

How is Autistic Identity in Adolescence Influenced by Parental Disclosure Decisions and Perceptions of Autism?

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Abstract

A large body of literature examines parental interpretations of their child's autism diagnosis. However, research examining intersections between parental disclosure of their child's autism diagnosis to their child and their child's identity development is lacking. The primary aim of this study was to analyze if parental decisions to disclose/withhold their child's autism diagnosis influence adolescents' perceptions of autism and identity development. Adolescent participants ($n=19$) and their mothers, recruited from an informal educational program, completed in-person interviews and online questionnaires, respectively. Adolescents were told about their autism diagnosis in varying ways. Adolescents whose parents voluntarily disclosed their autism diagnosis to them described autism and themselves more positively than adolescents who did not experience voluntary disclosure. Although parents and teens showed similarities on a group level when defining autism, parents and children expressed diverse themes in their definitions of autism. Findings suggest that parents can help their children develop neurodiversity-aligned perspectives about autism by mindfully discussing autism with them early in their development.

How is Autistic Identity in Adolescence Influenced by Parental Disclosure Decisions and Perceptions of Autism?

A large body of literature examines the effects of parenting an autistic child, often focusing on parental interpretations of the diagnosis. While parents often feel distressed by their child's diagnosis and seek to confront it as separate from their child, acceptance of their child's autism benefits the parent-child relationship (reviewed by Kapp, 2018). Research has found that the mental health and development of autistic children is highly vulnerable to parents' distress (Park et al., 2013; Totsika et al., 2015; Zaidman-Zait et al., 2014), indicating that parents' constructive interpretation of an autism diagnosis may be critical. However, parents often struggle with the process of deciding if, when, and how to tell their child about their child's autism (Crane et al., 2019; Finnegan, Trimble, & Egan, 2014). Lack of parental disclosure could contribute to many autistic adolescents' apparent lack of self-awareness of their autism (Green et al., 2000), as many parents may not disclose until adolescence or adulthood. Very little remains known about how parental disclosure of an autism diagnosis may impact autistic identity development. The present study aims to understand how parent perceptions and discourse about autism influence the development of a positive autistic identity among autistic adolescents. Neurodiversity-aligned perspectives, where autism and other diagnoses are recognized as valued aspects of human diversity, reject attempts at "normalizing" autistic people by situating autism as a central aspect of one's identity (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Singer, 2017).

Research with Autistics about Autistic Identity

Existing models of disability identity development, although limited in their empirical basis, often highlight that disability identity construction is inherently social (Forber-Pratt, Lyew,

Mueller, & Samples, 2017). Family members (and peers) may have a particular influence on disability identity development. When 20 autistic schoolchildren were asked to describe themselves, students who described autism and themselves negatively reported a strong desire to be “normal” (Humphrey & Lewis, 2008). The authors speculated that these students had incorporated negative feedback from others into their developing identities. Indeed, students who described autism and themselves positively indicated that they had strong social support.

Prior research has examined tensions between acceptance or rejection of an autism diagnosis and negotiating what it means to be “normal” as an autistic person (e.g., Jones et al., 2013; Jones et al., 2015). Autistic individuals often report attempting to camouflage autistic traits to be more like non-autistic peers, often with detrimental effects on mental health (Cage, Di Monaco, & Newell, 2018; Cage & Troxell-Whitman, 2019; Hull et al., 2017). In contrast, autistic adolescents and young adults who view autism as a positive difference express pride about being autistic (Jones et al., 2015; Mogensen & Mason, 2015). Knowing about one’s diagnosis and being afforded the opportunity to connect with other autistics may lead to positive outcomes. Indeed, autistic university students found community in experiences shared with other autistics (Jones et al., 2013).

However, it remains unclear how autistic people come to know about their diagnosis, specifically if and how autism is discussed with them. Of nine autistic college students who were asked about autism, four spoke about their parents’ delay in disclosing their diagnosis causing shock, disappointment, and disbelief when they were told (Huws & Jones, 2008). Possible reasons for a delay in disclosing include fear that a child might not be ready to understand the diagnosis or might find the label distressing (Camarena & Sarigiani, 2010; Huws & Jones, 2008).

Although peers typically play a large role in shaping adolescent identity development (Ragelienė, 2016), autistic adolescents may rely more on relationships with adults than their neurotypical peers do. In prior research, autistic adolescents self-reported more positive perceptions of their relationships with parents and teachers than typically developing peers, contrasted with poorly self-evaluated peer relationships (Cottenceau et al., 2012). A study of 185 autistic adolescents and 50 autistic adults found that very few autistic participants reported social relationships with same-age peers; autistic participants were more likely to engage in a social activity if their mother *also* engaged in that activity (Orsmond, Krauss, & Seltzer, 2004). A recent review article suggests that parents continue to shape the social contexts many autistic young people experience (Cresswell, Hinch, & Cage, 2019) and may thus have an impact on autistic identity development.

Parent Experiences with and Perspectives toward Autism

The parent literature concerning experiences with and perceptions of autism has often focused on the impact of autism on those surrounding an autistic person. Like autistic youth, parents often grapple with the concept of “normal,” contrasting their parenting experiences to those of parents with neurotypical children (e.g., Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Wachtel & Carter, 2008). Parents often focus on themes such as stress, demands of care, impact on parents’ well-being, and isolation when asked how their autistic children affects their family life (Myers et al., 2009). However, when parents ($n = 47$) were specifically asked to identify benefits of having an autistic child, most participants identified benefits (Pakenham et al., 2004). The majority of respondents described making-sense of their child’s autism through understanding autism (41%) and changing their perspective (29%). Indeed, parental

understanding and acceptance of autism has been associated with increased parenting self-efficacy and positive parenting behaviors (Oppenheim et al., 2012; Wachtel & Carter, 2008).

Parents may often delay seeking a diagnosis for their autistic child as they weigh benefits of a diagnosis, such as access to services and increased understanding, against costs, such as the possibility that the ASD label could negatively impact their child's life (Russell & Norwich, 2012). A diagnosis often helps them gain understanding of their child and support (Russell & Norwich, 2012). Parents who decide to have their autistic children diagnosed may be more likely to express neurodiversity-aligned perspectives and may be more open to talking about their child's needs than parents who resist seeking an autism diagnosis for their child despite the presence of autistic traits.

A recent review article revealed only five studies (representing 34 individuals) that focused on the process of disclosing an autism diagnosis to an autistic individual (Smith et al., 2018). Two studies focused on the perspectives of parents, two studies focused on the perspectives of autistic children, and only *one* prior study (a PhD dissertation) interviewed *both* parents (four sets) and 4 autistic adolescents about their experiences with disclosure (Rossello, 2015). This study reported mostly positive outcomes following disclosure of a diagnosis.

More recently, an online survey with parents of autistic youth in the UK ($N=558$) revealed that most participants had disclosed their child's autism diagnosis to the child (Crane et al., 2019). Many parents described valuing an early and gradual approach to disclosing and talking about autism, respecting their child's right to know about their own diagnosis, and feeling that knowing about one's diagnosis may be empowering and critical for self-understanding. Although the researchers indicated that recruitment methods emphasized that families could participate regardless of whether their child knew about their diagnosis, the study description, "a

survey on how parents talk about autism with their children (p. 9),” may have led to overrepresentation of parents who did choose to talk about autism with their children. The authors noted that the absence of perspectives from autistic youth was a limitation of their study.

To the best of our knowledge, possible impacts of discussions about autism between parents and their children on children’s perspectives about autism and self-understanding has not been examined in prior peer-reviewed research. The present study asked both autistic adolescents and their parents how they view autism. Parents and adolescents were each asked to describe the adolescents who participated in this study.

Research Questions and Hypotheses

The following research questions were addressed:

1. Do parents’ decisions about disclosing their child’s autism diagnosis to their child impact their child’s autism understanding in adolescence?
 - Hypothesis: Adolescents whose parents informed them that they are autistic will be better able to define autism and will include more strengths in their definitions of autism than autistic peers whose parents did not inform them of their diagnosis.
2. Do parental perceptions of autism influence their child’s perception of autism?
 - Hypothesis: Definitions of autism given by adolescents will mirror their parents’ definitions of autism.
3. Does parental disclosure influence adolescents’ self-descriptions?
 - Exploratory analysis: Given that autistic adolescents’ perceptions of both autism and *themselves* may be shaped by others’ interpretations (e.g., Humphrey & Lewis, 2008; Jones et al., 2015), we examined adolescents’ descriptions of themselves in relation to parental disclosure.

Methods

Participants

Participants included 19 adolescents (ages 14-19, $M_{age}=15.9$ years, $n=18$ males) with a parent-confirmed autism spectrum diagnosis and each of their mothers. The first author recruited families to participate via email. Any parent was allowed to participate, but only mothers elected to do so. Parents were not asked to disclose if they had any diagnoses. However, one mother self-identified as autistic. All research procedures were approved by the institutional review board of The City University of New York and parents/adolescents provided written consent/assent prior to participation.

All adolescent participants were recruited from an informal educational program in a large urban area where they were enrolled for at least a one-week period during July and/or August of 2018. The program was designed to help “students who learn differently” learn computer science principles and other STEM topics. While interacting with autistic adolescents in the program in the summers of 2016 and 2017 (prior to conducting this study), it became apparent that many were unaware of their diagnoses and unfamiliar with autism despite participating in a program which serves mostly autistic children and adolescents. This study and the accompanying interview protocol were designed based on this observation. At the time that this study was conducted, autism itself was not discussed openly during instruction as some program participants had not been informed of their diagnosis.¹ All students in this program use speech to communicate.

¹ Based on the findings in this study, we incorporated explicit instruction about the value of diversity, including autism and other forms of neurodiversity, into the curriculum after this study was conducted.

Table 1.

Participant Demographics

	%	N
Co-occurring ADHD	15.8%	3
Adolescent Racial/Ethnic Background¹		
<i>White/Caucasian, non-Hispanic</i>	47.4%	9
<i>Hispanic or Latino</i>	26.3%	5
<i>African American/Black</i>	26.3%	5
<i>Asian/Pacific Islander</i>	15.8%	3
<i>American Indian/Alaskan Native</i>	5.3%	1
<i>Students reporting greater than one race/ethnicity</i>	26.3%	5
Maternal education		
<i>Some college</i>	15.8%	3
<i>Technical/Trade/Vocational Training</i>	5.3%	1
<i>Associate degree</i>	5.3%	1
<i>Bachelor's degree</i>	31.6%	6
<i>Master's degree</i>	10.5%	2
<i>Doctoral degree</i>	26.3%	5
<i>Not reported</i>	5.3%	1
Parent Marital Status		
<i>Single, never married</i>	5.3%	1
<i>Married or domestic partnership</i>	63.2%	12
<i>Divorced</i>	21.1%	4
<i>Other/Not reported</i>	10.5%	2

¹*Survey items for race/ethnicity were not mutually exclusive*

Participatory Research Group

Participatory autism research, defined as research which includes autistic people in conceptualizing, conducting, and disseminating research, is increasingly recognized as a key

strategy for improving the social validity of autism research (e.g., Fletcher-Watson et al., 2018; Nicolaidis et al., 2019; Raymaker & Nicolaidis, 2013). A participatory research group designed, analyzed and disseminated this study. Group members could join meetings in person or virtually (depending on their location and/or preference) once every 6 weeks. People who joined virtually did so via Skype using whichever method of communication they preferred (audiovisual video, voice-only, text-only, or some combination). Two authors of this paper, an academic (SKK) and an undergraduate student (AJ), identify as autistic and one author is the parent of an autistic teen (AMD). The first and last authors, a doctoral candidate (AR) and her advisor (KGL), are not autistic.

The initial idea for furthering research about autistic identity built on discussions between the second and last authors after they developed an initial study about autistic identity. The lead author decided to spearhead this particular study as part of her dissertation. Interview protocols and coding schemes were developed by the full research group. As a group, we believe it is crucially important to involve autistic people in the research process from conceptualization through to data analysis and reporting.

Measures

Interviews and Surveys. Adolescent interviews were completed using a semi-structured interview protocol and held at the beginning of a one-week summer program. The first and last authors conducted all interviews with adolescent participants in-person. All interviews were recorded and transcribed by the first author in preparation for later data analysis. The semi-structured nature of the interview protocol allowed interviewers to ask for clarification or additional information if participants were exceptionally brief or indicated they did not understand the question. However, interviewers aimed to use the questions as outlined by the

interview protocol as closely as possible to achieve some standardization across participant responses. This interview protocol included questions about their self-concept, understanding of autism and other disabilities, and plans for their future education and employment.

Parent participants were asked to participate via email and completed an online survey hosted on the Qualtrics survey platform. Due to scheduling concerns and other logistical issues, parents preferred online participation and were not interviewed in-person. Only parents were asked the following questions: “Have you told your teen about their diagnosis?”, “What prompted you to tell/not to tell your teen about their diagnosis?”, and “What have you told your teen about their diagnosis?”

Key parent survey questions were designed to mirror the in-person interview questions asked of their children to allow for a comparison of parent and child attitudes about autism and the autistic adolescents. Questions asked of both adolescent and parent participants included: “How would you describe yourself/your teen to someone who doesn’t know you/them?” and “How would you define autism?” Because some adolescents were unaware of their autism diagnosis, questions posed to adolescents used general terms about autism as a concept (i.e. “How would you define autism?”) rather than as a personal experience (i.e. “How do you feel about being autistic?”) to avoid unintentional disclosure by the research staff.

Coding of Qualitative Responses. A directed content analysis was used to generate primarily deductive and primarily inductive codes (Hsieh & Shannon, 2006), independent coders obtained reliability, and the frequency of coding categories was tabulated to understand the data. We refer to coding as *primarily* deductive or *primarily* inductive to highlight the iterative nature of the process of hypothesis and coding category generation for this study (Armat et al., 2018). The first author conducted many participant interviews herself and was personally familiar with

all adolescent participants in this study. Our first hypothesis, that adolescent perceptions of autism would differ based on if adolescents' parents had informed them about their diagnosis, was developed *before* collecting the data for this study based on interactions with teens during prior summers at our recruitment site. Our second hypothesis, stating that adolescents would mirror their parents' perceptions of autism, was developed based on our research team's a priori notion that parental narratives about autism would directly influence their child's perceptions.

Codes were developed by the first author (a non-autistic doctoral student) and the second and third authors (an autistic academic and undergraduate respectively) after reviewing and discussing adolescent interview responses and parent questionnaire responses at length. To be fully reflexive and transparent, we will note that all authors of this report endorse a neurodiversity-aligned perspective on autism and these viewpoints influenced the development of coding schemes.

After identifying themes, the primary and secondary coders reviewed, labeled, and defined each code to develop a final scheme (see Appendix A). Sub-codes were added to many overall codes to provide additional detail within broader categories. Codes based on past research are labeled with a "d" for primarily deductive. Codes developed by identifying responses shared across multiple participants are labeled with an "i" for primarily inductive.

Coders were blind to the identity of each participant. Adolescent and parent responses were coded at different times to avoid any carry-over or unintentional coding bias when reviewing responses for themes, given that we hypothesized a mirroring effect between parents and their children. Coding categories were not mutually exclusive. The first author served as the primary coder and received 80% reliability or greater with a secondary coder across 20% of both adolescent and parent participant responses. Disagreements were resolved through discussion. To

provide examples of adolescent and parent responses, excerpts from select interviews are available in Appendix B.

Results

Parent and Adolescent Definitions of Autism: An Overview of Responses

Parent participants most often described challenges associated with autism ($n = 11$) when asked the question “How would you define autism?” Only one parent mentioned a strength in their definition of autism (see Table 2). Six parents described autism as a neurological condition, five as a neutral difference, and five as a spectrum. Three parents provided a stigmatized or stereotyped view of autism; two parents defined autism as related to cognitive difficulties and one defined autism as related to brilliance.

When asked to define autism, adolescent participants had more difficulties defining autism than parents (8 adolescents vs. 2 parents; Table 2). Like parents, adolescents highlighted challenges associated with autism ($n=11$), described autism as a “neutral difference” ($n=5$), and described autism as a spectrum ($n=4$). Three adolescents described autism as a neurological condition. Three adolescents mentioned strengths associated with autism. Two adolescents provided stigmatizing or stereotypical definitions of autism. Four adolescents, 2 of whom had been disclosed to voluntarily and 2 of whom had been disclosed to involuntarily, linked autism to their own identities when defining it.

Table 2.

Adolescent (n=19) and parent (n=19) definitions of autism as frequency and percent in each of three disclosure groups

	Presence of any strength	Presence of any challenge	Stereotype or stigma	Neutral difference	Improves with Development	Self-identifies as autistic	ASD is a spectrum	Support med model	Neurological condition	Difficulty defining autism
Parent Definitions (n(%))										
Disclosed to child voluntarily (n=9)	1 (11.1%)	7 (77.8%)	2 (22.2%)	2 (22.2%)	0	0	2 (22.2%)	0	2 (22.2%)	1 (11.1%)
Disclosed to child involuntarily (n=7)	0	4 (57.1%)	1 (14.3%)	2 (28.6%)	1 (14.3%)	1 (14.3%)	2 (28.6%)	1 (14.3%)	1 (14.3%)	0
Has not disclosed to child (n=3)	0	2 (66.7%)	0	1 (33.3%)	0	0	1 (33.3%)	0	2 (66.7%)	1 (33.3%)
Total (%)	5.3%	68.4%	15.8%	26.3%	5.3%	5.3%	26.3%	5.3%	26.3%	10.5%
Adolescent Definitions (n(%))										
Disclosed to by a parent voluntary (n=9)	3 (33.3%)	3 (33.3%)	0	5 (55.6%)	0	2 (22.2%)	2 (22.2%)	0	3 (33.3%)	3 (33.3%)
Disclosed to by a parent involuntarily (n=7)	0	6 (85.7%)	2 (28.6%)	0	0	2 (28.6%)	2 (28.6%)	1 (14.3%)	0	3 (42.9%)
Not told about their autism diagnosis (n=3)	0	2 (66.7%)	0	0	0	0	0	1 (33.3%)	0	2 (66.7%)
Total (%)	15.8%	57.9%	10.5%	26.3%	0	21.1%	21.1%	10.5%	15.8%	42.1%

Does a Parental Decision to Disclose their Child's Autism Diagnosis to their Child Impact Adolescents' Perceptions of Autism?

Participants were divided into three groups based on parental decisions around disclosure; adolescents who were told about their autism diagnosis by their parent voluntarily ($n=9$), adolescents who were told about their autism diagnosis by their parent involuntarily ($n=7$), and adolescents who had not yet been told about their autism diagnosis ($n=3$). When parents were asked "What prompted you to tell/not tell your teen about their diagnosis?", parents who chose to disclose a diagnosis voluntarily did so to help with self-understanding/self-advocacy

($n=6$), for their educational needs ($n=1$), or because they felt it was the child's right to know ($n=2$). The seven parents who had disclosed a diagnosis involuntarily indicated that their child found out at school ($n=3$) and/or their child asked if they were autistic on their own ($n=4$). When parents who had not disclosed were asked why they chose not to tell their child about their autism, they reported that they believed their adolescent lacked the capacity to understand their autism diagnosis ($n=2$) or that they avoid using the autism label ($n=1$).

When forming our hypotheses, we had not anticipated that some parents would not initiate a discussion with their child about their child's autism voluntarily and would instead be prompted to begin to talk with their child about their child's autism by others' disclosures or their own child's questions. This involuntary disclosure group consisted of adolescents who first learned or suspected that they were autistic without guidance from their parents. Given that their parents did not choose to disclose their diagnosis to them, we viewed these young people as more akin to youth whose parents had not disclosed their diagnosis to them at all than to youth whose parents had disclosed their diagnosis to them voluntarily. For all themes, we report the percentages of each group (voluntary, involuntary, and no disclosure) who endorsed each theme to explore our expectation that voluntary disclosure often reflects a different, and potentially more neurodiversity-aligned, process from involuntary and no disclosure groups.

In response to reviewer feedback, we examined potential relationships between maternal education and disclosure. Unexpectedly, more educated mothers appeared to be *less* likely to voluntarily disclose their child's autism diagnosis to their child than their less educated counterparts (see Table 3).

Table 3

Disclosure in Relation to Maternal Education

Disclosure Group	Maternal education level
Not disclosed to (<i>n</i> =3)	Bachelor's degree = 2 (66.7%) Doctorate = 1 (33.3%) Completed bachelor's degree or higher = 100%
Disclosed to involuntarily (<i>n</i> =7)	Not reported = 1 (14.3%) Trade/vocational school = 1 (14.3%) Bachelor's degree = 3 (42.9%) Doctorate = 2 (28.6%) Completed bachelor's degree or higher = 71.4%
Disclosed to voluntarily (<i>n</i> =9)	Associate degree = 1 (11.1%) Some college = 3 (33.3%) Bachelor's degree = 2 (22.2%) Master's degree = 1 (11.1%) Doctorate = 2 (22.2%) Completed bachelor's degree or higher = 55.6%

Do Parental Decisions to Disclose Impact their Child's Autism Understanding?

To address our first hypothesis, that adolescents whose parents disclosed their child's autism diagnosis to their child would be better able to define autism and more likely to describe autism in terms of strengths than their counterparts, we grouped adolescent definitions of autism based on if and how their diagnosis was disclosed to them (see Table 2). As noted previously, involuntary parental disclosure was an emergent theme in the data that we regarded as akin to not disclosing a diagnosis at all. Adolescents who were told they were autistic by a parent involuntarily or not told at all were more likely to include challenges in their definition of autism (6 out of 7 and 2 out of 3, respectively) compared to those told voluntarily (3 out of 9). These two groups were also proportionally more likely to have difficulties defining autism (3 out of 7 and 2 out of 3, respectively) compared to those told voluntarily (3 out of 9). Two students, both of whom were disclosed to involuntarily, provided a stigmatized view of autism which assumed cognitive difficulties. The only participants to include strengths in their definitions of autism (3 out of 9) were among those told about their diagnosis voluntarily. Five of the nine adolescents

who were disclosed to voluntarily were also the only adolescents to define autism as a neutral difference.

Do Parental Perceptions of Autism Influence their Child's Perception of Autism?

To address our second hypothesis, that adolescents' definitions of autism would mirror their parents' definitions of autism, coded responses to the question "How would you define autism?" were compared for each parent and adolescent pair (see Appendix B for examples of parent and child responses). Specific codes applied to responses by all parents and their respective adolescents are provided in Appendix C.

Adolescents whose parents had told them about their autism diagnosis were more likely to echo a theme from their parent's definition of autism in their own definition (6 out of 9 shared themes for those who experienced voluntary disclosure and 4 out of 7 shared themes for those who experienced involuntary disclosure) relative to adolescents whose parents had not told them they were autistic (1 out of 3 shared themes).

Shared themes almost exclusively focused on challenges associated with autism for the adolescents and parents in the no disclosure (1 out of 1 shared codes focused on challenges) and involuntary disclosure (3 out of 4 shared codes) groups. In one parent child pair in the involuntary disclosure group, both the mother and adolescent described ASD as a spectrum.

Although parents and adolescents in the voluntary disclosure group also tended to share a focus on challenges in their definitions of autism (3 out of 7 shared codes), they were more likely than the other groups to focus on other aspects of autism. For example, one parent child pair described both strengths and challenges associated with autism, another pair shared difficulty defining autism, another pair shared a neurological theme, and another pair described autism as a neutral difference.

Does Parental Disclosure Influence Adolescents' Self-Descriptions?

When parents were asked “How would you describe your teen to someone who doesn't know them?”, an overwhelming number of parents ($n=17$, 89.5%) mentioned their child's strengths. Thirteen parents (68.4%) mentioned social communicative strengths such as being empathetic or kind when describing their teen (See Appendix D). Ten parents (52.6%) mentioned autistic traits in their description, often highlighting social communicative challenges ($n=9$, 47.4%) and less frequently highlighting restricted interests and repetitive behaviors ($n=2$, 10.5%). Proportionally fewer parents who disclosed to their children voluntarily described their child in terms of their autistic traits (44.4% compared to 57.1% who disclosed involuntarily and 66.7% who did not disclose). Three parents (15.8%), one from each disclosure group, used autism as a descriptor when answering this question.

Although four teens identified themselves as autistic when providing their definitions of autism, none of the adolescent participants mentioned their autism diagnosis when asked “How would you describe yourself to someone who doesn't know you?” Three teens (15.8%) detailed social communicative challenges in their description of themselves (two were disclosed to involuntarily and one was not yet disclosed to). Only three adolescents, all of whom were disclosed to voluntarily, described social communicative strengths when describing themselves.

Discussion

Adolescents in our sample were told about their autism diagnosis in varying ways which seemed to influence their understanding of autism and subsequently may influence their identity development as they transition into adulthood. Consistent with our first hypothesis, autistic adolescents whose parents *voluntarily* disclosed their child's autism diagnosis to them were better able to define autism and more often used neurodiversity-aligned language when doing so

as compared to adolescents whose parents told them about their autism involuntarily or not at all. In fact, the only adolescent participants who described autism in terms of strengths or as a “neutral” difference were those whose parents disclosed their diagnosis to them voluntarily. These findings suggest that parents can help their children develop neurodiversity-aligned perspectives about autism by mindfully discussing autism with them early in their development.

Our findings also provide some preliminary evidence that open discussions about autism may foster positive identity development more generally. The only autistic participants who described themselves in terms of social-communicative strengths were those whose parents had voluntarily disclosed their diagnosis to them. Previous research has shown that autistic individuals often internalize a need to hide their autistic traits to appear normal (Cage & Troxell-Whitman, 2019; Hull et al., 2017), which mirrors parent sentiments surrounding interventions to ameliorate autism symptoms (Da Paz et al., 2018; Myers et al., 2009). Our findings align with research suggesting that learning about one’s diagnosis often helps autistic people understand their differences and reframe limitations into acceptable differences (Humphrey & Lewis, 2008; Mogenson & Mason, 2015; Russell & Norwich, 2012). Also like past research, some autistic participants, particularly those who had not been disclosed to voluntarily, viewed autism in stigmatizing ways and struggled to reconcile an autism diagnosis with their sense of who they are (Humphrey & Lewis, 2008; Mogenson & Mason, 2015).

Although parents and teens showed similarities on a group level when defining autism (e.g., a common focus on challenges), our second hypothesis, that parents’ definitions of autism would influence their respective child’s perceptions of autism, was not fully supported. Parents and children expressed diverse themes in their definitions of autism. As might be expected, parents and teens who had disclosed their child’s autism to their child (either voluntarily or

involuntarily) were more likely to express shared themes in their definitions of autism than those who had not discussed their child's autism. However, shared themes focused almost exclusively on negative aspects of autism for parents and children who had not shared voluntary disclosure. Although challenges associated with autism were also a common theme for parents and children who had shared voluntary disclosure, more diverse and neurodiversity-aligned ways of describing autism were shared among parents and children in this group. Findings suggest that open conversations about autism between parents and their children may contribute to less deficit-oriented perspectives about autism.

However, some parents in our study thought their adolescent lacked the capacity to understand their autism. A recent review of the small body of research examining the process of parental disclosure to an autistic child found that some parents may be reluctant to disclose a diagnosis to their children for this reason (Smith et al., 2018). The aforementioned large study that surveyed parents about their experiences discussing autism with their autistic child found that 75% of parents who had not yet disclosed a diagnosis felt their child would not understand their diagnosis (Crane et al., 2019). In the current study, more educated mothers appeared to be less likely to speak openly with their child about their child's diagnosis. Educated parents tend to have more resources to draw from when advocating for their children. It is possible that a focus on advocating for and protecting their child may draw some parents' attention away from helping their child understand and advocate for themselves. Similarly, more educated mothers may put more pressure on themselves to be a "really good mother" and experience a related ideology of "intensive mothering" (Meeussen & Van Laar, 2018; see Taylor, 2011). This may incline them toward "warrior motherhood" against autism (see Douglas & Klar, 2019), exposing them to more concerned peers and treatments. Educated mothers may experience additional social and self-

imposed pressure to have children who meet or exceed traditional markers of academic and professional success. Rather than feeling that their options broaden due to the resources afforded to them by their higher education, internalized stigma may impact their willingness to disclose their child's autism diagnosis to them. However, research has found autistic adolescents and young adults to have a greater sense of autonomy and control over their future than their parents perceive they do (Cribb, Kenny, & Pellicano, 2019). This research, coupled with our finding that disclosure leads to more positive perceptions of autism, indicates that parents' worries about their child's comprehension of autism may be unfounded and cause unintended negative feelings about the diagnosis.

When asked to describe the adolescents who participated in this study, almost all parents described their teen's strengths. Parents' focus on their child's strengths when describing their child contrasts with parents' focus on challenges when defining autism. Findings suggest that some parents may separate the autism diagnosis, which they described primarily negatively, from their child, who they described primarily positively. However, parents, particularly those who had not voluntarily disclosed their child's diagnosis to their child, were more likely to describe their teen as exhibiting autistic traits than the teens were.

Given the complexities of adolescence, it is perhaps unsurprising that teens were less likely to describe themselves in terms of strengths than their parents were. Adolescents whose parents had disclosed their autism to them voluntarily were less likely to include autistic traits in their self-descriptions and more likely to highlight their own strengths than those who had not experienced voluntary parental disclosure. Although four adolescents linked themselves to the label autism when defining autism, no adolescents included the label autism in their self-descriptions. This finding, in conjunction with prior research showing that only 1 of 22 autistic

college students referenced autism when describing themselves to researchers (DeNigris et al., 2018), suggests that autism may be a more salient identifier for researchers than it is for autistic young people. The current study is a first step towards understanding how parent perceptions of autism and parent-child discussions about an autism diagnosis may impact identity development among autistic adolescents, but it is not without limitations which impact the generalizability of these results.

Limitations

While this study addresses a gap in the literature, our sample was drawn from a single summer program in an urban area which is not representative of many other groups of parents and autistic children. Other research studies investigating autistic identity have recruited similarly small samples of adolescents and young adults in the past (i.e. Huws & Jones, 2015; Jones et al., 2015; Mogensen & Mason, 2015) but researchers should strive for larger and more diverse samples to better understand factors shaping autistic identity development moving forward.

While our sample of adolescents represented a range of races and ethnicities, a disproportionate number of mothers held at least a bachelor's degree, with many holding a doctorate degree (Table 1), which is not representative of the general population. Lack of diversity has also been an issue in past work in this field (e.g., Crane et al., 2019). Aligning with prior work about disclosure and identity development (Crane et al., 2019; Humphrey & Lewis, Jones et al., 2013; Jones et al., 2015; Mogensen & Mason, 2015; Smith et al., 2018), statistical analyses were not used to determine if the current findings are generalizable. We deemed statistical analyses to not be appropriate in the current study due the small sample size and because the sample was not representative of the broader population. Due to the small overall

sample, analysis groups were often particularly small. For example, the group of participants who have not yet been disclosed to consisted of only *three* adolescents. Given that the differences we describe often reflect just a few individuals per group, these findings should not be interpreted as generalizable. Future work with larger and more representative samples is needed to determine if our findings generalize to other contexts. Such work should examine similarities and differences between adolescents who experience involuntary disclosure and those who have not yet been disclosed to as the similarities between these groups noted in this paper are likely to co-occur with as yet unidentified differences arising from greater opportunities to discuss autism among those who have experienced involuntary relative to no disclosure.

Our interview and survey methodology, while workshopped and developed with a participatory group of autistic and non-autistic researchers, asked questions about autism using general terms and did not ask adolescents or parents to speak about their experiences with autism personally. Participants were not asked about the age at which children were informed of their diagnosis. We also did not ask specifics about how parents spoke about autism during disclosure or in the home more generally. This was necessary due to the nature of our sample being situated within an informal summer program and the desire of some parents to avoid specific discussions about autism with their child, in light of some adolescents' lack of awareness. This did limit the types of questions asked and the opportunity for participants to speak more candidly about their perspectives on autism. While the comfort of participants and sensitivity around issues of disclosure were paramount, a more comprehensive interview and survey protocol may yield more rigorous and informative results in the future. Parents also completed online surveys while

students were interviewed in-person. This was necessary to encourage parent involvement but not ideal for comparing parent and student responses directly.

For the purposes of this study, we did not formally verify diagnoses and instead relied on parent confirmation of a diagnosis. Review of the literature indicates that this is common within the identity literature and studies often rely on parent report (e.g. Jones et al., 2015) or school records (e.g., Huws & Jones, 2015; Mogensen & Mason, 2015) rather than clinical assessments conducted by researchers to confirm an autism diagnosis. Similarly, we lacked developmental data on the cognitive and adaptive abilities of the adolescents, as was also the case in related other studies (e.g. Jones et al., 2015; Morgensen & Mason, 2015).

Future Directions

More research is needed to fully discover how autistic young people's understanding of autism and themselves develops. A longitudinal study of identity development from childhood to adulthood would help us to understand how perceptions of autism and the broader self change across the lifespan. Given that parents gain knowledge about autism from their child as their child develops, such a study would benefit from considering bidirectional relationships between parents' and children' perspectives on autism and development more generally. Such research should recruit a diverse sample of autistic people and should assess cognitive and linguistic skills directly. The current study demonstrated that purposeful disclosure of an autism diagnosis is important, but we cannot say *when* is the most beneficial time to disclose based on these data. Another study in preparation by our research team examines how autistic adults reflect on when and how they learned they were autistic, demonstrating associations between earlier parental disclosure and higher well-being and quality of life in adulthood (Oredipe et al., in preparation). As noted within our limitations, our sample of mothers had disproportionately high levels of

education relative to the general population. To better understand how parental education may contribute to disclosure decisions, a sample with a broader range of educational experiences should be surveyed in future research studies. Sample size is also a notable limitation of this study which we have discussed in some detail. Additional research with larger and more representative samples is needed to develop generalizable recommendations about disclosure.

It is also possible that autistic adolescents' identity development, as is the case with adolescent identity development more generally (Erikson, 1968; Hill et al., 2007; Steinberg & Morris, 2000), may be more heavily influenced by peers than parents. Given that some studies have highlighted that relationships with parents may be especially influential in the lives of autistic people (e.g., Orsmond et al., 2004), future research should compare the degree to which autistic adolescents feel that neurotypical and neurodivergent peers and parents shape their identities.

Conclusion

It is our hope that this work begins to elucidate how parent-child discussions about autism can contribute to the development of a positive autistic identity. The fourth author of this paper, herself a mother of an autistic adolescent and the director of an intervention center, reflected on the findings as follows: "I've met so many parents who I wished could see the value of disclosing their child's diagnosis to them. I had always seen it as something that would be 'freeing' to the child and that knowing about the diagnosis could/would empower the child...But dealing with mothers (as a provider) who are grappling with this diagnosis daily, wondering what is or is not the right thing to do, 'protecting' their children from the diagnosis, I found the result of the study difficult to digest (for them). Because the truth is, for some parents, the hesitation to disclose is embedded in denial, guilt and shame."

We aimed to increase the community's understanding of autism and the parent-child relationship and have no intention to instill any feelings of guilt or shame in parents and families who are working hard to understand how an autism diagnosis affects them and their family. Instead, we hope that this work may be useful in providing a resource for parents and adolescents who are learning more about their diagnosis and identities. Our results indicate that disclosing a diagnosis to autistic children and adolescents should be done holistically, mindfully, and intentionally.

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Appendix A

Qualitative Coding Scheme

Codes for “How would you define autism?”	
Code	Functional description
^d Presence of any strength	Mentions a strength associated with autism in their definition. Sub-codes include: Systematic thinking including detail orientation and intelligence/logic, empathy or feeling compassion for others, perseverance or working harder than others, access to community supports
^d Presence of any challenge	Mentions a challenge associated with autism in their definition. Sub-codes include: Social difficulties, restricted and repetitive interests or behaviors, executive functioning difficulties, independent living skills
^d Stereotypes/Stigma	Describes autism using a stereotype or stigma in their definition. Sub-codes include: assumes autistic people are brilliant, assumes autistic people have cognitive impairments
^d Neutral difference	Autism as “neutral difference,” atypical without valence, illustrating concepts of neurodiversity
¹ Improves with development	People describe difficulties associated with autism reducing with age or self-understanding increasing with age
¹ Self-identifies as autistic	Participant identifies themselves as autistic, exhibits some sense of ownership of the autism label
¹ ASD is a spectrum	Describes that not all autistic people are the same when asked to define autism
^d Supports medical model	Describes autism as something that can/should be fixed or cured.
^d Opposes medical model	Rejects the notion that autism should be cured.
¹ Neurological condition	Mentions the brain when describing autism, describes autism as a disability rooted in neurological differences
¹ Mentions functioning label	Describes themselves as autistic and uses a label such as “high-function” or “Asperger’s” to define autism, without providing further elaboration
¹ Difficulty defining autism	Exhibits difficulty defining autism, including saying they do not know what autism is
Codes for “How would you describe your teen/describe yourself to someone who doesn’t know them/you?”	
Code	Functional description
^d Uses autism label	Autism label in description of their teen
¹ Describes autistic traits	Describes autistic traits when describing their teen Sub-codes: social-communicative challenges, restricted interests and repetitive behaviors

^d Strengths	Describes their teens strengths Sub-codes: social-communicative strengths such as empathy and kindness, skills in area of interest, intelligence
^d Likes	Mentions things their teen likes when describing them
^d Relationship	Mentions teen's relations to others when describing them (i.e. friend, son, brother)
¹ Differences	Describes their teen in terms of how they think or act differently compared to others

Appendix B

Paired parents and teen definitions of autism by group

Teen/Parent Pair	Answer to “How would you define autism?”	Code Used	Disclosure Group
Teen R	“Autism ... means like you can’t it basically stops you from doing normal human tasks, you’re going to be walking like this (walks around tripping over foot and banging into things) ... it stops you from doing the normal things, you get frustrated that you can’t do the things you would normally do. And you start complaining every minute, I can’t do this why can’t I do this, and you go on mental breakdowns every minute and it can be really annoying for other people to have autism around...autism is bad and I don’t think anyone should have it... I am not autistic.”	Challenges associated with autism, supports medical model	Not disclosed
Parent R	“Deficit in social thinking and skills. Impaired communication”	Challenges associated with autism	Not disclosed
Teen C	“As a condition that makes it more difficult for people to understand certain things that other people say but brings their attention to other things that other people might not notice. It’s just a different way of thinking. It shouldn’t be called a disability or disorder.”	Strengths associated with autism, Challenges associated with autism, Neutral difference	Disclosed voluntarily
Parent C	“A complicated condition that is very different in different kids, but always involves 1) trouble with social interaction, 2) repetitive or self-stimulatory behaviors, and 3) challenges with imaginative play or unstructured activities. Often, it comes with great strengths. A disability but also an ability.”	Strengths associated with autism, Challenges associated with autism, Autism is a spectrum	Disclosed voluntarily
Teen L	“Autism is like a permanent disease or something. It’s a complicated disease that is mostly affecting boys. I’m one of them and it is really painful. Some say it was genetic, others say it was just a disease. Whatever it was the preferred term is called autism spectrum disorder. For some they can have delusional thoughts where they are unable to tell fantasy from reality. “	Challenges associated with autism, self-identifies as autistic, supports medical model	Disclosed involuntarily
Parent L	“There is no two-way communication with a person with autism. it's a one-way street, unless they receive a high level of adaptive training.”	Challenges associated with autism, assumes cognitive difficulties	Disclosed involuntarily

Appendix C

Codes received by parents and their respective adolescent on responses to “How would you define autism?”

Disclosure Group	Codes received by parents and their adolescents
Disclosed to Voluntarily	<p>Teen A: Neutral difference, ASD is a spectrum, neurological condition Parent A: Presence of a challenge</p> <p>Teen B: Presence of a challenge Parent B: Presence of a challenge, ASD is a spectrum</p> <p>Teen C: Presence of a strength, presence of a challenge, neutral difference Parent C: Presence of a strength, presence of a challenge, ASD is a spectrum</p> <p>Teen D: Difficulty defining autism Parent D: Presence of a challenge, neurological condition</p> <p>Teen E: Presence of a strength, neutral difference, difficulty defining autism Parent E: Other</p> <p>Teen F: Presence of a strength, difficulty defining autism Teen F: Presence of a challenge, stereotype/stigma, neurological condition, difficulty defining autism</p> <p>Teen G: Presence of a challenge Parent G: Presence of a challenge, neutral difference</p> <p>Teen H: Neurological condition, neutral difference Parent H: Neurological condition</p> <p>Teen I: Neutral difference, ASD is a spectrum, neurological condition Parent I: Presence of a challenge, Stigma (brilliant), neutral difference</p>
Disclosed to Involuntarily	<p>Teen J: Presence of a challenge, stereotype/stigma Parent J: Neutral difference, neurological condition, difficulty defining autism</p> <p>Teen K: Presence of a challenge, ASD is a spectrum Parent K: ASD is a spectrum, supports medical model</p> <p>Teen L: Presence of a challenge, supports medical model Parent L: Presence of a challenge, stereotype/stigma</p> <p>Teen M: Presence of a challenge Parent M: Neutral difference, ASD is a spectrum</p> <p>Teen N: Presence of a challenge, ASD is a spectrum, difficulty defining autism Parent N: Presence of a challenge, improves with development</p>

	<p>Teen O: Presence of a challenge, stereotype/stigma, difficulty defining autism Parent O: Presence of a challenge</p>
	<p>Teen P: Difficulty defining autism Parent P: Presence of a challenge, neurological condition</p>
Not disclosed to	<p>Teen Q: Presence of a challenge, difficulty defining autism Parent Q: Neutral difference</p> <p>Teen R: Presence of a challenge, supports medical model Parent R: Presence of a challenge</p> <p>Teen S: Difficulty defining autism Parent S: Presence of a challenge, ASD is a spectrum, neurological condition</p>

Note: Sub-codes have been removed from this table for simplicity. The code “links self to label” has also been removed as we would not expect children to mirror their parents when self-disclosing in their definitions of autism. Bolded codes indicate instances where adolescents and parents received the same code.

Appendix D

Adolescent ($n=19$) and parent ($n=19$) responses to the question “How would you describe yourself/your teen to someone who doesn’t know them as a frequency and percentage within each disclosure group.

	Autism label in description	Autistic traits in description	Strengths	In terms of things they like	In terms of one’s relationships	Thinking or acting in a different way	Other
Adolescents (n (%))							
Disclosed to by a parent voluntarily ($n=9$)	0	0	7 (77.8%)	3 (33.3%)	2 (22.2%)	1 (11.1%)	0
Disclosed to by a parent involuntary ($n=7$)	0	2 (28.6%)	3 (42.9%)	2 (28.6%)	0	0	1 (14.3%)
Not told about their autism diagnosis ($n=3$)	0	1 (33.3%)	0	3 (100%)	3 (100%)	0	0
Total (%)	0	15.8%	52.6%	42.1%	26.3%	5.3%	5.3%
Parents (n (%))							
Disclosed to child voluntarily ($n=9$)	1	4 (44.4%)	9 (100%)	3 (33.3%)	2 (22.2%)	1 (11.1%)	0
Disclosed to child involuntary ($n=7$)	1	4 (57.1%)	5 (71.4%)	3 (42.9%)	0	1 (14.3%)	0
Has not disclosed to child ($n=3$)	1	2 (66.7%)	3 (100%)	2 (66.7%)	2 (66.7%)	0	0
Total (%)	15.8%	52.6%	89.5%	42.1%	21.1%	10.5%	0