

Disability Discourse: How and when do parents  
talk to their children about autism?

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**Abstract**

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Autistic adults live vibrant lives, yet face numerous social inequities. The negative social construction of autism likely leads to this discrimination. Positive identity development may be a protective factor for people with disabilities, including autism. The current study investigates when and how parents talk to their children about autism and autistic identity development. Interviews with 7 autistic adults and supplemental interviews from 7 parents of autistic adults revealed four themes: (1) The role of society in shaping autism (2) Autism is neutral yet it is stigmatized (3) identity and (4) autism information, education and expertise. Practice implications include better usage of the social model, involvement of more autistic adults in supporting autistic youth, and providing space for parents to understand their own nondisabled identity in relation to autism.

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Autistic adults live vibrant and fruitful lives, yet face significant challenges due to discrimination and oppression. Negative and medicalized constructions of autism and subsequent barriers create unique challenges for autistic people. Often, these challenges create room for disability pride and community. For autistic youth, parents likely play a large role in supporting their children in understanding autism and how autism fits into their identity.

The following master's thesis addresses the social construction of disability and autism while exploring ways in which 'autism' becomes part of identity through two standpoints: autistic people and parents. First, previous literature is reviewed and used to inform the aim of the current study. Next, the methods of the current study are stated, which include participant demographics and recruitment, study procedures, study design, materials and the data analysis procedure. Next, findings are stated and finally, implications and limitations of the study are discussed.

### **Literature Review**

The following review of literature starts by introducing the history of autism discrimination and how eugenics ideology continues to play out today. Next, the literature covers the construction of social identities and the construction of disability. Key players who contribute to that construction are identified. Next the literature suggests ways these people impact identity development in autistic youth. Finally, based on the literature, the study question is stated.

### **Disproportionalities autistic people face**

According to the DSM-5, Autism Spectrum Disorder is characterized by challenges with social skills, repetitive behaviors, restricted interests and challenges with both verbal and nonverbal communication (American Psychiatric Association, 2013). Although access to services is typically contingent on a formal diagnosis, many individuals identify as autistic

without a DSM-5 diagnosis. Disabled self-advocates and their allies have made strides to secure civil rights for all people with intellectual and developmental disabilities (I/DD), like autism. However, the community remains underemployed (United States Department of Labor), overrepresented in the criminal justice system (Vallas, 2016), at the greatest risk of sexual abuse and assault (Johnson and Sigler, 2000) and at the greatest risk of suicide and other mental health conditions (Eaves & Ho, 2008). Additionally, there are still institutions operating in the United States that segregate people with I/DD from the rest of society where neurotypical people have the liberty to live, work, learn and play.

Autistic people face disproportionate life outcomes compared to neurotypical people and, in some cases, people with disabilities other than autism. Autistic adults are at a greater risk for suicide and mental health conditions than the general population (Eaves & Ho, 2008) and are at risk of premature mortality (Hirvikoski, Mittendorfer-Rutz, Boman, Larsson, Lichtenstein & Bolte, 2016). Autistic adults are employed more frequently than people with other developmental disabilities; however, they tend to work fewer hours and earn less wages than neurotypical people and people with disabilities other than autism (Cimera & Cowen, 2009). Lastly, people with intellectual disabilities score lower on measures of self-concept and self-esteem (Garaigordobil & Perez, 2007), and autistic people score much lower on measures of self-esteem (Cooper, Smith & Russell, 2017).

The disparities that people with disabilities and autistic adults face are well documented, yet people with disabilities are constantly left out of the decision-making processes that address these social issues. One example of this can be found in a published letter to the editor of the *Journal of Autism and Developmental Disorders*. Autistic adults called out the lack of autistic

voice in a journal publication regarding ethical and social issues for autistic people and subsequent guidelines for better supporting autistic people (Milton, Mills and Pellicano, 2014).

### **History of disability and autistic oppression**

This lack of autistic and disabled voice harkens back to before the nineteenth century. The history of disability oppression is rooted in “moral” ideologies of Social Darwinism (Kennedy, 2008). Social Darwinism operates on the premise that some populations of people and characteristic traits (genetics) are superior and benefit society more than others. This, now discredited ideology, was translated into the scientific practice of eugenics during the 20th century (Kennedy, 2008). People with disabilities were medically labeled as “feebleminded” and were forcibly sterilized in the name of “advancing the human race”. Eugenics disproportionately targeted disabled women of color. While the scientific eugenics era has ended, the ideology has not completely dissipated.

For autistic adults, the lasting effects of the eugenics era can be seen in current autism specific disparities. There is a push to cure, defeat or wipe out autism, popularized by parents and professionals (Langan, 2011). The gold standard for behavior treatment for autistic adults, Applied Behavior Analysis (ABA), is under scrutiny for having problematic methods which aim to eliminate autistic behaviors (Cascio, 2012). ABA has been likened to gay conversion therapy and other forms of social conditioning. In fact, the person credited with creating ABA used tenants of ‘gay conversion therapy’ in the creation of ABA (Rekers & Lovaas, 1974). Finally, tenants of eugenics continue to resurface in prenatal testing for autism (Cascio, 2012).

Barriers for autistic people also exist within the welfare system. Social services provide much needed support for people with disabilities, yet many autistic children and adults are

ineligible for these services. Barriers to service utilization are even greater for autistic people of color (Thomas, Ellis, McLaurin, Daniels & Morrissey, 2007).

### **Negative stigma of autism by society**

The barriers to services that autistic adults face may be related to societal views and values about autism. In general, autism is viewed negatively. Society often depicts autism as a disability that pertains only to children. This message is frequently upheld through parent-led advocacy groups, charitable organizations, popular media and the news industry (Stevenson, Harp and Gernsbacher, 2011). This phenomenon is referred to as infantilization which challenges the dignity and well-being of autistic children and autistic adults.

### **Social construction of autism and other identities.**

The ease with which society inflates a child-centered view of autism brings to question the social construction of autism itself. Social construction theory, originally popularized in the United States by Peter L. Berger and Thomas Luckmann (1966), suggests that concepts such as disability, gender and race are constructed according to social expectations and subsequently held to standards created and agreed on by humans across time. Social constructions are exemplified throughout history through the creation and reinforcement of binaries (male and female, racist and anti-racist, etc.). Social constructions and their implications are backed by institutional power. An example of this is the disproportionate incarceration of people of color in the United States, which both perpetuates and reinforces a societal justification for racism. Pamela Hays (2008) highlights different social identities and how people either oppress or are oppressed within these identities. Institutional power as it is organized in society informs whether people are oppressed or oppressors. Developmental disability is specified as one of these social identities in Hays' (2008) "addressing model".

The definition of disability and who is considered disabled or non-disabled has shifted over time. This shift strengthens the premise that disability is a social construction. We see this shift in the changing nature of the Diagnostic and Statistical Manual of Mental Disorders. Before it was dropped from the DSM-III-R, homosexuality was framed as a disability, originally paraphilia and then sexual orientation disturbance. The shifting nature of disability has historically been used as a tactic to marginalize other identities, based on the perceived capabilities and limitations of these population (Baynton, 2001). Dis/ability critical race studies (DisCrit) extends Baynton's work on the intersection of race and disability and the ways that they have both been divisively used to oppress people throughout history (Annamma, Connor & Ferri, 2012). Both people with disabilities and non-disabled allies alike, are indoctrinated into this social organization of power. People with disabilities internalize inferiority while nondisabled people internalize superiority (Campbell, 2007). These internalizations have very real and long-term consequences for society.

Despite the negative construction of autism, autistic people live vibrant lives and have formed community. The resilience of autistic people considering a negative societal framing, illustrates strength and bonds of the broader autistic community (Szatmari, 2017). Autistic resilience begins early on in life, through bullying survival (Denigris, Brooks, Obeid, Alarcon, Shane-Simpson, & Gillespie-Lynch, 2017). Beyond resilience, O'Neil (2007) writes, "Autistics succeed and amaze those around them often not in spite of but because of their autistic traits." More and more, society is moving towards accepting autism and finding the value in previously stereotyped traits.

### **Key contributors to the social construction of autism.**

Most people working in the medical field are neurotypical. Medical professionals have a platform for defining and theorizing autism and the needs of autistic people. Therefore, autism is popularized as a medical problem and most research describes autism through a medicalized lens. Parents and caregivers (in particular, mothers), have also been pointed out as key players in the construction of autism (Waltz, 2015). This may be due to a long history of advocacy fighting against claims of “refrigerator mothers” and other gendered societal messages that blame mothers for the birth of autistic children. Parents play both positive and negative roles in the movement around what is commonly known and understood about autism.

The discourse put forth by parents and professionals suggests that people’s disabilities, whether they be cognitive, physical or other, are barriers. This individualized view is often referred to as the medical model of disability (Oliver, 1983; Shakespeare, 1997). Through the medical model, autism and other disabilities are viewed as individual problems and are subsequently stigmatized. Autistic people are commonly labeled as either high-functioning or low-functioning, which seemingly denotes whether or not they can be perceived as neurotypical (Lim, 2015). Labeling and pathologizing individuals are hallmarks of the medical model. High- and low-functioning labels have been critiqued by autistic self-advocates and allies as a problematic minimization of the actual needs of autistic people. These labels encourage professionals to attempt to ‘normalize’ autistic people. Normalization, or the minimization of autistic traits, has been associated with higher levels of stigma towards autism (Gillepsie-Lynch, Kapp, Brooks, Pickens, Schwartzman, 2016).

The medical model supposes disability as a negative attribute and proposes ways to ‘fix’ disability, through intervention, therapy or even prayer. The social model of disability, on the other hand, focuses attention on society and its role in accommodating disability. The social

model calls for shifting attitudes towards disability (Shakespeare, 1997). When society takes responsibility for existing barriers that limit disabled people, disability is centered as an integral part of everyone's life, rather than only the person experiencing disability. Further, societal acceptance of disability is associated with better mental health outcomes for autistic people (Cage, Di Monaco & Newell, 2017).

### **Neurodiversity.**

The neurodiversity movement has risen from the social model of disability. Originally coined by autistic advocate, Judy Singer, neurodiversity states that neurological differences are natural expressions of diversity, and therefore should not be considered good or bad (Ortega, 2009). Many people, both autistic and neurotypical, see neurological conditions to be an equal and valid existence of human diversity which simply require tailored support, rather than elimination of autism altogether (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). The common medicalized construction of autism, which almost always omits the lived experience of autistic people, is a reason for the creation of critical autism studies (O'Dell, Rosqvist, Ortega, Brownlow & Orsini, 2016), and warrants further inquiry. Critical autism studies embraces autism, not as a monolithic category, rather a body of knowledge and lived experience that has changed throughout time. This dovetails with the social model of disability in moving towards a more inclusive society.

### **Disability Identity**

Whether or not autistic adults claim disability or autism as a part of their identity is based on the individual and their circumstances. Research related to other social identities has established the process and impacts that adoption of a social identity has on both individuals and groups. Disability identity development is still very limited in social science research.

**Identity development in youth of color.**

Racial identity development happens in stages for both white folks and people of color (Tatum, 1992). For people of color, the pre-encounter stage is comprised of seeking to assimilate into dominant white culture, until the encounter stage, where an individual is faced with a situation that forces them to acknowledge the very real impacts of racism. These two stages are followed by Immersion/Emersion, when one surrounds themselves with visible symbols of racial identity. Ultimately, an individual may reach the last two stages of racial identity development: Internalization where one becomes more secure with their racial identity and Commitment where one finds ways to translate their identity throughout other aspects of life (Tatum, 1992). Chávez & Guido-DiBrito (1999) identify the importance of racial and ethnic identity development and how doing so as a member of a minority group is fraught with emotional tolls. The process of disability identity development cannot be completely likened to racial identity development, however, there may be similarities in the stages at which this identity is formed and internalized.

Despite limited research on the effects and implications of positive identity development in autistic youth, there is preliminary evidence that suggests positive autism identity mediates self-esteem and improves mental health (Cooper, Smith & Russell, 2017). These findings encourage forward movement towards finding ways to support autistic youth in formulating a positive autistic identity.

The disability pride movement is a positive and integral part of disability history. By taking pride in disability, self-advocates celebrate their differences while also striving for political and social change. The autistic community has been powerful and resilient in pushing back against oppression and has gained traction and participation, potentially due to the changing medical definition of autism and the increase in self-advocacy movements and technology

(Bagatell, 2010). The rapid connection and creation of autistic culture is most visible online (Davidson, 2008). As a place where people can meet others like them, the internet has been used as a platform to celebrate and engage in disability pride and autistic pride.

### **Disability identity tensions and key players.**

Identity adoption and disability pride are complicated for people with disabilities. Disability Studies research has documented disability as an integral part of an individual's identity (Linton, 2010); however, this viewpoint is not always supported by non-disabled researchers, practitioners, professionals and parents. Complications play out in language and the ways that people talk about disability. There is a long running debate over the use of person-first language and identity-first language. Person-first language has grown out of professional and parent-led advocacy, which argues that disability does not define a person and therefore, people should be identified as “person with disability”. Identity-first language, on the other hand, stems from disabled self-advocates who declare that disability is an inseparable part of their own identity and cannot be separately described, yielding the language, “disabled person”, or “autistic”. Even among disability advocates, language is contested and there is no universal terminology for autism (Kenny, Hattersley, Molins, Buckley, Povey and Pellicano, 2016). This current study interchangeably uses terms “autistic” and “disabled” with terms “with autism” and “with disability”, as many other studies do (Cascio, 2012), to reflect both sides of this ongoing conversation.

Demo & Hughes (1990) found that Black parents and parental messages play a critical role in shaping Black youths' racial identity by helping their children know what it means to be Black. Adults who recall their parents telling them about being Black and getting along with white people had stronger feelings of connection to other Black people than those who do not

remember their parents telling them anything about being Black. Similarly, Black adults contribute to a positive racial identity in youth. Black role models in a Black youths' lives is also associated with positive racial identity development (Tatum, 2004).

### **Identity development for LGBTQ youth.**

Perhaps the role of parents and caregivers in the process of disability and autistic identity development is like that of racial identity development. However, because youth with autism usually do not share their disability identity with their parents or caregivers, research done with LGBTQ youth who have non-LGBTQ parents is helpful in theorizing these complexities.

LGBTQ youth are at greater risk of suicidal thoughts and attempts, victimization by peers and unexcused absences in school (Robinson & Espelage, 2011), like risks seen in youth with I/DD. Family acceptance predicts greater self-esteem, social support and general health status in LGBTQ youth. It also protects LGBTQ youth from suicidal thoughts and attempts (Ryan, Russell, Huebner, Diaz & Sanchez, 2010). These findings suggest the importance of families accepting and supporting their children's identity development. Further, LGBTQ youth have identified that their parents' identity, whether LGBTQ or not, plays a significant role in their own identity development (Kovalanka & Goldberg, 2008). The presence of accessible LGBTQ role models in the lives of LGBTQ youth are critical for healthy youth development. Formal mentoring support has been encouraged for this population (Bird, Kuhns, Garofalo, 2012).

### **The role of parents in identity formation.**

Parents' role in autistic identity development and stigmatization does not yet have the same press as Black and LGBTQ youth. Based on identity development work done with these populations, there is a reasonable expectation that parents and caregivers will impact disability and autistic identity development.

Since parents are active and reflective participants in their children's identity formation (Schachter & Ventura, 2008), research must investigate ways that parents influence autistic identity development in youth, and ways that they do or do not relate to autism. Very frequently, parents and professionals attempt to normalize their children with autism (Monteleone & Forrester-Jones, 2016). As previously mentioned, quantitative research on the impacts of normalization is limited at this point but scholars and self-advocates have noted that 'pretending to be normal' causes distress (Monteleone & Forrester-Jones, 2016), exhaustion, and impacts self-perception (Hirvikoski, Mittendorfer-Rutz, Boman, Larsson, Lichtenstein & Bolte, 2016).

Research has not explicitly documented the ways parents talk to their children about autism and at what age it should be done. Parenting articles do exist. However, they typically account for personal experiences of parents talking to their children about autism and include suggestions of words to use, techniques and at what age might be best to have this conversation with youth. These articles do not have concrete research backing any of their anecdotal claims. Further, much of the research on identity formation in relation to autism has not been framed within the social model of disability.

Parents hold a crucial role in both identity development as well as providing for their child's basic needs. Parents often take on the role of 'the advocates' for their children. This advocacy occurs in schools, medical clinics, social services and on social media (Wright & Taylor, 2014). Freedman and Boyer (2000) found that parents and other caregivers need support to address the array of unique family needs associated with raising a child with a developmental disability. These supports should provide opportunity for family choice and control, and should assist families in navigate the complex developmental disability systems. Parents are significantly involved in securing services for their children; however, this same level of

advocacy has not yet been documented in the context of supporting autistic youth's positive autistic identity development.

**Positive constructions of autism.**

Autistic people exhibit more scientifically based knowledge than non-autistic people. Additionally, autistic adults' descriptions of autism were neutral, personal and experiential. (Gillepsie-Lynch, Kapp, Brooks, Pickens, Schwartzman, 2016).

While the pervasive messaging of autism is negative, the writings and communities created by autistic people celebrate autism in a positive way. Some disability scholars have referred to this as the affirmative model of disability (Gaine, 2010). A sense of community comes from the shared resilience between autistic people, especially in reaction to a world that often combats them and attempts to normalize them (Benham, 2015). In fact, there has been documentation of autistic communities sharing cultural practices and valorizing autistic traits (Block, 2015).

Because disability status is considered by many, to be part of an individual's identity, it is important to investigate society's role in accommodating autistic people and impacting autistic identities. It is important to focus research on ways in which non-disabled people, specifically parents, help or harm people with disabilities. The current study investigates several questions through the lens of critical disability studies (Annamma, Connor & Ferri, 2012) and critical autism studies (O'Dell et al., 2016). First, what themes arise when autistic adults are asked to reflect on their experience being told about autism as a child? What do autistic adults recall about their parent or caregiver's role in helping them learn about autism? Second, how do autistic adults respond to questions about their autistic identity development, or lack thereof? Finally,

what strategies or suggestions do autistic adults have for parents and caregivers talking to their children about autism?

### **Method**

The following section outlines the methods used to conduct the current study. First, participants are identified and described. Next, the procedures that were taken to elicit and collect data are addressed in steps. Materials used to collect data are identified and finally, data analysis is described.

### **Participants**

Interviews were completed by 14 total participants. Of the 14 interviews, 7 were completed by parents and 7 were completed by autistic adults. The parent group consisted of parents of individuals with autism. The autistic adult group consisted of adults who identify as autistic and are over the age of 18. Of the interviews, four were completed by dyads of parents and their autistic adult children (8 participants total), one was completed by an autistic adult and both their mother and father together, two were completed by autistic adults without their parents present and one interview was completed by a mother without her autistic son present.

Documentation of autism was not required for inclusion in this study. Participants only needed to self-identify as someone with autism to qualify for participation in the study. Self-disclosure occurred during the recruitment stage of the study.

Participants were individuals who were familiar with the Arc of King County and frequently utilize Information and Referral programming services, as well as community events and trainings hosted by the Arc of King County.

Individuals who did not self-identify as autistic during recruitment were excluded from the study. Individuals self-identified and agreed to participation by email or phone during the

recruitment stage. Individuals under the age of 18, and parents of children with autism under 18 were not recruited for this study. Individuals who did not possess the ability to understand or comprehend a consent form (due to a co-occurring intellectual disability) were not recruited for this study.

The Arc of King County maintains a list of individuals who are willing to be contacted for participation in studies such as this one. An email contact list was generated through the organization's database, based on the individual's disclosed diagnosis (autism) and age (over 18). These participants were contacted via email by the researcher. The Arc of King County also monitors multiple Facebook and Yahoo groups for individuals with autism and parents of children with autism. These participants were invited to contact the researcher via contact information posted on the Facebook and Yahoo groups. See Appendix A for the full study invitation email. Parents and adults with autism were asked to complete the interview together, as a dyad, but were not excluded from the study if only one member of the dyad was available.

### **Procedure**

This study has been reviewed by the University of Washington Human Subjects Division (HSD) and was determined exempt status (category 2). See Appendix B for the Determination of Exempt Status by the University of Washington Human Subjects Division.

Before the study began, participants were thanked for agreeing to participate by email, and were sent a copy of the informed consent form, the demographic questionnaire and the full list of interview questions for both parents and autistic adults. Participants were given these materials so they could prepare if they chose to.

After arriving at the Arc of King County, participants were seated in a meeting room with the researcher. Parents and adult children completed the study while the other was in the room, if

they were participating as a dyad. The researcher provided a brief description of the study's purpose and what participants could expect. The researcher asked verbal permission to audio record participants during the interview portion of the study.

The researcher then provided participants with 2 informed consent forms each and gave a verbal description of information included in the forms. The researcher provided an opportunity for participants to ask any questions about the informed consent form or about the study. Participants were informed that one of the forms was for their records and the other for the study. See Appendix C for the informed consent form used in this study.

After participants signed the informed consent form, the researcher asked participants to complete the demographic questionnaire. Participants were told that they can skip any questions that they either do not know the answer to or do not wish to answer.

Upon completion of the demographic questionnaire, the researcher informed the participants that the audio recording had begun and started the interview. Participants' interviews were recorded using a Voice Recorder application. An audio voice recorder was connected to the researcher's computer. During the interview the researcher stated each question, one at a time. Interviews were semi-structured. The researcher frequently asked clarifying and follow-up questions to participants' responses. After each statement, participants were asked if they wanted to add anything else to their statement.

After the last question of the interview, participants were asked if they had anything else they wanted to add. If participants had nothing else to add, the researcher thanked the participant and stopped the audio recording. All participants were provided one \$25 Target gift card for their participation.

## **Design and Materials**

This study used a qualitative analysis to investigate themes from interviews. Study materials included a demographic questionnaire and an interview tool. During the interview, the researcher recorded subjects using a voice recorder, which allowed the researcher access to a digital copy of the interview to be transcribed.

The demographic survey included questions related to age, gender, race/ethnicity, siblings, profession, income and highest level of education attained. See Appendix D for the full demographic survey used in the study.

The interview tool included questions related to the conversation and discussion that parents and children have about autism throughout childhood. Interview prompts included two separate sets of questions for parents and for autistic adults. Questions for parents addressed how and when they told their children about autism. One example question was “What did you tell them [about autism]? Do you remember the words or some of the things you said?” Questions for autistic adults addressed the ways they received the information about having autism / being autistic. Two question examples in this section included “Do you remember the first time your parents told you that you had autism?” and “What did your parents tell you?” See Appendix E for the full interview tool.

Names of participants were changed at the time of the transcription of the interview. Interviews were transcribed from the Voice Recorder file using Microsoft Word. Transcriptions were coded using a qualitative content analysis process (Graneheim & Lundman, 2003). Text was broken down into meaning units (about 1-4 sentences that conveyed a thought). These meaning units were edited down to reflect the condensed meaning unit (extra words, pauses and unnecessary language was removed), then evaluated for overarching interpretations. These interpretations were used to identify the latent content in the participants’ quotes. Interpretations

were then narrowed down further, into a code. Codes were analyzed across all autistic adults and were further arranged into themes.

For example, the meaning unit “It’s who I am, I can’t separate the autism from me or me from autism” was condensed to “It’s who I am, I am inseparable from autism”. The interpretation was “Autism is part of my identity”, and the final code was “Identity”. This code was related to a variety of other codes and was ultimately grouped in a theme titled “Identity”.

While data from parent data was not coded and grouped into themes for this study, relevant quotes from parents were used to support or contrast the findings from autistic adults.

### **Findings**

Of the 7 adult self-advocates who participated, all were male identifying. Five participants were white, one participant was Hispanic/Latino and one participant was Asian. The average age of autistic adults was 30, with the youngest participant being 19 and the oldest being 57. Careers varied among participants and included registered nurse, office assistant, receiving department employee, students, and lab assistant. All participants had a high school degree or higher.

Of the 7 parents who participated and provided supplemental information, 5 were females and 2 were males. Five participants were white, one participant was Hispanic/Latino and one participant was Asian. The average age of parents was 54, with the youngest participant being 45 and the oldest being 59. Careers varied among participants and included certified public accountant, an office assistant, a waiter, a social worker, a registered nurse, and retiree.

Several themes emerged from autistic adults’ interviews. The top four most common themes were “The role of society in shaping autism”, “Identity”, “Autism is neutral yet it is stigmatized” and “Autism information, education and expertise”. Codes that were associated

with “The role of society in shaping autism” came up 37 times in autistic adults’ interviews, across 6 participants. Codes associated with “Identity” came up 26 times, across 6 participants. Codes associated with the theme, “Autism is neutral yet it is stigmatized” came up 22 times, across all 7 participants. Finally, codes related to the theme “Autism information, education and expertise” came up 21 times across 5 participants’ interviews.

These themes are explored in two sections: “The construction of autism by society” and “Identity and autistic voice”. In the first section, “The construction of autism by society”, participants outline how they viewed the societal construction of autism by society, followed by discussion about language used to uphold this construction. Next, the findings identify the two key players that autistic adults name as major contributors to the negative construction of autism: parents and non-disabled peers. Supplemental parent data is used to strengthen statements made by autistic participants. Lastly, the social model is proposed as a suggestion for reshaping this negative construction. The second section, “Identity and autistic voice”, starts by documenting the diversity of experiences participants have with their connections to an ‘autistic identity’ and to a broader autism community. Next, the complexity of autism information, education and expertise is described from the point of view of autistic people and opposing views of parents. Quotes are used to illustrate how information and education lacks autistic voice and autistic role model representation, and how that impacts identity and well-being.

### **The construction of autism by society**

The two themes, “The role of society in shaping autism” and “Autism is neutral yet it is stigmatized” have both intersecting similarities and distinct differences. These two themes together create a larger umbrella theme that is hereby discussed as “The construction of autism by society”. While not all the participants explicitly named the ‘construction’ of autism, each

participant identified that autism is socially constructed through ideologies, words, and behaviors of the greater society. Autistic adults stated that neurotypical people uphold these societal messages.

### **Autistic adult perspectives on the negative construction of autism.**

All seven participants stated that autism is negatively viewed by society, despite their own personal beliefs that autism is natural and neutral. One participant, Evan, said

*It's – I always compare it [autism] to just being Belgian or something like that.*

Similarly, Ronald stated:

*It's [Autism is] fine. We are all different and the same, all at the same time.*

Autism's negative construction leads to stigma. This stigma is difficult for autistic children and adults to navigate. Many autistic adults internalize negative messages, which could impact mental health and self-esteem. Evan also stated in his interview,

*There was a lot of self-stigma and stigma of others on the spectrum who might appear a little more autistic than I would, initially.*

Many of the autistic adults who were interviewed stated needing to justify the neutrality of autism and disability. Keenan said the following,

*But don't get me wrong just because I have a disability doesn't mean I'm not a good citizen and student.*

### **Autistic adult perspectives on language related to functioning.**

The stigma of autism is supported by language people use to describe it. Autistic adults spoke of the terminology of 'high-functioning' and 'low-functioning'. 'High-functioning' and 'low-functioning' are labels that are socially assigned to autistic people, but do not come with a stable set of criteria. It is unclear how autistic adults define high-functioning versus low-

functioning; however, two participants were averse to the terminology and found it problematic.

One participant, Gregory, said,

*I don't like the term "high-functioning". I think it's descriptive and it serves a purpose in certain settings ... But "higher functioning" or "lower functioning" I don't like, because as soon as someone identifies me as "higher functioning" that means they have totally discounted the fact that I have some challenges. And it means they have ignored the fact that I'm autistic. The other side of that is that as soon as they call me "high functioning" they've discounted anyone that might be called "low functioning". In other words, 'they can deal with me, but they have no idea what to do with those other people'. I think it removes someone's ability to see us all as individuals and to look and learn and explore. I think when you get to know someone, it's not about learning what their challenges are. It's about learning what their abilities are.*

These findings are consistent with previous research by self-advocates. Many autistic people distance themselves from language and terminology associated with "functioning" (Lim, 2015).

When parents and professionals define autistic people by their 'level of functioning', generalizations are made about both the challenges and accomplishments of all autistic people.

Evan described the divisiveness of 'high-functioning' and 'low-functioning' terminology and how it creates divides between autistic people,

*I mean, the thing I remember hearing about it the most was always that I would just grow out of my Asperger's and that is something that I sort of internalized up until I was in my early 20's. I was always told I was so much more 'high-functioning' than those other autistics, and I don't really need to worry about it.*

Alas, there were autistic adults who do use the terminology to describe themselves. Tom said in his interview, describing how he fits in with the rest of society,

*I'm just more higher functioning than most.*

### **Parent perspectives on the construction of autism.**

High functioning and low-functioning terminology was used frequently in parent interviews; however, there was not an emphasis on this terminology being problematic. Five out of 7 parents used terminology related to functioning. One parent said, in an interview where their child was not involved,

*He's what you would consider to be middle functioning and he - even though - um - so he has enough communication to get his needs met but he can't carry on a full conversation.*

Another parent used functioning to distinguish differences between their child and other autistic children,

*He was the one who helped some of the lower functioning kids do more things with money or talking to people at restaurants ordering dinner -that sort of thing.*

One parent said,

*No. I don't see it [autism] as a disability. We're lucky because he is high functioning. He might struggle with some things. I'd say if a person can't take care of their everyday needs and be independent, then yes - it is a disability.*

### **Autistic adult perspectives on the role of parents.**

All but one participant stated that society plays a central role in the negative construction and stigmatization of autism. Neurotypical parents and student peers were the two groups most frequently mentioned as key contributors to the negative construction of autism.

Autistic adults stated that parents play a crucial role in shaping what autism means for their child. There was not a unified consensus on when autistic adults thought that parents should talk to their children about autism. Timmy stated that, ideally parents would tell their children in their teenage years:

*I'd like to think [parents should tell their children about autism] in their teenage years.*

*That is when they are starting to learn things and the more they know the better.*

Other participants specifically named early elementary school as a critical time for this conversation. Gregory, in contrast, felt that parents have a responsibility to have conversations about autism as soon as a diagnosis is made:

*[parents should tell their children about autism] from the beginning. As soon as they're aware. And, actually, to expand that to my ideas about the general population I think that everybody should learn about it and everybody should talk about it and it shouldn't be so foreign in anybody's life. I think the biggest thing with challenges, or any type of condition, is other people not knowing what it is but assuming that they know. And, you know, this idea that autistic people could be better if they just tried, that would substantially go away if people understood that the wiring is wired the way its wired and it's not gonna change.*

Despite the lack of consensus regarding when parents should talk to their children about autism, all participants agreed that parents should communicate to their children with openness and honesty. Participants emphasized the importance of conveying the neutrality of autism and that it is not a bad thing. Tom stated:

*I think they [parents] should um just tell them [their autistic children] that they're unique- that they're not an abomination or something.*

Participants found it important that parents to talk to their children about autism because it provides context for why children (and adults) might be having struggles or different experiences than their neurotypical peers. Evan stated:

*I've also heard from a lot of group members or other people that there are times when the parent knew early on that their kid was on the spectrum, but the parent never told the kid, and that was something that was super hurtful for the autistic person. You know they – you know it's nice to have an explanation for why these certain things are happening. And when you don't have that explanation, you know, you blame yourself. You think of yourself as less of a person. Having that explanation as early as you can will provide a benefit, and will sort of help relieve the mental health stress that comes with just being different and not necessarily being able to label why.*

Similarly, Gregory stated finding out about autism later in life provided context for many negative things he had previously experienced,

*For the second time in my life I went to Google and typed in 'why does everybody hate me?' The first time they suggested ADHD, which is probably true- but seeking treatment for that just didn't fix anything. So the second time it brought me to Asperger's syndrome and I was like 'wow, this is the only thing that has ever made any sense in my life'.*

Unfortunately, several autistic adults stated that their parents did not tell them about autism in ways they thought were ideal. Timmy stated that his mother did not tell him until much later in life and that they had very few conversations about what autism even was.

*I was never really told anything about it [as a child]. Sometimes we have conversations now. They go like... well we talk about the subject a lot when it comes up....*

Arthur stated his parents were overprotective when they talked to him about autism:

*So that's why they tried to protect me. But no offence to them, it's kind of over protective.*

### **Parent perspectives on the role of parents.**

Parent data provides interesting insight into the ways that they view disability and autism. They also provide insight into the ways in which they do or do not tell their children about autism. One parent had a negative outlook on autism and said,

*I look at his disability as 'god I hope someday they come up with a cure – because this is an awful way for somebody to have to live their life'.*

Another parent said that their own coming to terms with their child's autism diagnosis was more difficult than telling their child and helping them understand autism,

*So by the time whenever that "ah ha" moment was for him, for us it was another step in the journey. So him finding out was sort of a non-event.*

One parent mentioned the need for an ongoing conversation about autism,

*Well it's tricky because he struggles with that part of who he is. He knew he was different but, then again, he always say things like "well everyone is different". He's very deep. It is an ongoing conversation that we have.*

One parent noted the additional complexity of culture, and how that intersects with autism and disability,

*You know it's been really hard I can honestly say because being Asian, they're not really receptive to special needs culturally, especially the Chinese. It's been really hard. I cannot really say that I talked about disability pride early on because it was very difficult. And dealing with the cultural parameters that my in-laws - mother-in-law couldn't accept it. She thought there was something wrong with me. So it's very hard to explain to them what it is.*

Many parents mentioned feeling scared to talk to their children about autism. One parent stated,

*I remember saying that they “had” autism as opposed to saying, “you are autistic”.*

*“You are autistic” I thought meant that it meant who you are and that it would define you, where, saying that you “had” autism was more like something that you ‘had’, like a disease; and I see now that was probably not the best way to go about it and it probably was taken wrong. So, at the time, I was scared because I felt like I had to tell him that he had something.*

### **The role of non-disabled peers in constructing autism.**

The second group of people identified as key contributors to the negative construction of autism was peers in school. Most autistic adults spoke about their struggles in school, due to bullying and isolation. Tom said,

*I just... um... when I was 15 people started calling me the most disrespectful word when they found out I was different. It’s the word retard. It’s very disrespectful.*

Arthur described having trouble connecting with neurotypical peers in school,

*Well I did get taken out of the classroom and I was terrible at hanging out with those different people. That’s okay though cause I did hangout with a few. I was right. I did avoid it. Hanging out with them...*

Bullying is a common experience for students with disabilities, particularly autistic students.

Autistic adults addressed the importance of neurotypical student peers understanding autism better, to be more inclusive and accommodating of differences.

### **Moving towards a positive construction of autism.**

The social model of disability theorizes disability as a form of diversity. Through this model, the struggles faced by disabled people are due to barriers created by society, rather than

individual characteristics (Shakespeare, 1997). The social model of disability gives a name to concepts put forward by participants and it provides insight into key contributors of this negative construction. Gregory said,

*That's the perspective I have about educating the general population. I'm okay – we need to talk about YOU people.*

Similarly, Ronald stated,

*Autism is a social barrier that we need to overcome.*

The social model of disability specifies society as having a central role in addressing ableism, rather than blaming the person with the disability.

### **Identity and autistic voice**

The next two themes discussed are identity and autism information, education and expertise. These two themes were combined into an umbrella theme hereafter called “Identity and autistic voice”, to reflect the overlap between autistics folks’ identity and what is popularized and taught about autism. This theme identifies who is commonly considered ‘autism experts’, and who is left out.

#### **Inconsistent connection to autistic identity.**

Responses regarding participants’ connection of autistic identity were varied. This variation is consistent with previous autism identity research. Three participants responded with inconsistent answers and waffled between autism being part of their identity and autism being a medical condition or diagnosis, that is only partially relevant to them. Keenan stated,

*Autism is a thing. It's a disorder. A condition and the type of disability and it's also- we need to learn to talk.*

Similarly, Arthur stated,

*I'll tell you the full answer of this. So, I was born being autistic because my brains went the wrong direction. And that caused me to become autistic.*

This framing of autism contradicts other statements made by the same participants about the general neutrality of autism. These inconsistencies might reveal participants' internalization of negative messages related to autism. Timmy said,

*I always knew that something was wrong – well my mom and dad both knew also. I don't really remember that much. Yeah that's about it.*

Other participants viewed autism as a prominent part of their identity and even expressed membership of a larger community of autistic people. Evan said,

*It's who I am; I can't separate the autism from me or me from autism. It's like one of my friends said, 'autism is something that flavors everything that she does'. Autism isn't 100% her but you can't remove it from who she is or what she does. It's always there. It's always present. It's just existence for me, really.*

Additionally, to this point, Evan said,

*But those of us in the community think of it more like- as our own culture. You know we have our own norms we have our own values we have our own different experiences within our own subset of people.*

This quote, highlights the strength and resiliency of autistic folks in the community. Tom identified this community, as well,

*I'm part of the unique society.*

Participants who felt connection to their autism identity more frequently mentioned a connection to a broader autistic community and more readily identified societal issues and inequities faced by all autistic adults.

### **Autism information and education.**

Participants spoke about the complexity of autism information, education and expertise. With the increased prevalence of autism diagnoses, there has been an increase in publications, literature and personal accounts about autism. Participants specified that parents and school peers need ‘education’ and ‘information’ about autism to best support autistic children. Timmy said,

*Well, parents should probably be educated about it. In the way they talk to maybe another ‘expert’ about the subject- anybody who has maybe even a little bit of expertise on anything about it. Even if it’s just a little that could go a long way. And then it can be given to the teenager in a way they can understand; and it can help them develop and help them develop empathy if they ever meet someone with these kinds of difficulties.*

Similarly, Gregory said,

*And it [children being told about autism] should be done by someone who knows what they’re talking about- so the parent has to become educated too. And parents are going to be uniquely educated on their own child...*

The question of where parents, professionals and peers can go for accurate information was not asked in the interview, but participants noted that there is an overwhelming amount of misinformation about autism. Timmy said,

*I know that there’s a lot more to it than things that are popularly seen. And that people can still function in society but they have a different mindset of things.*

This idea graphs onto the construction of autism by society, and suggests the importance of autistic representation in shaping this construction. Subsequently, identity could be positively impacted with increased autistic contribution to construction.

### **The importance of autistic voice.**

Several participants described the importance of the lived experience of people with autism. Evan stated,

*And that's something that needs to be looked at. There needs to be more autistic adults involved in, you know, working with autistic children and helping frame the narrative around autism itself.*

Gregory also stated the importance of autistic people shaping the messaging and education related to autism,

*I think there is tremendous benefit for people on the spectrum and people not on the spectrum; for everyone to know what it is, how to recognize it, how to handle it, what to be scared of what not to be scared of. Lived experience is important. The rest of the world, they don't know what autism is. Either they've seen Rain Man, or it's something about a vaccine. And for things to get better for us, that education has to change.*

Additionally, both Evan and Gregory mentioned the importance of having autistic adults and mentors in the lives of autistic youth. Evan said,

*[Parents need] other sources of information, especially if the parent isn't on the spectrum themselves. You know they really gotta be connected with autistic adults as well.*

Gregory said,

*I look back and yes, now I think - they're probably autistic. I guess I was the one who realized that they were weird. I never called them weird but the best of that situation would have been me, as someone with autism growing up, to know for me that they had it too. But for me to realize that they were strange, and for me to think of myself in the same way, but to not know what it is called- then there is no way to connect and have a conversation about it.*

**Parent views of their own expertise.**

Parents also provided insight into the complexity of autism information, education and expertise. One parent noted her child's ability and unique positionality to communicate with other autistic people,

*I don't know what he has in his brain that allows another autistic kid to calm down. But something passes between the two of them. But he gets someone in a meltdown to calm down. I don't know what it is. Some parents just look and they're like, "Oh my god! The horse whisperer!"*

Overall, parents were confident in their own autism expertise, despite none of them identifying as autistic themselves. Parents frequently mentioned their ability to identify autistic people in public,

*Just the other day at work when I was at a conference there was a man who came up to the group and said, "what's going on" because there were a bunch of attorneys and accountants hanging around for a conference- a bunch of people who were not usually there. He said,, "what's going on" and I said "I know- we're here for a conference, we won't be here tomorrow, we're just here today" and he said "okay well I'm going to class." I said, "we won't be here tomorrow, and we won't be here on Monday either" and he says "okay well I was just curious about that". Just a young man who wanted to know what was going on. Just an interruption to the routine. He just really needed to know. And I in 165. He was not shy about asking, he just needed some information. Some of the people that I was working with were like, "what did he want" and I was like, "that young man is on the spectrum and something had just disrupted his routine and he just wanted to know what all these people were doing here and now he's on his way to class -*

*look at him, he's on a mission". As soon as he had that information he was like "okay, file that away, on to the next thing." But it could have ruined his whole day.*

Additionally, parents often self-identified as 'special needs parents' or 'autism parents,

*It was hard for me to come to grips with being a special needs parent. It just came out of the blue.*

Parents had varying language to describe the ways that they felt about autism. The way parents understand autism impacts the way autistic children and adults learn about autism. Evan said,

*The way the parent views disability and autism and other forms of neurodiversity- it directly impacts what the child is going to think about themselves and how they see the world.*

## **Discussion**

The results highlight two themes that fit into previous literature: Autism is negatively constructed by society and Identity and autistic voice. In this section, the findings will be summarized. Next, implications for practice will be addressed, which include shifting the narrative of autism, facilitating better autistic identity development and envisioning these two major themes as cyclical. Lastly, limitations of the study will be discussed.

### **Summary of findings**

The first theme, The construction of autism by society, links into research about social construction of other identities like race and gender. Autistic adults all agreed that autism is natural and neutral, however there is significant stigma attached to being autistic. This construction becomes clear through language used to describe autism. Terms like 'high-functioning' and 'low-functioning' are used to situate autism as a deviance from 'normal'. Some

participants were averse to these terms, while others actively used them to describe themselves. People who used terms related to functioning generally used other negative and deficit based language to describe autism. Autistic adults stated that the two main contributors to the negative construction of autism are parents of autistic people and non-disabled peers. Participants suggested deploying the social model of disability and emphasizing neurodiversity to work towards making society more inclusive.

The theme Identity and autistic voice related to the ways that autism does, or does not, become an integral part of autistic people's identity. Identity and connection to a greater autistic community was inconsistent for participants in this study. For those participants who did strongly identify as autistic, they stated that this identity and larger community was important to them. Autistic people are often excluded from autism information, education and expertise due to a medicalized construction. Information, education and expertise regarding autism informs how and when parents tell their children about autism, and subsequently how autistic people do or do not adopt an autistic identity. Some participants strongly identified the need for autistic adults and role models for autistic youth. None of the participants had openly autistic adults supporting their identity development throughout their youth.

### **Practice Implications**

The findings from this study provide preliminary suggestions for the social work field, directly from autistic people. First, the negative construction of autism will be addressed and suggestions will be provided to shift the construction to focus on the strengths and resilience of autistic people. Next, autistic identity development will be established as a protective factor for autistic youth. Information, education and expertise should have better representation by autistic people. This will create a more accountable understanding of autism and will contribute to the

availability of autistic adult role models. Finally, it is suggested that these two themes, The construction of autism by society and Identity and autistic voice, are inextricably linked together and cyclical.

### **Shifting negative construction to positive.**

Parents and non-autistic peers have been named key contributors to the negative stigma of autism. There is significant work to be done with these populations on understanding disability, power and allyship. Autistic adults specify that even though autism is natural and neutral, and even a source of strength and resilience, the primary rhetoric surrounding autism is based in the medical model. The social model of disability challenges the medical model by conceptualizing the challenges faced by people with disabilities as societal barriers rather than limitations and impairments created in their bodies or brains (Shakespeare & Watson, 1997). Parents, professionals and peers must become educated on the social model of disability to better understand autism. Through the social model, messaging about autism can shift from negative to neutral to positive.

Rhetoric and language are reinforcers of oppression. “High-functioning” and “low-functioning” terminology was specifically addressed in the findings. While some participants used this language themselves, others found it problematic. Supplemental data from parents showed that parents frequently use these terms to distinguish and compare intensity of needs. The universal impact of this language creates divides for people with autism (Lim, 2015). As one participant explicitly mentioned, being told they were ‘more high-functioning’ lead to a negative internalization of their identity. Terminology related to functioning must be used thoughtfully, or not at all, to minimize negative impacts on autistic people.

Lastly, the negative construction of autism may be upheld through the ways in which parents do or do not talk to their children about autism. The ongoing debate about when to talk to children about autism implies that there is something bad about autism. Most autistic adults stated the importance of parents and caregivers telling their children about autism early in life. All autistic adults felt that parents should be open and honest with their children about the realities of autism. Ideally, conversations between parents and autistic youth will be based in the social model. It is suggested that parents tell their children about expected challenges and that these challenges are not because of the child, rather they are societally based. These conversations should be ongoing and age appropriate. Future research should continue to investigate how to have this conversation, and what role autistic adults can play in the curation of this conversation.

#### **Facilitating positive autistic identity development.**

Positive identity development and family support is a protective factor for people of color (Chávez & Guido-DiBrito, 1999) and LGBTQ people (Ryan, Russell, Huebner, Diaz & Sanchez, 2010). Preliminary research suggests disability identity may be a protective factor for disabled youth as well (Cooper, Smith & Russell, 2017). Professionals and parents must focus on ways to support positive autistic identity development in autistic youth, despite a lack of consensus across autistic participants to claim and own this social and political identity. Because the societal construction of autism is primarily negative, autistic people may feel averse to identifying as autistic when it is socially stigmatized. Additionally, since autism is defined across a spectrum, it might be difficult for autistic people to create community and shared identity; especially when there are more differences than similarities in their experiences. Research going

forward should look at the complex barriers that keep autistic people from connecting with positive autistic communities.

There is a need for cross collaboration between parents, professionals and, most importantly, autistic adults. Since parents and professionals will usually not share the same autistic identity as the children they are supporting, it is recommended that autistic adults are utilized as both mentors and collaborators. Autistic people know best what it is like to live with autism (Gillespie-Lynch et al., 2017) and therefore are optimal resources for youth to learn about tools for making it through the difficult times and ways to connect with positive aspects of autistic culture.

Supplemental data from parent interviews showed that parents have unique identities themselves. While parents themselves may not share an autism diagnosis or identity with their child, they face unique challenges related to parenting. As primary advocates for their children, there is a need for parents to form their own non-disabled identity, to engage in accountable allyship. Like racial identity development, people who are not members of the target identity group will inevitably be assigned power and privilege (Hays, 2008). The complicated nuances of this dynamic are yet to be looked at in non-disabled parents and warrant further inquiry.

### **Two themes as a cycle.**

The two primary themes in the data stand individually but are also connected. Social constructions both rely on people to construct them, and contribute to shaping people's identities. Similarly, identity development will be impacted by the valence of the social construction of said identity. This cycle makes it particularly important for autistic voices to be at the forefront. If autistic people had more opportunities to illuminate the positive aspects of autism publicly, then

the social construction could shift and barriers to positive identity development could be disrupted.

### **Limitations**

There are several limitations to the current study. First, the demographics of participants challenge this studies generalizability. All autistic adults who participated in the study identified as male. While autism is more common in men than in women, autistic women have a different experience than autistic men, and therefore additional complexities related to gender should be considered. As with most autism research, participants in this study were majority white and upper-middle class. Future research on social constructions and identity development must interrogate the intersection of race, class and disability. Lastly, none of the parents in the current study identified as autistic, themselves. It is crucial to understand how conversations and identity development may be different for youth raised by autistic parents.

Additionally, all but one autistic participant had traditional biological parents in their lives. The one participant who did not was adopted and did not disclose involvement in the foster care system. The intersection of disability and the foster care system is notoriously underexplored. Future research should intentionally work to build knowledge and capacity in this realm. A larger sample size or more intentional participant recruitment could address the limited diversity in the demographic data.

Another limitation is related to the procedure design. During most interviews, both parents and autistic adults were present in the room. This dynamic likely lead to both parents and autistic adults censoring their responses. Future extensions of this research should interview these two populations separately, unless seeking a discourse analysis. By interviewing

participants separately, more information may become available regarding dynamics between parents and autistic youth and adults.

### **Conclusion**

Autistic adults revealed that both disability and autism are social constructions, which are negatively stigmatized. Participants further addressed how this construction fits into their own identity development. Parents, caregivers and peers, moderate how this identity development happens and what the overall messaging about autism means for youth. Most participants noted that they could imagine the benefit of having more autistic adults in their lives during their youth.

There is a need for more autistic voice and representation in all fields supporting autistic people. Through increased representation of autistic people, a better collaboration between parents, professionals and autistic adults can be built.

## REFERENCES

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Annamma, S. A., Connor D. & Ferri, B (2012) Dis/ability critical race studies (DisCrit): theorizing at the intersections of race and dis/ability, *Race Ethnicity and Education*, 16:1, 1-31, DOI: 10.1080/13613324.2012.730511
- Bagatell, N. (2010). From Cure to Community: Transforming Notions of Autism. *Ethos*, 38(1), 33-55. doi:10.1111/j.1548-1352.2009.01080.x
- Baker, B. (2002). The Hunt for Disability: The New Eugenics and the Normalization of School Children. *Teachers College Record*, 104(4), 663-703. doi:10.1111/1467-9620.00175
- Baynton, D.C. (2001). Disability and the justification of inequality in American history. In P. K. Longmore & L. Umansky (Eds.) *The New Disability History*, pp. 33-57.
- Benham, J. (2015). "Proud to be Autistic: Metaphorical Construction and Salience of Cultural and Personal Identity in #StopCombatingMe". *All Theses, Dissertations, and Other Capstone Projects*. Cornerstone Minnesota State University Mankato. Paper 420.
- Berger, P. L. and T. Luckmann (1966), *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*, Garden City, NY: Anchor Books.
- Block, P. (2015). The Emergent Landscape of Autistic Communities and Autistic Studies. *Culture, Medicine, and Psychiatry*, 39(2), 351-355. doi:10.1007/s11013-015-9453-8
- Cage, E., Monaco, J. D., & Newell, V. (2017). Experiences of Autism Acceptance and Mental Health in Autistic Adults. *Journal of Autism and Developmental Disorders*, 48(2), 473-484. doi:10.1007/s10803-017-3342-7

- Campbell, F. A. (2008). Exploring internalized ableism using critical race theory. *Disability & Society, 23*(2), 151-162. doi:10.1080/09687590701841190
- Chávez, A., & Guido-DiBrito, F. (1999). Racial and ethnic identity and development. In M. C. Clark & R. S. Caffarella (Eds.), *An update on adult development theory: New ways of thinking about the life course* (New Directions for Adult and Continuing Education No. 84, pp. 39-47). San Francisco: Jossey-Bass.
- Cimera, R. E., & Cowan, R. J. (2009). The costs of services and employment outcomes achieved by adults with autism in the US. *Autism, 13*(3), 285-302. doi:10.1177/1362361309103791
- Cooper, K., Smith, L. G., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology, 47*(7), 844-854. doi:10.1002/ejsp.2297.
- Davidson, J. (2008). Autistic culture online: Virtual communication and cultural expression on the spectrum. *Social & Cultural Geography, 9*(7), 791-806. doi:10.1080/14649360802382586.
- Denigris, D., Brooks, P. J., Obeid, R., Alarcon, M., Shane-Simpson, C., & Gillespie-Lynch, K. (2017). Bullying and Identity Development: Insights from Autistic and Non-autistic College Students. *Journal of Autism and Developmental Disorders, 48*(3), 666-678. doi:10.1007/s10803-017-3383-y.
- Demo, D. H., & Hughes, M. (1990). Socialization and Racial Identity Among Black Americans. *Social Psychology Quarterly, 53*(4), 364. doi:10.2307/2786741.
- Eaves, L. C., & Ho, H. H. (2007). Young Adult Outcome of Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 38*(4), 739-747. doi:10.1007/s10803-007-0441-x.

- Freedman, R. I., & Boyer, N. C. (2000). The Power to Choose: Supports for Families Caring for Individuals with Developmental Disabilities. *Health & Social Work, 25*(1), 59-68.  
doi:10.1093/hsw/25.1.59.
- Gaine, C. (2010). Celebrating Diversity In chapter 5 of *Equality and diversity in social work practice*.
- Garaigordobil, M., & Pérez, J. I. (2007). Self-Concept, Self-Esteem and Psychopathological Symptoms in Persons with Intellectual Disability. *The Spanish journal of psychology, 10*(01), 141-150.
- Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Frontiers in Psychology, 8*. doi:10.3389/fpsyg.2017.00438
- Hays, P. A. (2008). *Addressing cultural complexities in practice assessment, diagnosis, and therapy*. Washington, DC: American Psychological Association.
- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bolte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry, 208*, 232-238.
- Hull, L., Petrides, K., Allison, C., Smith, P., Baron-Cohen, S., Lai, M., & Mandy, W. (2017). "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *J Autism Dev Disord, 47*(8), 2519-2534.
- Johnson, I & Sigler R. (2000). Forced Sexual Intercourse Among Intimates. *Journal of family violence (15)* 1, 95-108.
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, Difference, or Both? Autism and Neurodiversity. *Developmental Psychology, 49*(1), 59-71

- Kennedy, A. C. (2008). Eugenics, “degenerate girls,” and social workers during the Progressive era. *Affilia*, 23, 1, 22-37.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462. doi:10.1177/1362361315588200
- Kuvalanka, A. K. & Goldberg, A. E. (2008). “Second Generation” Voices: Queer Youth with Lesbian and Bisexual Mothers. *Journal of Youth and Adolescence*. 38:904.
- Langan, M. (2011). Parental voices and controversies in autism. *Disability & Society*, 26(2), 193-205. doi:10.1080/09687599.2011.544059
- Lim, C. (2015). Accommodating Autistics and Treating Autism: Can We Have Both? *Bioethics*, 29(8), 564-572. doi:10.1111/bioe.12154
- Linton, S. (2010). *Claiming disability: knowledge and identity*. New York: New York University Press.
- Milton, D., Mills, R., & Pellicano, E. (2012). Ethics and Autism: Where is the Autistic Voice? Commentary on Post et al. *Journal of Autism and Developmental Disorders*, 44(10), 2650-2651. doi:10.1007/s10803-012-1739-x
- Monteleone, R. & Forrester-Jones, R. (2016). Disability means, um, dysfunctioning people’: A qualitative analysis of the meaning and experience of disability among adults with intellectual disabilities. *J Appl Res Intellect Disabil*. Epub Ahead of Print.
- O'Dell, L., Rosqvist, H. B., Ortega, F., Brownlow, C., & Orsini, M. (2016). Critical autism studies: Exploring epistemic dialogues and intersections, challenging dominant understandings of autism. *Disability & Society*, 31(2), 166-179.
- Oliver, M. (1983) *Social Work with Disabled People*. MacMillan, Basingstoke

- O'Neil, S. (2007). The meaning of autism: Beyond disorder. Retrieved from <http://www.tandfonline.com/doi/abs/10.1080/09687590802469289>
- Ortega, F. (2009). The Cerebral Subject and the Challenge of Neurodiversity. *BioSocieties*, 4(4), 425-445. doi:10.1017/s1745855209990287.
- Rekers, G. A., & Lovaas, O. I. (1974). Behavioral treatment of deviant sex-role behaviors in a male child. *Journal of Applied Behavior Analysis*, 7(2), 173-190. doi:10.1901/jaba.1974.7-173
- Robinson, J. P., & Espelage, D. L. (2011). Inequities in Educational and Psychological Outcomes Between LGBTQ and Straight Students in Middle and High School. *Educational Researcher*, 40(7), 315-330. doi:10.3102/0013189x11422112.
- Ryan, C., Russell, S. T., Huebner, D., Diaz, R., & Sanchez, J. (2010). Family Acceptance in Adolescence and the Health of LGBT Young Adults. *Journal of Child and Adolescent Psychiatric Nursing*, 23(4), 205-213. doi:10.1111/j.1744-6171.2010.00246.x
- Schachter, E. P., & Ventura, J. J. (2008). Identity Agents: Parents as Active and Reflective Participants in Their Children's Identity Formation. *Journal of Research on Adolescence*, 18(3), 449-476. doi:10.1111/j.1532-7795.2008.00567.x
- Shakespeare, T., & Watson, N. (1997). Defending the Social Model. *Disability & Society*, 12(2), 293-300. doi:10.1080/09687599727380
- Stevenson, J. L., Harp, B., & Gernsbacher, M. A. (2011). Infantilizing Autism. *Disability Studies Quarterly*, 31(3). doi:10.18061/dsq.v31i3.1675
- Szatmari, P. (2017). Risk and resilience in autism spectrum disorder: A missed translational opportunity? *Developmental Medicine & Child Neurology*, 60(3), 225 - 229. doi:10.1111/dmcn.13588

- Tatum, B. D. (1992). Talking About Race, Learning About Racism: The Application of Racial Identity Development Theory in the Classroom. *Racism: Essential Readings*, 311-325. doi:10.4135/9781446220986.n31
- Tatum, B. D. (2004). Family Life and School Experience: Factors in the Racial Identity Development of Black Youth in White Communities. *Journal of Social Issues*, 60(1), 117-135. doi:10.1111/j.0022-4537.2004.00102.x
- Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to Care for Autism-Related Services. *Journal of Autism and Developmental Disorders*, 37(10), 1902-1912.
- Vallas, R. (2016). Disabled Behind Bars. Retrieved December 04, 2017, from <https://www.americanprogress.org/issues/criminal-justice/reports/2016/07/18/141447/disabled-behind-bars/>
- Waltz, M. (2015). Mothers and Autism: The Evolution of a Discourse of Blame. *The AMA Journal of Ethics*, 17(4), 353-358. doi:10.1001/journalofethics.2015.17.4.mhst1-1504
- Wright, A. C., & Taylor, S. (2014). Advocacy by Parents of Young Children With Special Needs: Activities, Processes, and Perceived Effectiveness. *Journal of Social Service Research*, 40(5), 591-605. doi:10.1080/01488376.2014.896850

## APPENDIX A

Dear \_\_\_\_\_,

I hope you are well and are enjoying the fall weather. My name is Scott Brown and I am a graduate student at the University of Washington School of Social Work, who is placed at The Arc of King County for my practicum experience. For a masters level thesis project I am conducting a research study on the ways that parents inform their children about autism and disability. The results of the research will be presented to Arc of King County staff and will help inform the organization's ongoing work.

You are being contacted because you have previously consented to being contacted by The Arc of King County for studies like this. We are looking for participants (both parents and their children with autism / ASD) to participate in a **45 to 60 minute confidential interview**. The interviews will focus on when you were told you have autism or when you told your child they have autism. There will also be a short demographic questionnaire to fill out (3-5 minutes).

Interviews will take place at The Arc of King County at participants' convenience. No documentation of autism diagnosis is required for participation. Your participation will add to a growing body of research related to autism and will help social workers who work with parents of children with autism. Both parents and sons/daughters must be present for the interviews.

Your participation is completely voluntary. If you agree to participate, you may end the interview at any time. Upon completion of the interview, participants will receive a **\$25 gift card to Target**.

If you are interested in participating please reply to this email and contact me to set up a time to be interviewed.

Cheers,



**Scott Torrance Brown** | Information and Outreach Coordinator  
Direct 206.829.7035  
[For people with intellectual and developmental disabilities.](#)

## APPENDIX B

**DETERMINATION OF EXEMPT STATUS**

October 24, 2017

Scott Brown  
stb1992@uw.edu

Dear Scott Brown:

On October 24, 2017, the University of Washington Human Subjects Division (HSD) reviewed the following application:

Type of Review:	Initial Study
Title of Study:	Disability Discourse: How and when do caregivers talk to their children about autism?
Investigator:	Scott Brown
IRB ID:	STUDY00003470
Funding:	None

**Exempt Status**

**HSD determined that your proposed activity is human subjects research that qualifies for exempt status (Category 2).**

- This determination is valid for the duration of your research.
- This means that your research is exempt from the federal human subjects regulations, including the requirement for IRB approval and continuing review.

If you consider changes to the activities in the future and know that the changes will require IRB review (or you are not certain), you may request a review or new determination by submitting a Modification to this application.

Thank you for your commitment to ethical and responsible research. We wish you great success!

Sincerely,

Jennifer Maki  
IRB Review Administrator  
(206) 543-4798 | makij2@uw.edu

## APPENDIX C



**UNIVERSITY OF WASHINGTON  
INFORMED CONSENT FORM**

**How and when do caregivers talk to their children about autism?**

**Researcher:** Scott Torrance Brown, The Arc of King County  
Graduate Student, University of Washington School of Social Work  
206-829-7035 | [sbrown@arcofkingcounty.org](mailto:sbrown@arcofkingcounty.org)

**Faculty Advisor:** William Vesneski, PhD, UW School of Social Work

**Researchers' statement**

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we will ask you to do, the possible risks and benefits, your rights as a participant, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called “informed consent.” We will give you a copy of this form for your records.

**Purpose of the Study**

We are asking you to participate in a study that investigates the ways and strategies that parents and caregivers use to inform their children about autism and disability. Little research has been done to understand the words that parents and caregivers use to explain disability and autism and how youth understand their autism. The information gathered through this study will help social workers who work with parents and caregivers who have children with autism.

**Study Procedures**

Participants will be seated in a meeting room at the Arc of King County with the researcher. The researcher will provide a brief description of the purpose of the study and what participants can expect.

The researcher will provide both participants (parent and child) with an informed consent form and explain the consent form and process and answer any questions that you have. If you agree to participate, you will sign the consent form and complete a demographic questionnaire. Once the questionnaire is completed, the interview will begin. The entire interview should take no more than one hour. The interview will consist of questions about parent/caregivers experience talking to their children about autism and the children's experiences learning about autism. Upon conclusion of the interview the researcher will ask the participants if they have anything else they would like to add. If participants have nothing more to add, the researcher will thank the participants, stop the recording and provide an incentive gift card.

### **Risks, Stress or Discomfort**

You are unlikely to experience stress or discomfort during the interviews. If you are uncomfortable responding to a question, you may skip the question or end the interview.

### **Benefits of the Study**

Your participation in the study will help social workers assist parents who have children with autism. You will receive a \$25 Target gift card as a thank you for your participation.

### **Source of Funding**

The gift card was purchased with funds from the University of Washington, School of Social Work.

### **Confidentiality of Research Information**

The interview will be recorded and stored electronically. The file will be destroyed one year after the project ends. Printed copies of the transcripts may be made to help complete the study. These will be destroyed (shredded) once the research project ends, in June 2018. No names, affiliations or identifiers will be used in any reports or publications stemming from this research project. Your name and other information will remain confidential. During the interviews, however, if we learn that you intend to harm yourself or others, as mandatory reporters we must legally inform the proper authorities.

### **Other Information**

You may refuse to participate and you are free to withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled. Upon completion of the study, you will receive a \$25 gift card to Target. If you end the interview before it is completed, you will still receive the gift card.

## **RESEARCH-RELATED INJURY**

If you think you have been harmed from being in this research, contact Scott Torrance Brown at [sbrown@arcofkingcounty.org](mailto:sbrown@arcofkingcounty.org) or 206-829-7035.

Subject's statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, or if I have been harmed by participating in this study, I can contact one of the researchers listed on the first page of this consent form. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098 or call collect at (206) 221-5940. I will receive a copy of this consent form.

---

Printed name

Signature

Date

Copies to:    Researcher  
                  Subject

## APPENDIX D

## Demographic Questionnaire

Name \_\_\_\_\_

Date \_\_\_\_\_

1. Do you identify as a person with autism / autistic? Yes / No

2. Date of birth? \_\_\_\_/\_\_\_\_/\_\_\_\_

3. Gender: \_\_\_\_\_

4. Race and/or Ethnicity (circle all): White Hispanic / Latino Black / African American  
Native American / American Indian Asian / Pacific Islander Other

5. How many siblings do you have? \_\_\_\_\_

6. What do you do for a living (school, work part time, work full time, etc.)?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

7. Household Income (check):

\_\_\_\_ Less than \$10,000      \_\_\_\_ \$10,000 to \$29,999      \_\_\_\_ \$30,000 to \$49,999

\_\_\_\_ \$50,000 to \$99,999      \_\_\_\_ \$100,000 to \$149,999      \_\_\_\_ \$150,000 or more

8. Highest Level of Education Completed (check):

\_\_\_\_ Some high school, no diploma      \_\_\_\_ High school graduate, diploma or GED

\_\_\_\_ Some college credit, no degree      \_\_\_\_ Trade/technical/vocational training

\_\_\_\_ Associate degree      \_\_\_\_ Bachelor's degree

\_\_\_\_ Master's degree      \_\_\_\_ Professional degree      \_\_\_\_ Doctorate degree

APPENDIX E  
How And When Do Caregivers Talk To Their Children About Autism?

Interview Questions

***Interview Questions For Parents:***

1. How old was your child when they were first diagnosed with ASD?
2. Did they find out they had ASD from you or from someone else?
3. How old was your child when you told them they had a disability?
4. How did you feel before telling your child they had autism / were autistic?
5. What did you tell them? Do you remember the words or some of the things you said?
6. Did you talk about disability pride?
7. Did you talk about disability identity?
8. How did they react?
9. How has your view of disability/autism changed since that first communication?

***Interview Questions For Son/Daughter's:***

1. Do you remember when you found out or realized you had autism?
2. What did you feel?
3. Do you remember the first time your parents told you that you had autism?
4. What did your parents tell you?
5. Did your parents talk about disability pride?
6. Did your parents talk about disability identity?
7. What does autism mean to you now?
8. When do you think parents should talk to their children about autism?
9. How do you think parents should talk to their children about autism?
10. What words would YOU use?

