination by employers are the main reasons why ***autistic*** people are unemployed.
2. It isn’t easy for ***autistic*** people to be treated as “normal.”
3. ***Autistic*** people need to fight for their rights more than ***non-autistic*** people do.
4. The biggest problems faced by ***autistic*** people are the attitudes of other people.
~~All buildings should be accessible to people with disabilities.~~
~~I am familiar with the Americans with Disabilities Act (ADA) and think it is a good law.~~
5. I am familiar with the Disability Rights Movement and support its goals.

Stigma Consciousness Scale (Perry et al., 2020; Link & Phelan, 2014)

Scale is reversed as observed in Perry et al. (2020): Strongly agree (0), Agree (1), Disagree (2), and Strongly disagree (3).

Adaptations are made to replace terms of “mentally ill” and “mental illness” with “autism” and “autistic.”

Scores could range between 0 and 15, with higher scores indicating a higher awareness of stigmatization.

1. Stereotypes about ***autistic*** people have not affected me personally.
2. Most people do not judge someone on the basis of ***them being autistic***.
3. ***Being autistic*** does not influence how people act with me.
4. I almost never think about the fact that I ***am autistic*** when I’m around others.
5. I think that people are often unfairly accused of being biased against people with ***autism***.

Outness (Botha & Frost, 2018; Meyer et al., 2002)

Responses are scaled from being out as autistic to all (4), to being out to none (1).
- None (1 point)
- Some (2 points)

- Most (3 points)
- All (4 points)

Scores could range between 5 and 20, with higher scores indicating higher outness and disclosure of autism.

1. Are you out as autistic to none, some, most, or all of your **autistic peers**?
2. Are you out as autistic to none, some, most, or all of your **family**?
3. Are you out as autistic to none, some, most, or all of your **healthcare providers**?
4. Are you out as autistic to none, some, most, or all of your **co-workers or colleagues**?
5. Are you out as autistic to none, some, most, or all of your **non-autistic friends**?

Warwick-Edinburgh Mental Wellbeing Scale; WEMWBS (Tennant et al., 2007)

This is measured using a 5-point Likert scale: 1 (None of the time), 2 (Rarely), 3 (Some of the time), 4 (Often), and 5 (All of the time).

Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each over the last 2 weeks.

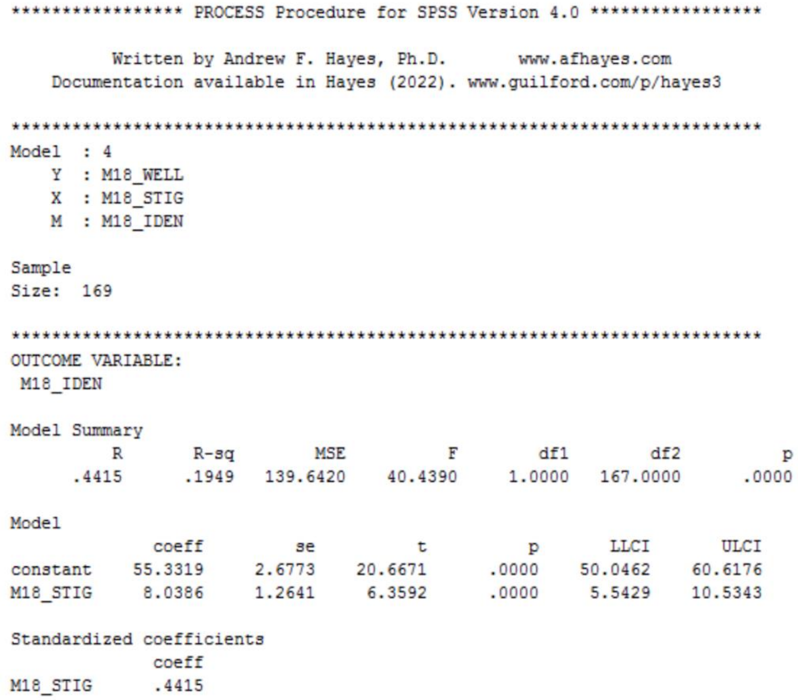
1. I’ve been feeling optimistic about the future.
2. I’ve been feeling useful.
3. I’ve been feeling relaxed.
4. I’ve been feeling interested in other people.
5. I’ve had energy to spare.
6. I’ve been dealing with problems well.
7. I’ve been thinking clearly.
8. I’ve been feeling good about myself.
9. I’ve been feeling close to other people.
10. I’ve been feeling confident.
11. I’ve been able to make up my own mind about things.
12. I’ve been feeling loved.
13. I’ve been interested in new things.
14. I’ve been feeling cheerful.

Appendix B

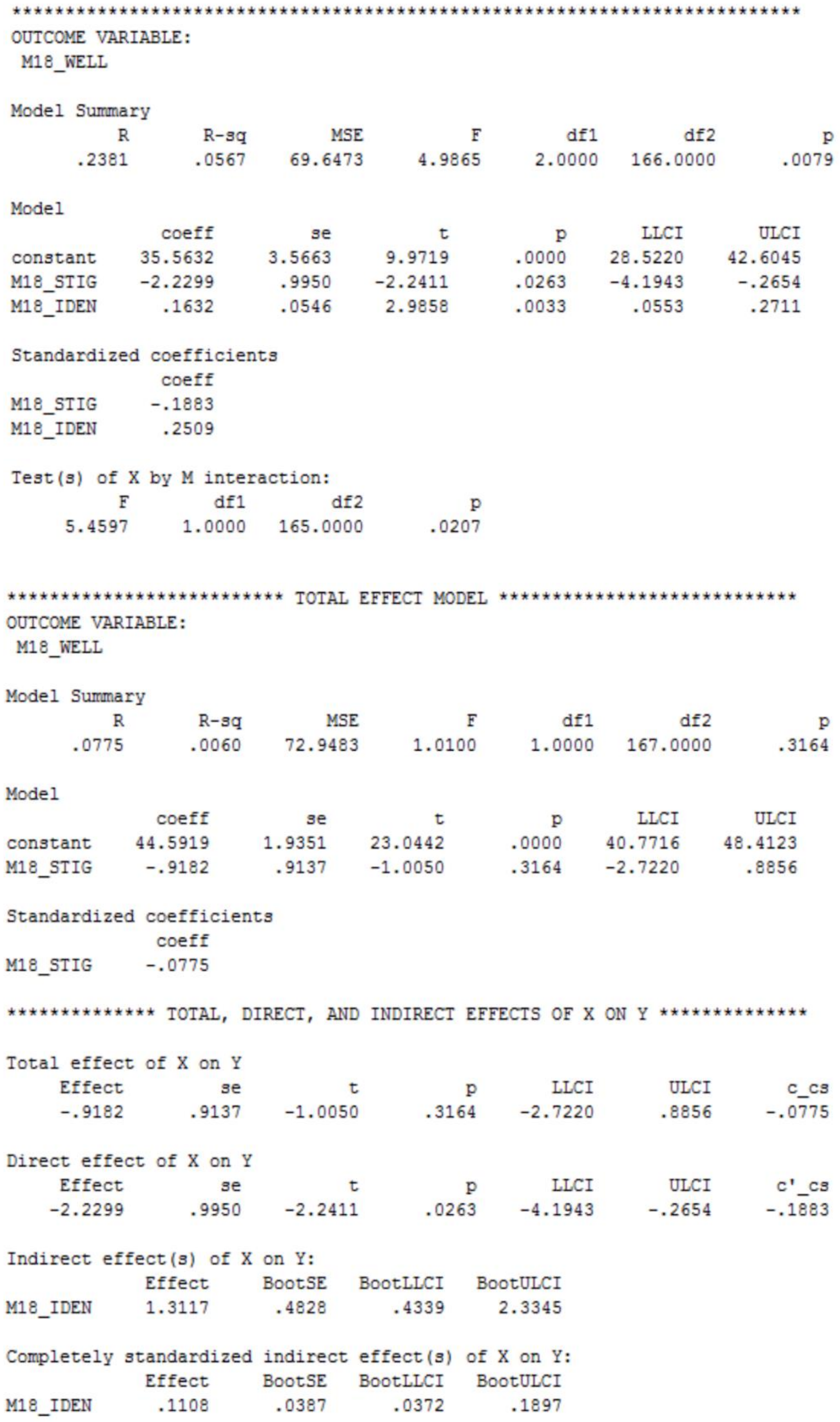
Additional Mediation Analyses

The following are additional mediation analyses and accompanying figures from five randomly selected imputed data sets generated.

Imputed Dataset 18



```
***************** PROCESS Procedure for SPSS Version 4.0 *****************

          Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
    Documentation available in Hayes (2022). www.guilford.com/p/hayes3

**************************************************************************
Model  : 4
    Y  : M18_WELL
    X  : M18_STIG
    M  : M18_IDEN

Sample
Size:  169

**************************************************************************
OUTCOME VARIABLE:
 M18_IDEN

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .4415      .1949   139.6420    40.4390     1.0000   167.0000      .0000

Model
              coeff         se          t          p       LLCI       ULCI
constant    55.3319     2.6773    20.6671      .0000    50.0462    60.6176
M18_STIG     8.0386     1.2641     6.3592      .0000     5.5429    10.5343

Standardized coefficients
              coeff
M18_STIG      .4415
```



```
**************************************************************************
OUTCOME VARIABLE:
 M18_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .2381      .0567    69.6473     4.9865     2.0000   166.0000      .0079

Model
              coeff         se          t          p       LLCI       ULCI
constant    35.5632     3.5663     9.9719      .0000    28.5220    42.6045
M18_STIG    -2.2299      .9950    -2.2411      .0263    -4.1943     -.2654
M18_IDEN      .1632      .0546     2.9858      .0033      .0553      .2711

Standardized coefficients
              coeff
M18_STIG     -.1883
M18_IDEN      .2509

Test(s) of X by M interaction:
          F        df1        df2          p
     5.4597     1.0000   165.0000      .0207


************************** TOTAL EFFECT MODEL ****************************
OUTCOME VARIABLE:
 M18_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .0775      .0060    72.9483     1.0100     1.0000   167.0000      .3164

Model
              coeff         se          t          p       LLCI       ULCI
constant    44.5919     1.9351    23.0442      .0000    40.7716    48.4123
M18_STIG     -.9182      .9137    -1.0050      .3164    -2.7220      .8856

Standardized coefficients
              coeff
M18_STIG     -.0775

************** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y **************

Total effect of X on Y
     Effect         se          t          p       LLCI       ULCI       c_cs
     -.9182      .9137    -1.0050      .3164    -2.7220      .8856     -.0775

Direct effect of X on Y
     Effect         se          t          p       LLCI       ULCI      c'_cs
    -2.2299      .9950    -2.2411      .0263    -4.1943     -.2654     -.1883

Indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M18_IDEN     1.3117      .4828      .4339     2.3345

Completely standardized indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M18_IDEN      .1108      .0387      .0372      .1897
```

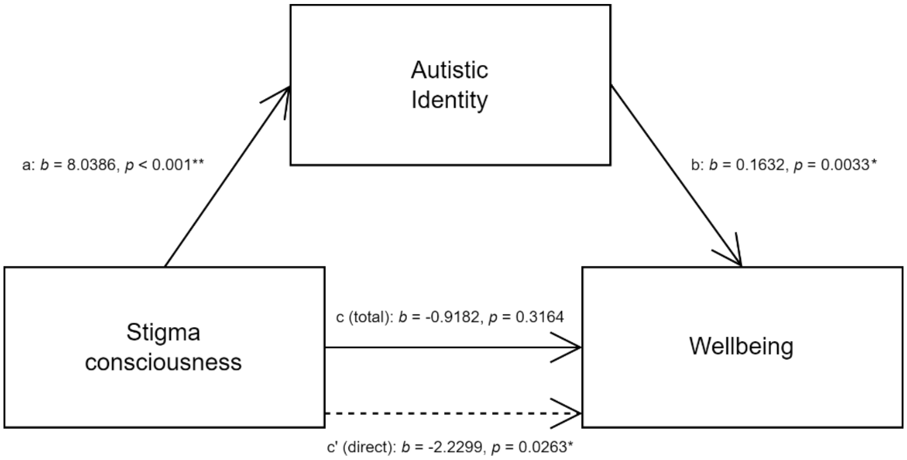
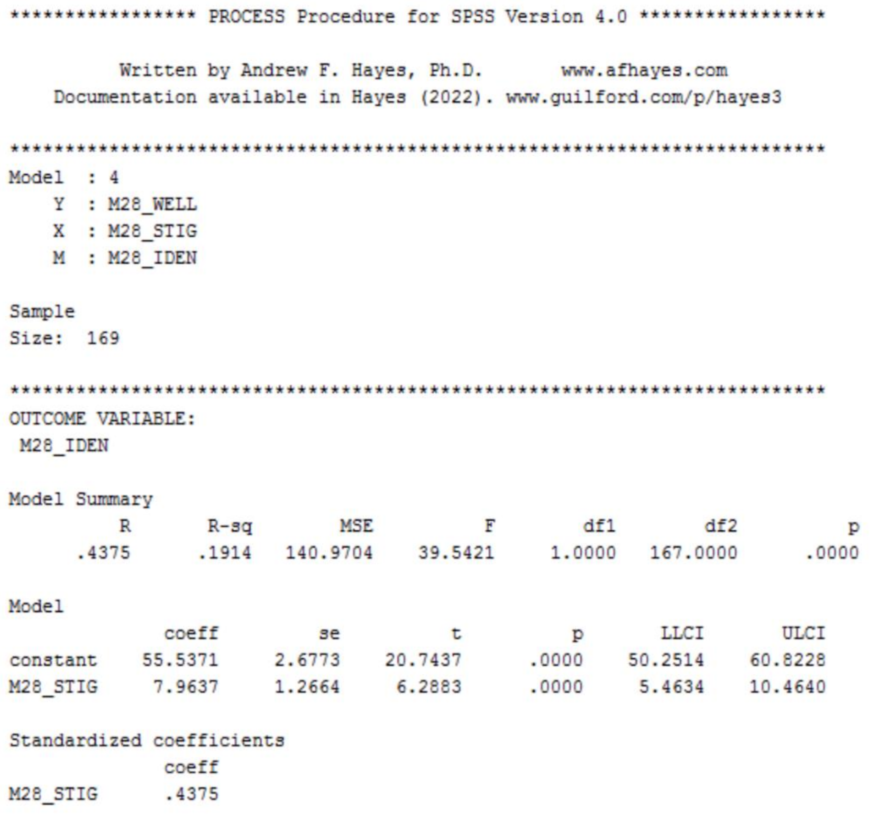
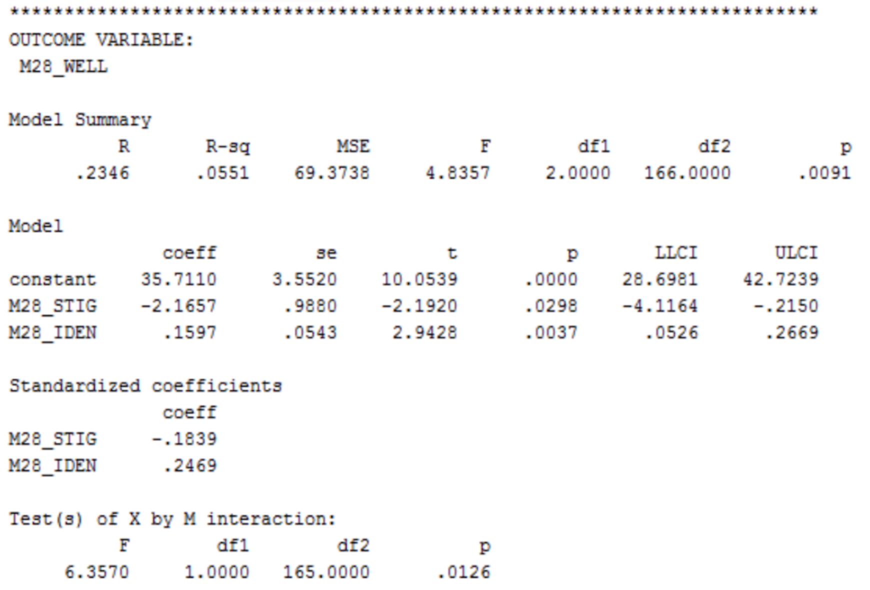


Fig. B1. The mediating effect of autistic identity on the relationship between stigma consciousness and wellbeing. *$p < 0.05$, **$p < 0.001$

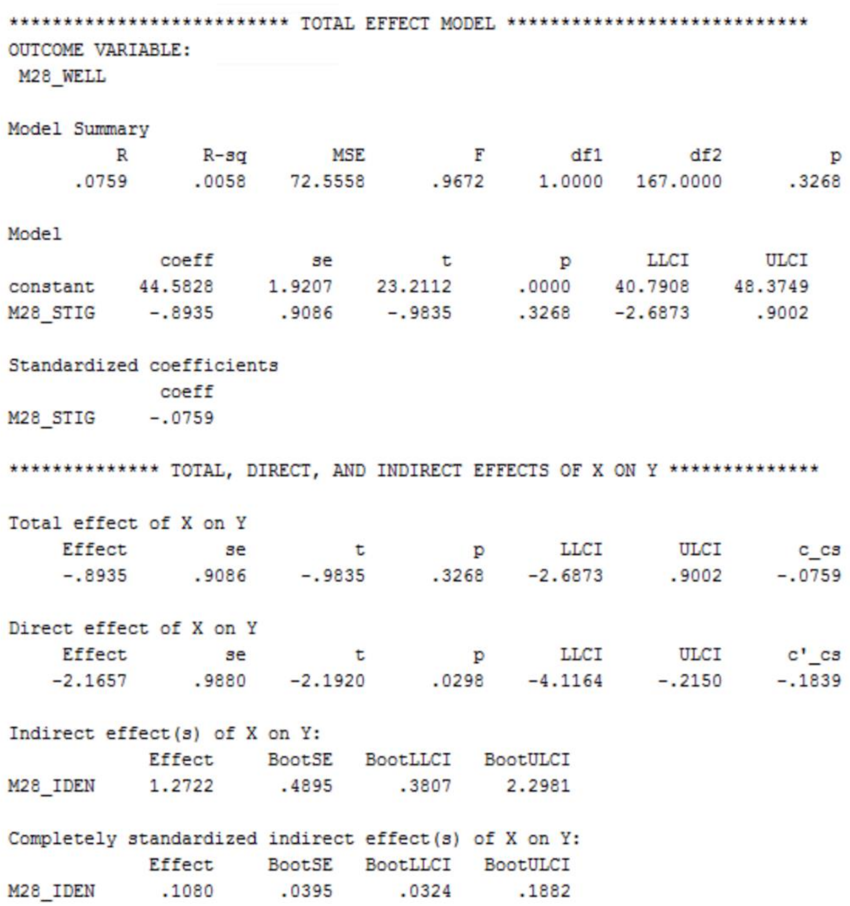
Imputed Dataset 28



```
***************** PROCESS Procedure for SPSS Version 4.0 *****************

          Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
    Documentation available in Hayes (2022). www.guilford.com/p/hayes3

**************************************************************************
Model  : 4
    Y  : M28_WELL
    X  : M28_STIG
    M  : M28_IDEN

Sample
Size:  169

**************************************************************************
OUTCOME VARIABLE:
 M28_IDEN

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .4375      .1914   140.9704    39.5421     1.0000   167.0000      .0000

Model
              coeff         se          t          p       LLCI       ULCI
constant    55.5371     2.6773    20.7437      .0000    50.2514    60.8228
M28_STIG     7.9637     1.2664     6.2883      .0000     5.4634    10.4640

Standardized coefficients
              coeff
M28_STIG      .4375
```



```
**************************************************************************
OUTCOME VARIABLE:
 M28_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .2346      .0551    69.3738     4.8357     2.0000   166.0000      .0091

Model
              coeff         se          t          p       LLCI       ULCI
constant    35.7110     3.5520    10.0539      .0000    28.6981    42.7239
M28_STIG    -2.1657      .9880    -2.1920      .0298    -4.1164     -.2150
M28_IDEN      .1597      .0543     2.9428      .0037      .0526      .2669

Standardized coefficients
              coeff
M28_STIG     -.1839
M28_IDEN      .2469

Test(s) of X by M interaction:
          F        df1        df2          p
     6.3570     1.0000   165.0000      .0126
```



```
************************** TOTAL EFFECT MODEL ****************************
OUTCOME VARIABLE:
 M28_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .0759      .0058    72.5558      .9672     1.0000   167.0000      .3268

Model
              coeff         se          t          p       LLCI       ULCI
constant    44.5828     1.9207    23.2112      .0000    40.7908    48.3749
M28_STIG     -.8935      .9086     -.9835      .3268    -2.6873      .9002

Standardized coefficients
              coeff
M28_STIG     -.0759

************** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y **************

Total effect of X on Y
     Effect         se          t          p       LLCI       ULCI       c_cs
     -.8935      .9086     -.9835      .3268    -2.6873      .9002     -.0759

Direct effect of X on Y
     Effect         se          t          p       LLCI       ULCI      c'_cs
    -2.1657      .9880    -2.1920      .0298    -4.1164     -.2150     -.1839

Indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M28_IDEN     1.2722      .4895      .3807     2.2981

Completely standardized indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M28_IDEN      .1080      .0395      .0324      .1882
```

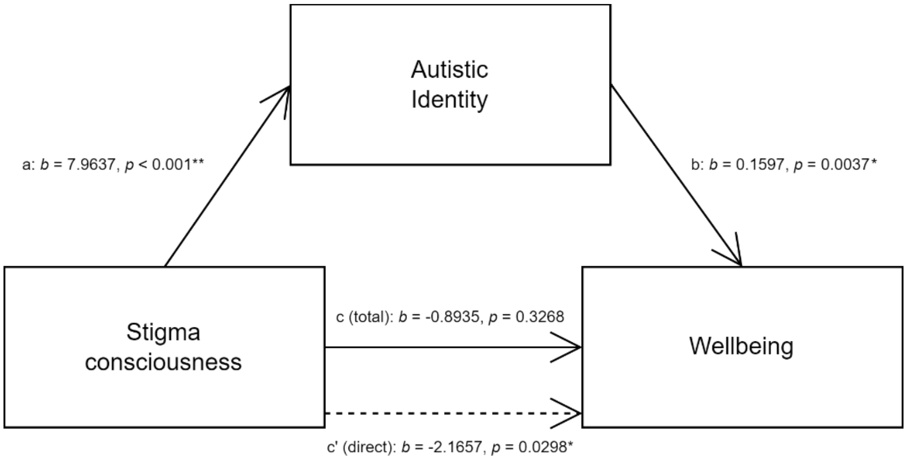
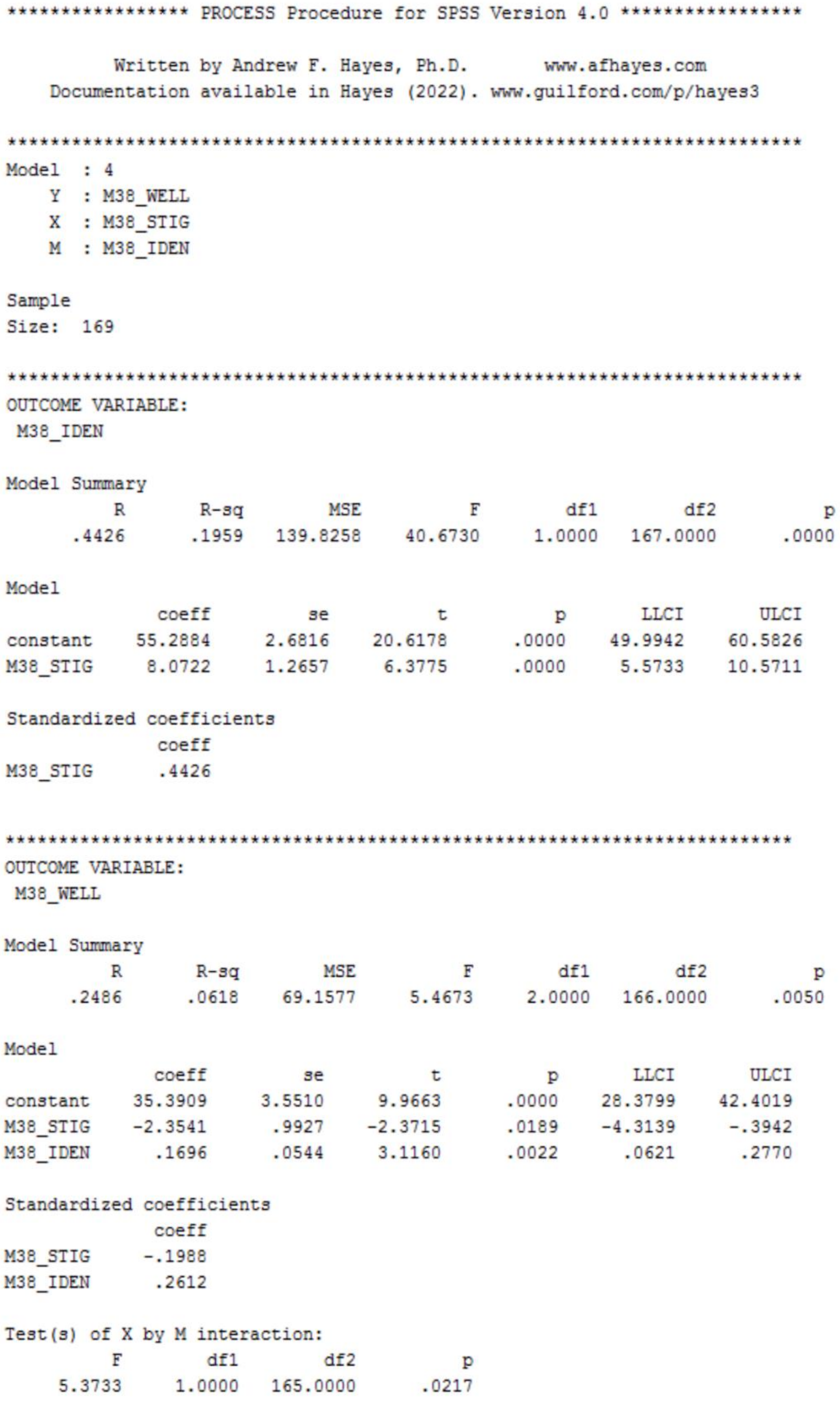
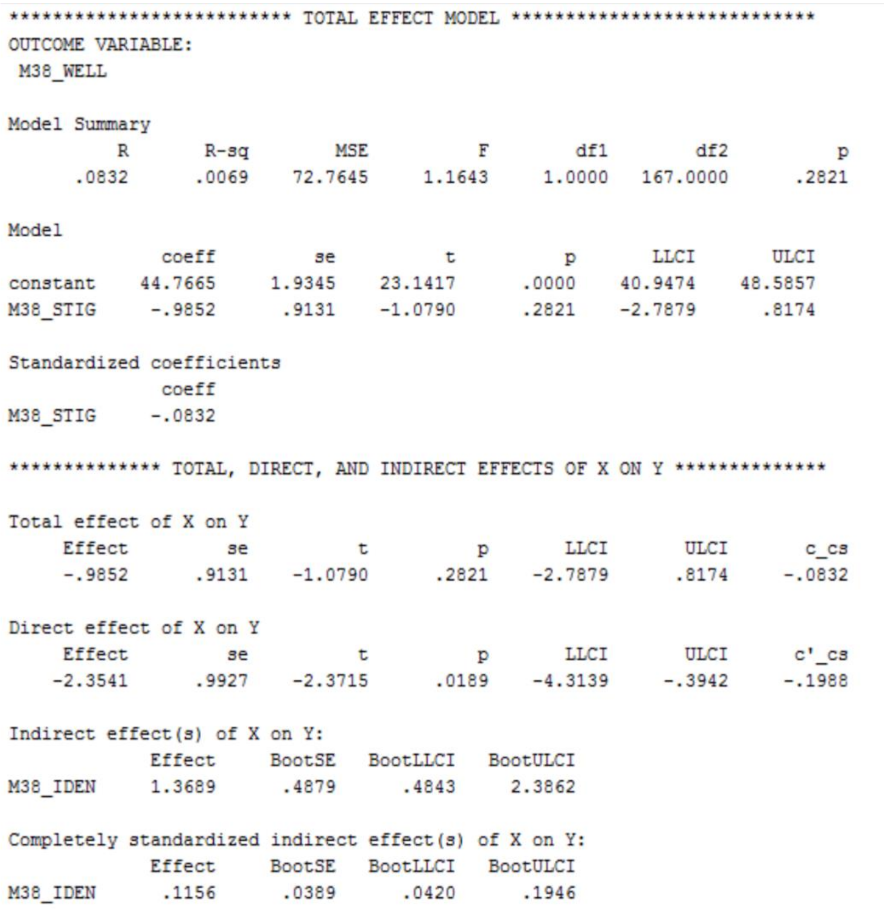


Fig. B2. The mediating effect of autistic identity on the relationship between stigma consciousness and wellbeing. **p* < 0.05, ***p* < 0.001

Imputed Dataset 38



```
***************** PROCESS Procedure for SPSS Version 4.0 *****************

          Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
    Documentation available in Hayes (2022). www.guilford.com/p/hayes3

**************************************************************************
Model  : 4
    Y  : M38_WELL
    X  : M38_STIG
    M  : M38_IDEN

Sample
Size:  169

**************************************************************************
OUTCOME VARIABLE:
 M38_IDEN

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .4426      .1959   139.8258    40.6730     1.0000   167.0000      .0000

Model
              coeff         se          t          p       LLCI       ULCI
constant    55.2884     2.6816    20.6178      .0000    49.9942    60.5826
M38_STIG     8.0722     1.2657     6.3775      .0000     5.5733    10.5711

Standardized coefficients
              coeff
M38_STIG      .4426


**************************************************************************
OUTCOME VARIABLE:
 M38_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .2486      .0618    69.1577     5.4673     2.0000   166.0000      .0050

Model
              coeff         se          t          p       LLCI       ULCI
constant    35.3909     3.5510     9.9663      .0000    28.3799    42.4019
M38_STIG    -2.3541      .9927    -2.3715      .0189    -4.3139     -.3942
M38_IDEN      .1696      .0544     3.1160      .0022      .0621      .2770

Standardized coefficients
              coeff
M38_STIG     -.1988
M38_IDEN      .2612

Test(s) of X by M interaction:
          F        df1        df2          p
     5.3733     1.0000   165.0000      .0217
```



```
************************** TOTAL EFFECT MODEL ****************************
OUTCOME VARIABLE:
 M38_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .0832      .0069    72.7645     1.1643     1.0000   167.0000      .2821

Model
              coeff         se          t          p       LLCI       ULCI
constant    44.7665     1.9345    23.1417      .0000    40.9474    48.5857
M38_STIG     -.9852      .9131    -1.0790      .2821    -2.7879      .8174

Standardized coefficients
              coeff
M38_STIG     -.0832

************** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y **************

Total effect of X on Y
     Effect         se          t          p       LLCI       ULCI       c_cs
     -.9852      .9131    -1.0790      .2821    -2.7879      .8174     -.0832

Direct effect of X on Y
     Effect         se          t          p       LLCI       ULCI      c'_cs
    -2.3541      .9927    -2.3715      .0189    -4.3139     -.3942     -.1988

Indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M38_IDEN     1.3689      .4879      .4843     2.3862

Completely standardized indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M38_IDEN      .1156      .0389      .0420      .1946
```

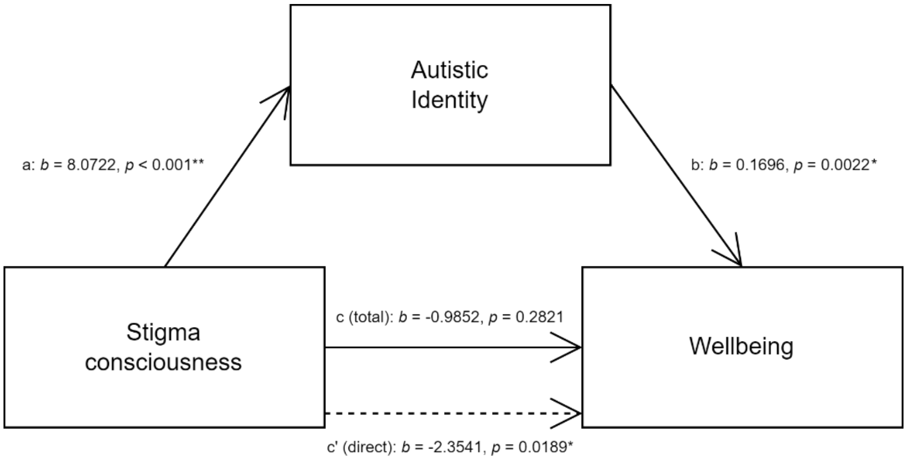
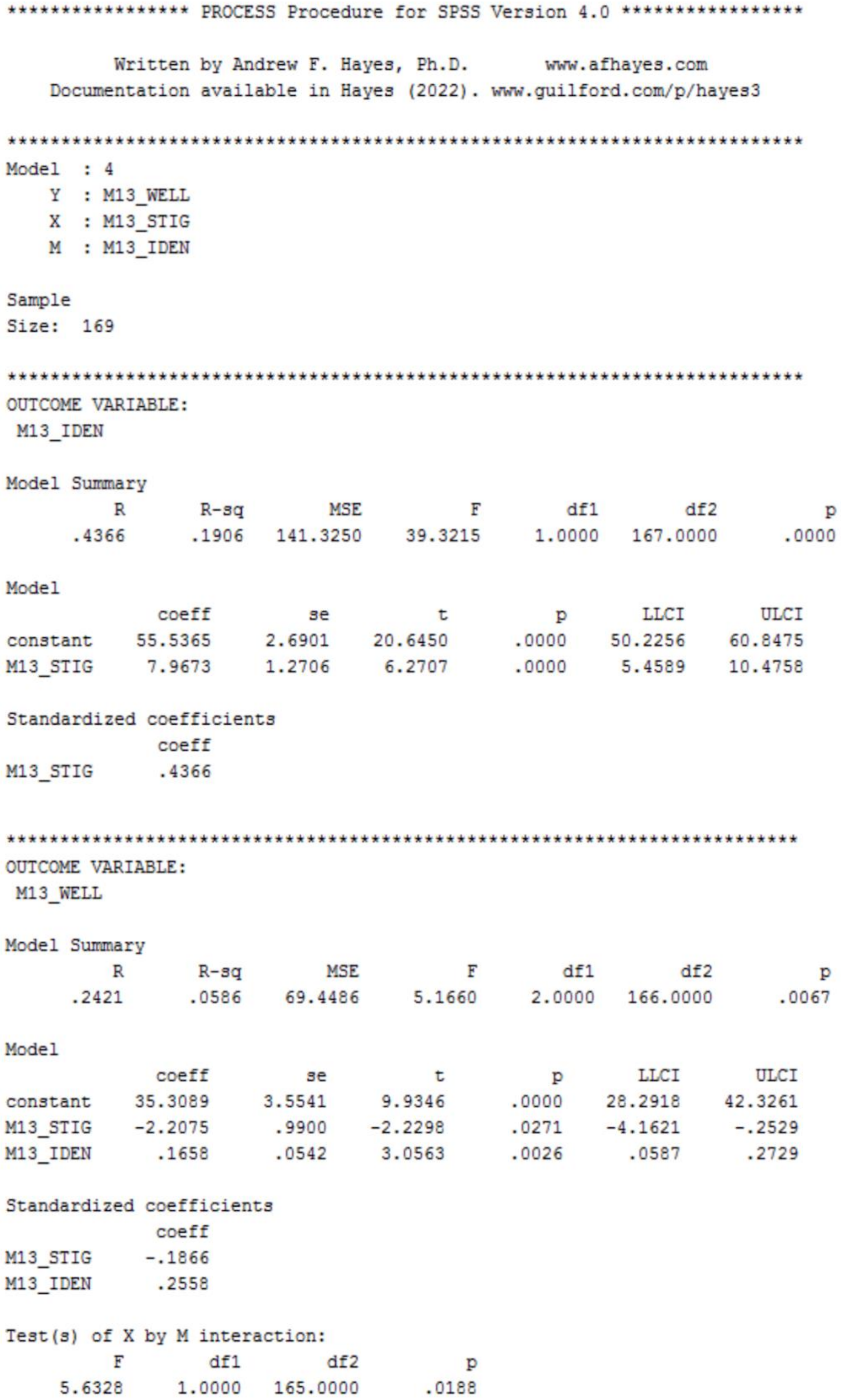
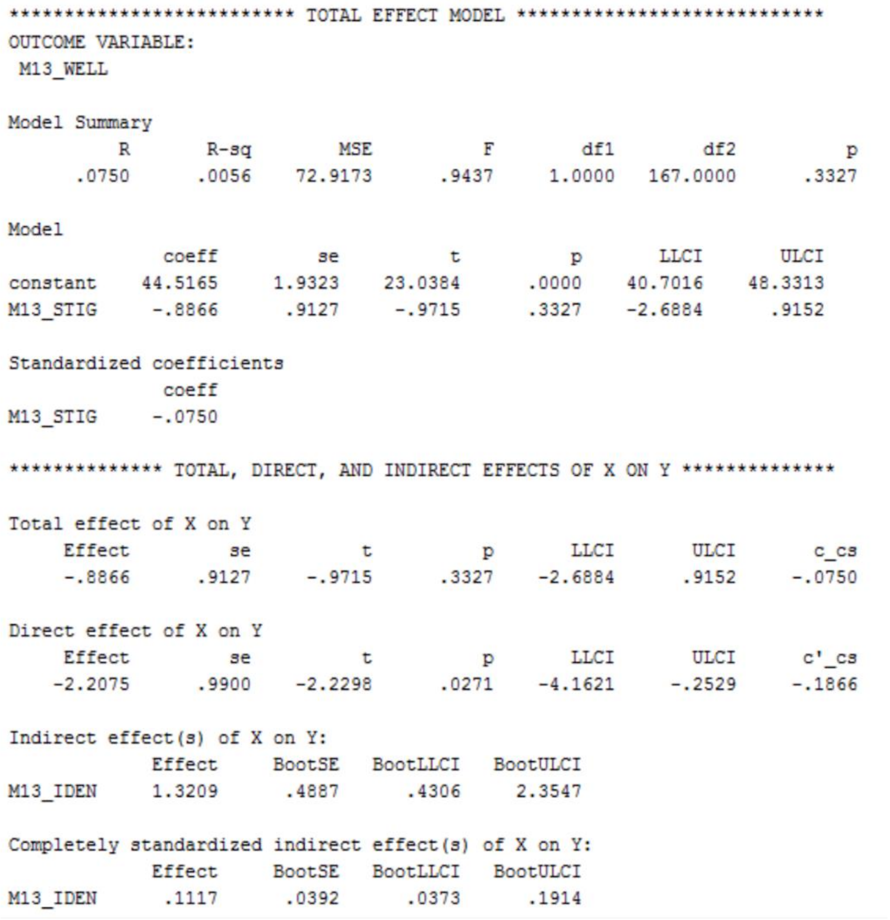


Fig. B3. The mediating effect of autistic identity on the relationship between stigma consciousness and wellbeing. *$p < 0.05$, **$p < 0.001$

Imputed Dataset 13



```
***************** PROCESS Procedure for SPSS Version 4.0 *****************

          Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
    Documentation available in Hayes (2022). www.guilford.com/p/hayes3

**************************************************************************
Model  : 4
    Y  : M13_WELL
    X  : M13_STIG
    M  : M13_IDEN

Sample
Size:  169

**************************************************************************
OUTCOME VARIABLE:
 M13_IDEN

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .4366      .1906   141.3250    39.3215     1.0000   167.0000      .0000

Model
              coeff         se          t          p       LLCI       ULCI
constant    55.5365     2.6901    20.6450      .0000    50.2256    60.8475
M13_STIG     7.9673     1.2706     6.2707      .0000     5.4589    10.4758

Standardized coefficients
              coeff
M13_STIG      .4366


**************************************************************************
OUTCOME VARIABLE:
 M13_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .2421      .0586    69.4486     5.1660     2.0000   166.0000      .0067

Model
              coeff         se          t          p       LLCI       ULCI
constant    35.3089     3.5541     9.9346      .0000    28.2918    42.3261
M13_STIG    -2.2075      .9900    -2.2298      .0271    -4.1621     -.2529
M13_IDEN      .1658      .0542     3.0563      .0026      .0587      .2729

Standardized coefficients
              coeff
M13_STIG     -.1866
M13_IDEN      .2558

Test(s) of X by M interaction:
          F        df1        df2          p
     5.6328     1.0000   165.0000      .0188
```



```
************************** TOTAL EFFECT MODEL ****************************
OUTCOME VARIABLE:
 M13_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .0750      .0056    72.9173      .9437     1.0000   167.0000      .3327

Model
              coeff         se          t          p       LLCI       ULCI
constant    44.5165     1.9323    23.0384      .0000    40.7016    48.3313
M13_STIG     -.8866      .9127     -.9715      .3327    -2.6884      .9152

Standardized coefficients
              coeff
M13_STIG     -.0750

************** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y **************

Total effect of X on Y
     Effect         se          t          p       LLCI       ULCI       c_cs
     -.8866      .9127     -.9715      .3327    -2.6884      .9152     -.0750

Direct effect of X on Y
     Effect         se          t          p       LLCI       ULCI      c'_cs
    -2.2075      .9900    -2.2298      .0271    -4.1621     -.2529     -.1866

Indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M13_IDEN     1.3209      .4887      .4306     2.3547

Completely standardized indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M13_IDEN      .1117      .0392      .0373      .1914
```

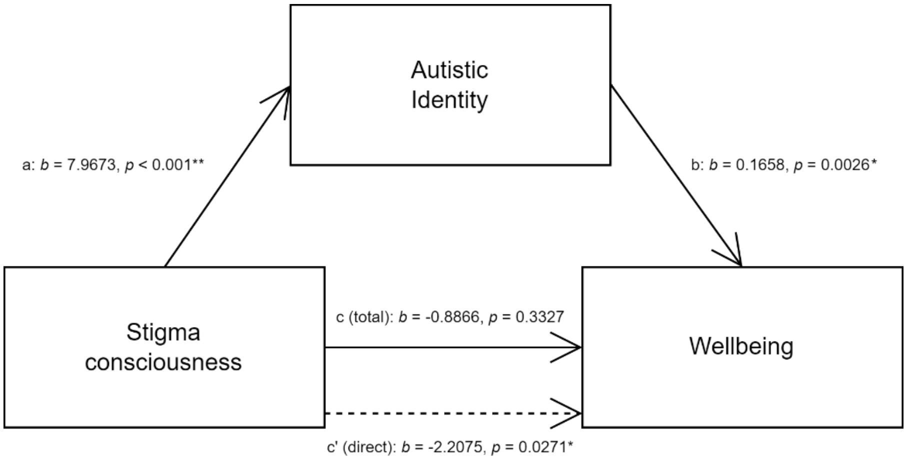
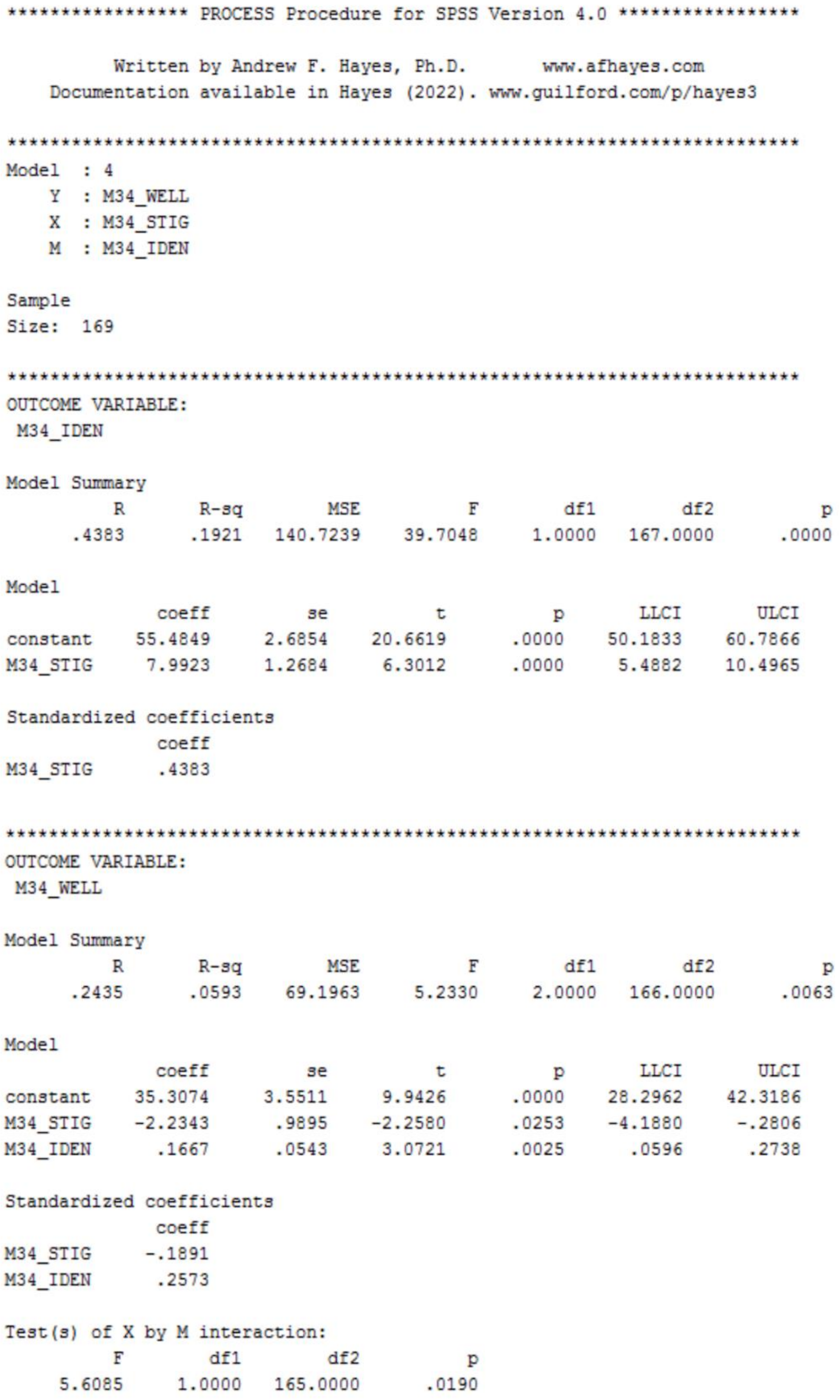
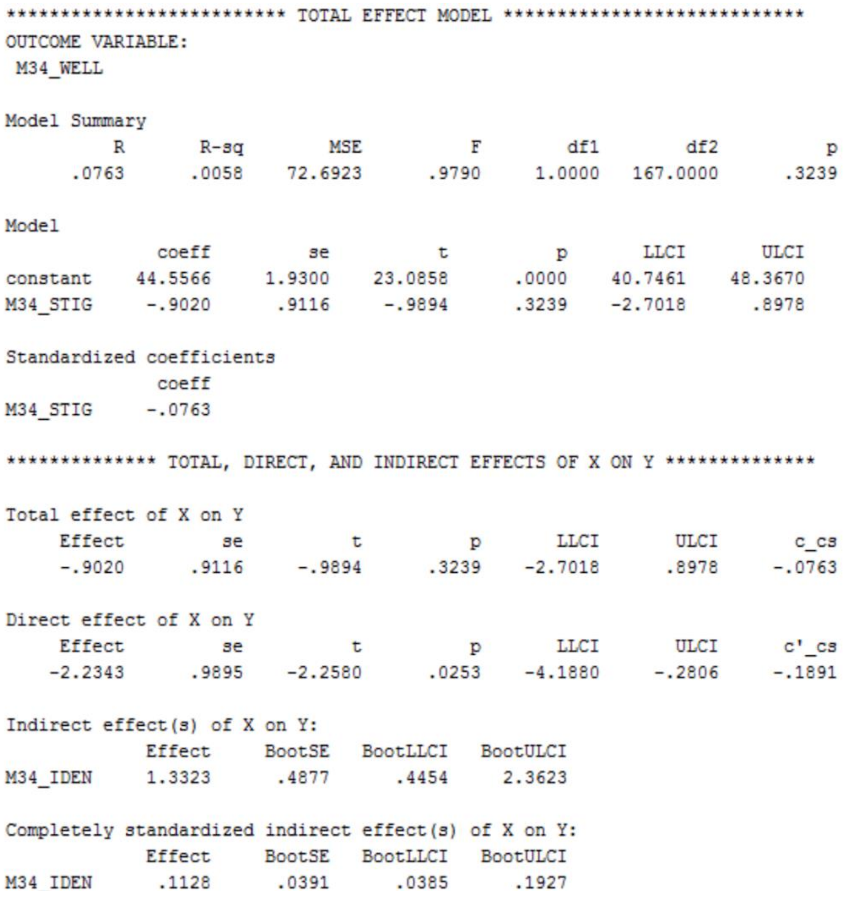


Fig. B4. The mediating effect of autistic identity on the relationship between stigma consciousness and wellbeing. **p* < 0.05, ***p* < 0.001

Imputed Dataset 34



```
***************** PROCESS Procedure for SPSS Version 4.0 *****************

          Written by Andrew F. Hayes, Ph.D.       www.afhayes.com
    Documentation available in Hayes (2022). www.guilford.com/p/hayes3

**************************************************************************
Model  : 4
    Y  : M34_WELL
    X  : M34_STIG
    M  : M34_IDEN

Sample
Size:  169

**************************************************************************
OUTCOME VARIABLE:
 M34_IDEN

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .4383      .1921   140.7239    39.7048     1.0000   167.0000      .0000

Model
              coeff         se          t          p       LLCI       ULCI
constant    55.4849     2.6854    20.6619      .0000    50.1833    60.7866
M34_STIG     7.9923     1.2684     6.3012      .0000     5.4882    10.4965

Standardized coefficients
              coeff
M34_STIG      .4383

**************************************************************************
OUTCOME VARIABLE:
 M34_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .2435      .0593    69.1963     5.2330     2.0000   166.0000      .0063

Model
              coeff         se          t          p       LLCI       ULCI
constant    35.3074     3.5511     9.9426      .0000    28.2962    42.3186
M34_STIG    -2.2343      .9895    -2.2580      .0253    -4.1880     -.2806
M34_IDEN      .1667      .0543     3.0721      .0025      .0596      .2738

Standardized coefficients
              coeff
M34_STIG     -.1891
M34_IDEN      .2573

Test(s) of X by M interaction:
          F        df1        df2          p
     5.6085     1.0000   165.0000      .0190
```



```
************************** TOTAL EFFECT MODEL ****************************
OUTCOME VARIABLE:
 M34_WELL

Model Summary
          R       R-sq        MSE          F        df1        df2          p
      .0763      .0058    72.6923      .9790     1.0000   167.0000      .3239

Model
              coeff         se          t          p       LLCI       ULCI
constant    44.5566     1.9300    23.0858      .0000    40.7461    48.3670
M34_STIG     -.9020      .9116     -.9894      .3239    -2.7018      .8978

Standardized coefficients
              coeff
M34_STIG     -.0763

************** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y **************

Total effect of X on Y
     Effect         se          t          p       LLCI       ULCI       c_cs
     -.9020      .9116     -.9894      .3239    -2.7018      .8978     -.0763

Direct effect of X on Y
     Effect         se          t          p       LLCI       ULCI      c'_cs
    -2.2343      .9895    -2.2580      .0253    -4.1880     -.2806     -.1891

Indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M34_IDEN     1.3323      .4877      .4454     2.3623

Completely standardized indirect effect(s) of X on Y:
             Effect     BootSE   BootLLCI   BootULCI
M34 IDEN      .1128      .0391      .0385      .1927
```

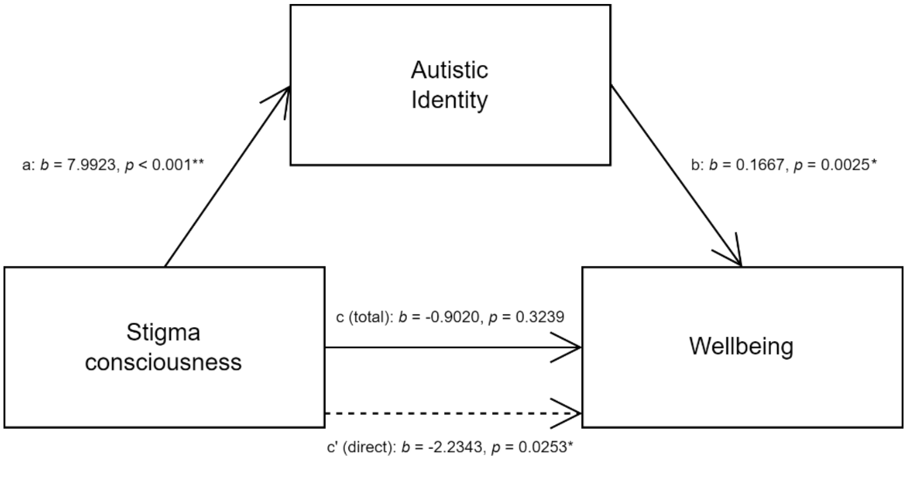


Fig. B5. The mediating effect of autistic identity on the relationship between stigma consciousness and wellbeing. *$p < 0.05$, **$p < 0.001$

V

CONCLUSION

Conclusion

The studies comprising this dissertation sought to expand on the burgeoning field of autistic identity research each adopting a distinct approach and methodology:

Study 1 used a sociolinguistic perspective in analyzing the talk-in-interaction of self-identified autistic adults to learn more about how autistic identities are constructed through their narratives of disclosure and talking about autism with others. Autistic adults without a formal diagnosis have elected to claim membership to an autistic ingroup and their identity construction is underexplored using a discourse analytic approach.

Also qualitative in its approach, Study 2 uncovered how conversations about autism between a caregiver and autistic adolescent can be formative in developing autistic identities. The caregiver perspective was included as a complement to the autistic experience of talking about autism to amass a more comprehensive view of this exchange. To date, no publication tackles describing this experiential phenomenon with the collective perspectives of caregivers and autistic person, so this is additive to the field.

Offering a quantitative approach to analyzing autistic identity, Study 3 contributes information about how autism knowledge and awareness, orientation and alignment with perspectives of the neurodiversity paradigm, consciousness of autism-related stigma, and level of outness predict autistic identity development and how autistic identification mediates the effect of stigma consciousness on the mental wellbeing of autistic adults.

These three studies are intentionally centered around the autistic voice and perspective, seeking to adopt inclusive recruitment practices that would invite the participation of autistic people (i.e., self-identified/not formally diagnosed, nonspeaking) who are underrepresented in autism research. It is purposeful that each of these studies adopts a distinct methodological approach to examining autistic identity so that a more textured understanding of autistic identification can be gathered.