ABSTRACT

LOY, CATHERINE. “Autism Does Not Mean Anything”: Are Parents Re-conceptualizing Autism in Their Own Families? (Under the direction of Dr. Annie Hardison-Moody).

Recent literature has illustrated a shift in how we view neurological differences in those with special needs, most notably autism spectrum disorder. The neurodiversity paradigm posits that neurological differences are biologically advantageous and should be promoted within our society. However, little is known about how this paradigm fits within parenting, family life, and the public sphere (Ozturk et al, 2014). This thesis explores the experiences of parents of children with autism through their parenting choices, advocacy, and their impressions of current societal perceptions. Findings from this study support that parents are incorporating the neurodiversity paradigm into their families in productive ways while continuing to advocate for the same integration of neurodiversity in the professional and public spheres.
“Autism Does Not Mean Anything”: Are Parents Re-conceptualizing Autism in Their Own Families?

by

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DEDICATION

This thesis is dedicated to the memory of my grandfather, J.C. Loy, who taught me to trust in God, my family, and myself. You are forever present in our hearts. I am thankful for your impact, influence, and love that contributed to shaping my life.
BIOGRAPHY

Catherine Loy received her Bachelor of Arts in Psychology at Meredith College. Supporting and advocating for children with special needs and their families is a passion that stemmed from a family member’s autism diagnosis and was further ignited during her academic career at Meredith College, where she worked with children with autism in the Meredith Autism Program. Currently she resides in North Carolina near her family and fiancé. In her spare time, she enjoys spending time with her family and her three cats, hiking, and reading historical fiction.
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“AUTISM DOES NOT MEAN ANYTHING”: ARE PARENTS RE-CONCEPTUALIZING AUTISM IN THEIR OWN FAMILIES?

Introduction

“Autism does not mean anything- autism does not mean anything except a way to handle why people get upset. Having autism doesn’t mean you will always be a certain way or you could never achieve a certain thing. All it means is that you may need different strategies to teach your child.” This quote from Tiffany, a mother of a six-year old daughter and a four-year old son who are both on the autism spectrum, exemplifies the changing needs of families of children with special needs. Parents are adopting new paradigms for understanding their child’s diagnosis, such as the neurodiversity paradigm. This framework allows parents to understand their child’s characteristics as a neurological difference rather than a neurological impairment. In this study, I explore parenting behaviors and public perceptions, and how each of these intersects with the neurodiversity paradigm.

Autism Spectrum Disorder (ASD), commonly referred to as autism, is a neurodevelopmental disorder that appears during a critical developmental period in a child’s life (American Psychiatric Association, 2013). ASD is characterized by deficits in social and communicative behaviors, as well as the appearance of repetitive behaviors and specialized interests (American Psychiatric Association, 2013). The number of children diagnosed with autism has increased significantly since the year 2000. In 2012, about 1 in 68 were considered to have Autism Spectrum Disorder (Christensen et al., 2016). With the increase of children diagnosed with autism, the neurodiversity paradigm is gaining popularity, especially among advocacy groups. These groups advocate for celebrating the uniqueness of those with autism and deemphasizing the focus of any deficits that may be present (Armstrong, 2010). This has become
extremely popular among self-advocacy groups who view autism as a disability rather than a disorder that needs to be treated and cured (Cascio, 2012). The recent influence of the neurodiversity paradigm could promote the development of family centered care and public policies to support those with autism (Cascio, 2012). This study addresses gaps in literature by exploring parenting strategies, family functioning, and public perceptions through a neurodiversity paradigm.

**Literature**

Recent literature on the neurodiversity paradigm is beginning to illustrate a shift in how we view neurological differences (Cascio, 2012). However, more work is needed to understand how a neurodiversity paradigm fits within parenting and family life.

**Neurodiversity paradigm**

There is clear evidence that there is a neurobiological basis for autism (Hill & Firth, 2003). As this research has progressed, a paradigm embracing and supporting neurodiverse brains has emerged alongside it. The neurodiversity paradigm focuses on a social model approach to autism rather than the traditional medical or deficit focused approach (Kapp et al., 2012; Cascio, 2012; Singh, 2016). According to the neurodiversity paradigm, not all variations in the human operating system are maladaptive (Silberman, 2015). The paradigm views autistic individuals as having brains that are simply wired differently, best characterized as a difference in neurological connectivity. There is no evidence to show deficits in neurological function or disorder in those with autism (Baron-Cohen, 2017). From an autistic person’s perspective, a typical human brain suffers from limited attention to detail, is easily distractible, and is needlessly obsessed with social interactions (Silberman, 2015).
Another distinction of this paradigm is the differences placed between neurological impairment and neurological diversity. For instance, autism is viewed as a neurological difference rather than a neurological impairment (Krcek, 2013). Neurological diversity is viewed as a biological advantage therefore changing the perception of unique brains as simply neurologically different rather than impaired because they deviate from the typical (Krcek, 2013). Some autistic individuals, who self-advocate for their disability, hope that parents view their child as an autistic child with their own strengths and differences rather than focus on the loss of a normal child (Krcek, 2013). As the neurodiversity movement has gained popularity, self-advocates and professionals have provided suggestions to make the world friendlier to less typical brains. For instance, a sensory-friendly environment, such as an inclusive school, would consist of quiet areas for students who feel overwhelmed, where distracting sensory input is kept to a minimum. Other accommodations might include sound reducing headphones or sunglasses for light sensitivity (Silberman, 2015).

**Social model & medical model of disability**

Traditionally, practice and research have approached autism and similar disabilities from a medical model focusing on treating and diminishing autistic behaviors. However, there is evidence, seen through the adoption of the neurodiversity paradigm, that a move towards a social model is occurring. In one study parents reported positively viewing their child’s patterns of thought as simply a different variation of thinking rather than a dysfunctional pattern, which falls within the social model (Singh, 2016). Many parents have reported feeling hopeless when faced with only the information provided from medical professionals, especially after a diagnosis of ASD (Singh, 2016). The medical model views the environment and surroundings as unproblematic to functioning of the disabled individual. This model relies heavily on diagnosis
and treatment, as well as use of diagnostic materials such as the Diagnostic and Statistical Manual of Mental Disorders. Thus, the medical model is implying that the disabled person could not be fully productive in society and should be categorized with other groups labeled deficient (Krcek, 2013). Autism has been primarily viewed though the medical model as a form of pathology that requires diagnosis and treatment. However, within the social model, parents are active participants in the path of their child’s life (Singh, 2016). The social model proposes that individuals are disabled through interaction with the environment and surroundings. Society’s role in this model is labeling, inducing, and sustaining disability for affected individuals. At the core of this model is a rights-based perspective that ultimately gives participants a space to advocate for their own needs, and against social exclusion (Krcek, 2013). The social model is positively reframing autism to help children with autism and their families.

**Strengths-based approaches**

In conjunction with the social model, strengths-based approaches are being implemented into services for those with autism. A strengths-based approach draws on the skills, interests, and characteristics of individuals to foster resilience, a sense of self-accomplishment, and increased satisfaction within relationships (Cosden, 2006). The strengths-based approach generally focuses on multiple contexts within the child’s life, including personal characteristics, family characteristics, school strengths, and community resources. Addressing these contexts may also create an attitudinal change in the individual that can increase hope and productivity. The strengths-based approach invites educators and practitioners to move beyond alleviating deficits to focusing on goals that increase the overall satisfaction of life for those with autism and their families (Cosden, 2006). Specific strategies implemented in strengths-based interventions could include positive behavior replacement for disruptive behaviors that would allow the child to
better communicate, using preferences to support greater autonomy, and using high interest areas or repetitive behaviors as shared interests with others (Cosden, 2006). This approach may also suggest a lifetime approach for all ages rather than just for younger children with ASD, where professionals place most emphasis for success (Cosden, 2006).

**Parenting behaviors**

Although there is an abundance of research concerning parenting of typically developing children and even parenting stress for parents of children with autism, little is known about specific parenting behaviors of parents of children with autism, especially concerning strength-based strategies (Lambrechts, 2011). Studies have shown that parents have different strategies for their children with autism that are not always used by those with typically developing children (Lambrechts, 2011).

Often parents of children with autism adopt parenting strategies in direct response to a child’s behavior, which may not always represent a healthy response. Common strategies include reinforcement using material rewards, positive and harsh discipline, and communication patterns. Research also suggests that parents of children with autism respond to specific cognitive impairments with strategies that are less common for parents of neuro-typical children. These might include promoting independence by allowing the child to make their own choices, adjusting the environment by reducing disruptive stimuli, creating a consistent routine, or explaining other’s feelings to their child (Lambrechts, 2011). Another key parenting behavior for those with children with autism is developing an appropriate communication pattern, which can be challenging due to the child’s limitations (Osborne & Reed, 2009). Osborne and Reed (2009) suggest that parents often choose parenting behaviors and strategies based directly on their child’s communication capacities. In another study, Hall and Graff (2011) noted that parents
reported that their children had low adaptive behavior in the communication domain as well as socialization and daily living skills. These challenges influence parenting behaviors and increase parenting stress because of parental concerns, including a child’s limited ability to relate with peers and others. Another challenge for parents is their child’s low adaptive behavior in daily life activities, sometimes seen in limited motor skills by those with autism (Hall & Graff, 2011). Another area where parents of children with autism and those of neuro-typical children differ is the area of play and joint engagement with their child (Freeman, 2013), which later influences social interactions as the child ages. Research suggests that when children with autism play with children of typical development they will observe and learn age-appropriate play skills (Provost, Lopez, & Heimerl, 2007). Parents attempt to employ strategies that will increase their child’s ability to play within an age appropriate level, such as pretend play or turn-taking. However, research suggests that some parents find it challenging to find an appropriate level for their child with autism (Freeman, 2013).

**Parenting stress and perception**

In addition to parenting challenges, existing research has shown that parents of children with autism often report higher levels of stress than parents of neuro-typical children (Hall & Graff, 2011; Ozturk et al., 2014; Osborne & Reed, 2009; Myers et al., 2009; Twomey & Shevlin, 2016) as well as decreased secure attachment levels than typically developing children (Rutgers et al., 2017). Higher parental stress can influence parenting behaviors, which can ultimately lead to poorer outcomes and problem behaviors among children (Osborne & Reed, 2009). Along with this higher stress, parents report feeling social isolation. This isolation is often experienced through the judgments of bystanders in public settings and from extended family members (Myers et al., 2009; Neely-Barnes et al., 2011). Many parents have reported feeling hopeless
based on the information provided from medical professionals, especially after a diagnosis of ASD (Singh, 2016). Despite these challenges, parents have reported positive aspects of having a child with autism such as learning compassion and patience, feeling the child is “a blessing in disguise,” and feeling that the experience enriches their marriage and spiritual life (Myers et al., 2009; Neely-Barnes et al., 2011). Literature suggests that finding meaning in adversity could be a coping strategy used by parents to cope with the stress of parenting a child with autism (Myers et al., 2009). Additionally, many parents continue to push away from the boundaries of deficits presented by the medical model by focusing on their child’s interests and abilities, such as a sense of humor (Myers et al., 2009: Neely-Barnes et al., 2011). As parents push farther from a deficit focus or a medical model, parents advocate and embrace the neurodiversity paradigm by accepting and celebrating their unique child.

Because autism is characterized by impairments in communication, socialization, and repetitive behaviors and interests, parents of children with autism must implement unique strategies and behaviors (National Research Council, 2001). While parents have reported positive aspects of this work such as the cultivation of empathy, joy, humility, and new outlooks, the link between positive parenting perceptions and strength-based parenting strategies is not well known (Ozturk et al., 2014). This study addresses this lacuna through interviews with parents of children with autism. By asking parents to describe their parenting behavior and practices, I examine whether parents are drawing on elements of the neurodiversity paradigm, even if unaware, in their parenting practices. The purpose of this study is to hear experiences of parents of children with autism, to explore if parents are incorporating the neurodiversity paradigm into their parenting practices what might that consist of and what are challenges surrounding those practices.
Methodology

Although the neurodiversity paradigm is becoming more well known in the autism community, not much is known about the paradigm’s influence on family life and family functioning when integrated into parenting styles and behaviors. Are parents incorporating this paradigm into their parenting to better support and teach their child with unique needs? Through interviews and survey data, I asked parents to discuss parenting strategies for their children with autism, their child’s school environment, and how they feel children with autism are accepted in the public sphere.

Procedure

For this study, I recruited participants from local parenting and support groups for parents with children with autism. After initial outreach to these groups, snowball sampling was used to recruit additional participants. From there, I interviewed and collected demographic information for seven parents.

Participants were interviewed individually and in-person. The interviews lasted from 40 minutes to three hours. The average interview time was an hour and a half. The location of the interview varied, but included participants’ homes, offices, and public spaces like coffee shops. Prior to the beginning of the study, an interview guide was developed and tested by the researcher (See Appendix B) and it was pilot tested with three parents of children with autism. No interview questions were reworded or removed based on the initial pilot testing. The questions were created based on existing literature, behavioral characteristics found in the diagnostic criteria for ASD, and the current breadth of parent education and interventions for children with autism. The interview questions were developed to explore the participants’ experience and understanding of the process being studied (Creswell, 2013), which in this study
is the parenting behaviors of parents of children with autism. Duncan (2010) found that using open and closed-ended questions in her research allowed her to gather a more nuanced understanding of the subject she was investigating. Therefore, I used open-ended questions to explore how parents viewed their child’s differences and how they might support their child in various settings including school. Questions that explored parent’s understanding of the perception of those with autism were included to explore the incorporation of the neurodiversity paradigm within public environments.

In addition to the interview, parents completed a demographic and parent survey which consisted of three main portions: participant background information, a parenting styles questionnaire, and a family functioning scale. In the demographic survey, information collected included age, race, gender, income levels, education levels, and employment status. Parents also completed was the short version of the Family Assessment Device (Epstein, Baldwin, & Bishop, 1983) and a parenting style questionnaire (Robinson, Mandleco, Olsen, & Hart, 1995). The parenting style scale was included to analyze parent’s overall parenting style. Family functioning was recorded to assess the big picture of how families are influenced by the differences of a child with autism and parenting choices. Participants provided no identifying information on the parenting scales or demographic forms. A participant code & pseudonym were used during interview memos and transcriptions in lieu of any identifying information that was collected during recruitment. After each interview, I created a memo that allowed me to see the initial themes from the interviews as they emerged.

During the interviews, participants were very open to talking to me about their experiences as a parent. Parents may have felt more comfortable talking about their experiences and feelings about parenting a child with autism because of my personal background with autism.
in my family. This insider status may have allowed me to gain access to information and build a stronger rapport with participants more easily than someone who does not have these similarities (Hesse-Biber, 2014). To ensure rigor, before interpreting the findings I worked with my advisor to create a codebook (Appendix C). We held a series of meetings to discuss the creation of codes, drawing on memo and interview transcripts to establish a codebook, which I used to code all transcripts. To strengthen internal reliability, we each separately coded two of the seven transcripts, then met to discuss our coding. We recoded transcripts as necessary, and addressed any discrepancies. I then coded the remaining five transcripts with these guidelines.

All interviews were audio recorded and transcribed by the researcher. For the analysis of the transcription data, I used a grounded theory approach (Creswell, 2013) to create open and closed codes. Grounded theory allows us to build a theory surrounding the data collected by understanding the process and the steps involved (Creswell, 2013). I created the codebook based on both the iterative themes that emerged and the aims of the study, and coded all transcripts by hand. First, each memo, written directly after each interview, was used to determine broad themes and open codes to begin the coding process. From there, closed codes were created to examine the main aims of the study and develop a better understanding of the process being studied. The codes examined in this thesis include 1) parenting strategies and behaviors parents implement to promote their child’s strengths and positive characteristics, 2) parenting behaviors that (implicit and explicitly) promote neurodiverse brains, and 3) parents’ current understanding of others’ perceptions of children with autism.

Results

Here I discuss the results of my analysis of both sources of data, the qualitative interview with parents, and the demographic information collected from each. Interviews revealed parents
are adopting elements of the neurodiversity paradigm in their parenting behavior and practices, even when not explicitly naming it as such. They are doing so by accepting their child’s differences, modifying surrounding environments, and promoting their child’s strengths. Along with demographic information, I also analyzed family functioning and parenting styles for each parent of this study.

**Participants**

I interviewed seven parents of children with autism. The children ranged from age four to adulthood. Most parents were married with two or more children. One participant was divorced. One participant had only one child. One participant had two children with autism while the other participants only had one child with autism. Participants ranged in age from 38 to 62 years old. All participants reported having either a bachelor or graduate degree. The income levels of participants ranged from $75,000 to $100,000 per year with one participant reported $150,000 per year. All families resided in a southern state of the USA and reported either living in an urban or suburban city. Several participants were homemakers. Other worked full time at a local university and software company. Some participants worked in the healthcare field. For more information about each participant see Appendix D.

**Parenting & family scales**

All participants completed a parenting style questionnaire (Robinson, Mandleco, Olsen, & Hart, 1995) and the Family Assessment Device (FAD), short version (Epstein, Baldwin, & Bishop, 1983). The scores for parenting style and general family functioning can be found in Table 1. Three parenting styles were examined with this scale: authoritative, authoritarian, and permissive. Authoritative parenting is associated with valuing the child’s will but exerting control when needed but without restrictions (Baumrind, 1971). Authoritarian parenting is
associated with aims to shape the child’s behavior based on a set of standards, characterized with obedience and punishment. Lastly, permissive parenting is characterized by few demands, relying on input from the child on decisions and little punishment (Baumrind, 1971). All parents scored as having an authoritative parenting style. The lowest scored parenting style was authoritarian with permissive parenting scoring only slightly higher.

Family functioning scales are used to measure the following: responsiveness, communication, roles, problem solving, involvement, behavior, and control. The FAD examines these domains to better understand the family as a complex system. Research has suggested that some strategies are more effective and healthy for families, such as clear and direct communication rather than passive communication, and following through the problem-solving process when an issue arises in a family (Epstein, Baldwin, & Bishop, 1978). However, less is known about how autism influences one’s ability to use healthy strategies, therefore affecting overall family functioning. For family functioning, the scores ranged between 1.3 and 2.25. A score two or below is considered high or good functioning while a score of two and above is considered poor functioning. Two families scored above a 2.00, with scores of 2.17 and 2.25.

Table 1
*Parenting Style & Family Functioning Scores*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Parenting Style</th>
<th>Family Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sally</td>
<td>Authoritative</td>
<td>1.58</td>
</tr>
<tr>
<td>Jeff</td>
<td>Authoritative</td>
<td>1.30</td>
</tr>
<tr>
<td>Karen</td>
<td>Authoritative</td>
<td>2.25</td>
</tr>
<tr>
<td>Susan</td>
<td>Authoritative</td>
<td>1.92</td>
</tr>
<tr>
<td>Brenda</td>
<td>Authoritative</td>
<td>1.66</td>
</tr>
<tr>
<td>Jean</td>
<td>Authoritative</td>
<td>2.17</td>
</tr>
<tr>
<td>Tiffany</td>
<td>Authoritative</td>
<td>1.91</td>
</tr>
</tbody>
</table>
Interviews

Through these interviews, I learned that parents are adopting the neurodiversity paradigm into their parenting of their child with autism, even if they are not naming it as such. This emerged through discussions of their overall parenting approaches, advocacy and support, and differences in parenting siblings. Some ways parents are adopting a neurodiversity paradigm include adopting a strengths-based approach to parenting, expressing tolerance for differences and adjusting the child’s environment to account for those differences. A table of themes and quotes from the interviews can be found in Appendix E.

Accepting differences

The interviews revealed that one way that parents were adopting the neurodiversity paradigm, even if implicitly, was in how they embraced their child’s differences. This was expressed by most parents, some multiple times during the interview. Jean, a mother of two explained, “I don’t view Chris as being disabled. I view him as being different. I view him as being differently abled.” Jean went on to say, “if we could just view special needs children as we are all unique and that is the way they are unique.” In other words, what makes her son unique are the differences because of his autism. Tiffany, a mother of two young children with autism, said:

People with autism and kids with autism are still just people. Having the way your brain works is no different than having the things that you like different. That it is not as different as you think - its more just a way to teach people differently - I do believe that.

In addition to celebrating their uniqueness, parents also mentioned positive traits of their child’s autism. Brenda, a mother of a son with autism, said, “I think he has a lot of strengths related to his autism. Like when I think through them they are autism traits that happen to be strengths.”
These experiences demonstrate how parents are accepting their children’s differences within their parenting style and parenting behaviors. While most parents talked about celebrating their differences, Sally, a mother of two, said that one important parenting behavior for her was to teach her child “to want to be like everyone else kind of…you know when he really bought into that and wanted to make it work, you know that’s when life got easier.”

Parents spoke of the hope for tolerance for their child(ren) who were different, without putting pressure on them to change or be “normal.” Jean, a mother of two, said, “I would like the people of the community to no treat him like he is that far off from the norm.” Jean, when discussing friendships, said:

Just like you are an individual with your own likes and dislikes and things that make you comfortable and the things that make you uncomfortable. While Chris’s seem to be more pronounced, perhaps it really is all there is about this. It is not only perfectly fine but encouraged you to be his friend. And yes, it is going to be a little bit harder sometimes than perhaps to be with another friend because you are going to have to work at it. But know that even though it doesn’t seem that he is working at it. He is. He is working at being your friend too.

Promoting strengths

A second way that parents are adopting a neurodiversity paradigm in their parenting is by realizing and utilizing their child’s strengths as part of their parenting behavior. Some parents discussed using their child’s strengths as a way for their child to learn or a way to increase social opportunity. Sally, a mother of two, said, “he would read those game manuals so that was a good way to get him to read.” Sally also explained when realizing that her son had autism, “I was like ok just teach him to use the problem-solving ability to compensate for the things that are hard
from him.” Tiffany, a mother of two children with autism, discussed using her children’s strengths to distract her children:

If she gets really upset about something you can calm her down by counting. And sometimes she will be screaming about something and I will just start counting - I will say I am counting by 4s and I will go 4, 8, 12, 16, 21, 25- and she will be like no that’s not right. And it kind of shuts her off for whatever else was upsetting her. So, we use it for our advantage.

When talking about strengths in a social setting, Tiffany, the same mother of two children with autism, also said:

And if a kid with autism has a really good strength exploit it, like if that kid is really good at math bring them into your math group and make them do all the hard problems. Like learn from them. That’s what I think - that should be true of anyone in any group setting. I am all about using your friends and their abilities.

These examples demonstrate how parents are supporting their child’s differences by finding their child’s strengths and using them as tools in multiple settings. Parents are finding ways to use children’s strengths as advantages for their own parenting and for their children in social settings. In addition to overall parenting style, parents described specific parenting behaviors that illustrated how they were using a neurodiversity paradigm, even when not naming it, to teach their children with autism. Brenda a mother of one son with autism, said:

I realized that what we have always kind of done is countdown to be finished. I talk about that we will be leaving soon then I finally get to the point that I say one more fun thing. But yeah, I think since we have discovered that about him it makes our home life fairly smooth I would say - because we are trying to understand him.
When talking about strategies to keep her son on a schedule, Karen, a mother of two, also mentioned the use of a countdown or “a clock…because he takes forever for him to brush his teeth, wash his hands, everything…he would just stand there all day and let the water run on his hands.” Parents overwhelmingly discussed behaviors and strategies that showed tolerance for their child’s differences. These behaviors fall within a social model approach by changing the environment to support the child rather than to focus on the extinction of stigmatized behaviors within the medical model

**Adjusting the environment**

In addition to embracing differences at home, parents discussed ways they advocate and support their child(ren) with autism in other settings, mainly school. When talking about helping her son learn at school, Brenda explained that her son loved pretending that balls were robots from Star Wars which he calls bo-bots. When talking about her son’s school she said:

> They have asked me a lot about his interests and things - you know…Can we instead of counting animals count bo-bots to accomplish the goal that we need to…But at home if I am helping him with his homework I feel like it does help.

Sally, a mother of two, said:

> I always felt like if he communicated I could help him. So, I tried not to be ‘you’re just gonna do this.’ If something was distressing him then I tried to say let’s talk about it, try to tell me. Even when he couldn’t communicate I would try to guess. And encourage him to talk about what it was. I was trying to communicate the idea that if you tell me what is wrong I can help you.

Brenda, a mother of one son with autism, when discussing her personal expectations for her child, said:
I guess I am more of a realist so I know he can improve but if he can’t do something right then, then he can’t do that right then. I don’t push. I just don’t feel like that is the way to go about something to push him into an uncomfortable situation… because I would feel, I don’t want him to not trust me.

In addition to adjusting environments, these parents also used their child’s diagnosis as a form of empowerment for their child(ren). Tiffany, a mother of two children with autism, shared her decision to tell her children about their autism diagnosis as way to better understand their differences. When discussing autism with her son she said, “they both know they have autism, but I am like Sarah’s autism is a lot different than yours - her autism is a lot harder.” She then said, “so when autism month is April, I am like well what is the point in not knowing you have autism, especially when I am telling everyone everywhere we go.” Tiffany talked about an experience at a social group where the instructor suggested using the diagnosis as a kind of icebreaker during social interactions by saying:

She has the kids introduce themselves by saying hi my name is (name), I have autism and I like to repeat myself. And it just breaks the ice in a way that when she does repeat herself everyone is like oh she knows she does that… I don’t think her autism is going to go away and I don’t see any reason to hide it.

Tiffany said that since talking about her children’s diagnosis, her son “approaches his friends more functionally.” This example exemplifies how parents are supporting their children with neurodiverse brains by using her child’s diagnosis as a socializing tool while simultaneously removing stigma associated with children with autism. Her approach promotes overall education about autism by creating a safe place for other children to ask questions, since her children are open about their diagnosis. As she describes it, “the diagnosis is out there and then everyone can
move on.” Susan, a mother of three, talked about helping her older son who has autism to understand his differences. She said, “when we finally got him to talk about it and to listen we really talked about it’s a spectrum. There are some people that are like this, some people that are like that.” Sally, a mother of two, who has an adult son with autism discussed that even now she encourages him to be open about his diagnosis to help him accomplish tasks and navigate the world. When talking about a misunderstanding about a test result between her son and his doctor she said to her son:

Look, you and your previous doctor had this miscommunication because he was trying to be nice to you and you didn’t understand that it was a serious situation so just go in here - I’m plenty smart, I have autism, you need to be direct with me. And he did it.

These examples of parents helping their children understand their diagnosis illustrate a two-pronged approach. These parents are supplying their children with tools to explain their differences while also giving everyone an open space to learn about autism. As many of these parents mentioned throughout their interview, As mentioned by many during interview, several participants feel we, as a society, do not have language to begin to learn and accept these differences. However, being open about an autism diagnosis could aid in creating that space for language and dialogue.

**Differences in siblings**

All but one parent interviewed had multiple children. Parents with multiple children reflected about differences they could see between their neuro-typical child and their child with autism, describing how this influenced their parenting choices. Sally, a mother of two, reflected on her realization that her son with autism did not want the same kind of attention as her neuro-typical daughter:
At first when he didn’t want attention, in a way that was comforting because you know my daughter wanted all the attention and he didn’t want any. Then it kind of dawned on me that even though he didn’t want attention he really needed attention. Things really flipped there for her so I wish I would have had more time with her.

This experience shows how parents with neuro-typical children and children with autism are finding different approaches for each child’s unique needs. For Sally, her daughter wanted her attention and physical affection, while her son did not but needed the attention to develop social and play skills. Other parents went on to say they felt they were overall more lenient with parenting because they had a child with autism. However, there were differences among participants on which child, their neuro-typical child or their child with autism, they were more permissive with. Jeff, a father of four, explained, ‘well the truth is we are far more lenient and accepting of stuff he does that you would never accept from a normal child.’ He explained that his other children recognized this disparity, “and they are used to it now but there have been times - how come Mark blank? How come Mark blank? Because Mark has autism.” In contrast, Karen, a mother of two sons, explained that she felt she was permissive on her oldest son, who she explained has been instrumental in the care for her younger son with autism:

My older son, I have been a little more lenient on him because he has helped so much…But I think it has made him grow up faster. But he has to do so much that I really haven’t been too hard on him. I try to give him a break on some of the chores in the house because he has to do so much.

Parents talked about finding a parenting approach that worked best for each child. Susan, a mother of three, said “balance and consistency are big.” Jean, when discussing both her children not just her child with autism, said:
I guess I kind of learned growing-up that you have to figure out not only punishment but how you encourage your child to do and what you discourage them from doing. What works for them…Yeah figuring out what works and what doesn’t work for each child. Parents reflected on parenting their neuro-typical child and child with autism differently by modifying their parental expectations. This finding shows that parents are drawing on the neurodiversity paradigm, even for their neuro-typical children, by realizing that parenting must be unique for each child.

External challenges

Despite the benefits these parents found in adopting a neurodiverse or strengths-based approach to parenting, they also discussed the external factors that made this difficult, including societal perceptions and misconceptions about those with autism. Multiple parents reported feeling judged by others in public. They felt that when their child with autism was upset about something that parents were judged on their parental responses. Brenda, a mother of one son with autism, talked about her son’s response to a loud car alarm during a beach vacation, by saying:

But I still feel like the general public is going to view those temper tantrums and like I’m not a good parent because I am not saying you know need to whatever, you are going to get something taken away if you don’t calm down.

Karen, a mother of two sons, echoed Brenda’s feelings, explaining:

I think the community is helpful and understanding, but the general public, I still don’t think people are educated about it. When we did take him places and he would act up, they thought it was behavioral. And it was very unfortunate. My older son would say oh he is autistic. And I still don’t think they understood what it was.
These parents describe their experiences with environments that are unsympathetic toward their child’s unique needs, characterized by the medical model. These environments are in direct opposition to the tolerance shown in their homes. This disconnect can be challenging for both the parent and the child. Parents expressed a hope for education so others can better understand what autism looks like and how to support families. Several parents had specific examples, even with their own families, about a lack of understanding of the variation and uniqueness of those with autism. Brenda, a mother of one son with autism, touched on this misconception several times when discussing all the things people have said to her about her son, such as “oh he can’t have autism because he is so social.” She later stated that her in-laws made a similar comment when they said, “but he is so smart.” Brenda also expressed “I would say I don’t feel it is well accepted. Or it is accepted as long as it is in the framework that someone else imagined.” She also talked about feeling like her son’s school does not support his visual sensory needs:

That idea of society thinks of sensory issues and autism and it is just not...maybe people think they are being supportive by being open to those things we are learning about weighed blankets and all of those. But if it doesn’t fall into those exactly then people aren’t accepting of it.

These experiences illustrate the current disconnect between parents who wish to support the neurodiversity paradigm and professionals who are still operating under a medical model. Possibly because of the lack of understanding, parents also expressed feeling that there was a lack of inclusion for those with autism and their families. Susan, a mother of three, talked about her experience on field trips with her son where “other parents act like your child and you are aliens and they have no idea how to treat you. So, they are just going to ignore you. That is the worst thing.” Susan, when talking about after school activities for her son, said, “he is never
going to fit into like a - you know I don’t even know if there are kind of specialized special needs school programs but he wouldn’t fit in there if there were. And he doesn’t quite fit into a typical group.” Susan went on to say there were times she did not feel that she belonged:

It is this weird polarizing thing where other parents…some parents’ perspectives you don’t really count. You’re not really in our world. I am. I need and he needs to be accepted. Because we don’t fit in anywhere as it is. It is tough.

Jean, a mother of two, echoed Susan’s feelings when she explained her experience finding out that her son was the only child from the class not invited to a peer’s birthday party:

I wish people knew that our children are just children. There are a lot of things they are just not capable of saying. And that is one of them. If you are going to invite the whole dog-on classroom please invite me too.

She went on to say that “if people just understood that regardless of what the child’s special need is, they are still children first.” Parents also discussed unrealistic expectations expressed by others, possibly due to misconceptions or lack of knowledge of autism. Jean, a mother of two, explained “You are asking him to do something that he cannot do. It is just the way he is constructed.” Karen, a mother of two sons, discussed her sister’s unreasonable expectations and confusion on why this parent would go to such lengths to ensure her son was comfortable at home. She explained “my sister tells me ‘he needs to do whatever’ well no - he can’t do that. He is autistic. What are you talking about?” These experiences exemplify the common misconceptions of those in the public sphere that influence parenting choices for these parents.

Parents in this study talked about the negative impacts for both themselves and their children, especially social isolation. This finding, that public perception did not support the neurodiversity
paradigm is in direct opposition to how parents are using the neurodiversity paradigm to support their unique child at home.

**Discussion**

Although the neurodiversity paradigm is becoming more well known, traditionally, most research and practice for those with autism focuses on deficits (Krcek, 2013). In this study, I gathered qualitative and demographic information to understand parents’ experiences of parenting a child with autism by asking them to reflect on what their parenting style looks like at home, at school, and in the public sphere. I invited parents to share parenting choices and describe their experiences with educators and others in the community. Through these conversations, a picture of what neurodiverse parenting might look like emerged.

From this study, we can see that parents are using the neurodiversity paradigm with their parenting choices with their children with autism. In this study, neurodiverse parenting was seen in how parents approached their child’s unique needs and created the best environment to raise and teach their child. Susan, a mother of three, described how she provides reasoning behind her requests or rules, especially for her child with autism so that he can better understand the expectations. Jean, a mother of two, acknowledged that her child’s “brain just doesn’t work that way,” and that sometimes her child is asked to do something “that he simply cannot do.” Current research suggests that parents of children with autism use permissive and authoritarian parenting behaviors due to parenting stress and a lack of perceived control of child behaviors (Hutchison, 2016). This parenting stress has been associated with poor child outcomes (Osborne & Reed, 2009). However, this study suggests that neurodiverse parenting, seen in these parents, parallels authoritative parenting. Authoritative parenting, which is associated with positive outcomes for children, is characterized with a verbal give and take, recognizing the child’s autonomy, self-will
and needs, as well as restrictions not based solely on parental control (Baumrind, 1971). Parenting choices and behaviors discussed by the parents of this study reflect both what a proposed neurodiverse parenting style might include as well as an authoritative parenting style through striving to understand their child’s differences and choosing their parental responses accordingly. This finding suggests that because of the similarities between authoritative parenting and the neurodiverse parenting described by these parents, parenting with the neurodiversity paradigm could yield similar outcomes for both parents and children. Since these parenting aspects are associated with better child outcomes, it could also suggest that parenting stress would reduce as well. Brenda, a mother of one son with autism, suggested this idea when talking about choices that helped her son understand his environment which ultimately made her and her son’s home life easier, and reduced her stress.

Parents also rejected a medical model approach to autism and seemed to move towards a social model approach to their child’s diagnosis. Some parents chose to tell their children about their autism diagnosis to help children functionally approach situations and others. While commonly used to label, stigmatize, and treat within the medical model, these parents are using the autism diagnosis as a tool to empower their child. Tiffany, a mother to two children with autism, explained that by telling her son about his and other’s autism he can better identify his own needs and others’ needs. Additionally, by being open about their diagnosis, these families are creating a safe space for dialogue and for others to learn. This parenting choice puts into practice one of the tenets of the social model, by allowing parents and children to be active in the path of their child’s life. Because parents are making this choice, this suggests that a similar approach to a diagnosis could be effective for professional’s identification of unique needs rather than medical treatment alone.
This finding directly parallels with a proposed historical model of approaching and diagnosing autism described by Temple Grandin. When discussing historical and possible future shifts in professional diagnostic criteria and treatment of those with autism, Grandin describes a shift from using the diagnostic label to group people to using the label to examine characteristics to be followed by appropriate professional responses. As Grandin explains, “phase-two thinking says, lets group people together by diagnosis. Phase-three thinking says, forget about the diagnosis, forget about labels, focus on the symptoms” (Grandin, 2013, p. 114). This has serious implications for professionals, “because thinking about individual symptoms on a symptom-by-symptom basis will eventually allow us to think about diagnosis and treatment on a patient-by-patient basis” (Grandin, 2013, p. 115). The current study suggests that parents are either already or beginning to embrace a paradigm that brings families into what Grandin refers to as phase-three, where symptoms are being evaluated rather than used as a label. In addition to how parents approach symptoms with professionals, in this study we can see that parents are embracing the neurodiversity paradigm even if not naming it as such. This is seen in parents’ choice to find a unique parenting style that works for each child and in their advocacy for their children with autism. Although parents are doing this, the public sphere may still be operating under a medical model dominated by ineffective labels as a way of understanding those with autism.

This study suggests that within the public sphere, external factors and misconceptions influence parents’ choices for their children with autism. In this study, parents discussed a multitude of misconceptions about their children with autism including a lack of understanding about autism, the misconception between cognitive impairments and autism, and unrealistic expectations from others. One large misconception felt by parents in this study was that others perceived them as bad parents based on their responses to their child’s behaviors. As Brenda, a
mother of one son with autism, put it “the general public is going to view those as temper tantrums and like I’m not a good parent because I am not saying you know need to whatever.” However, in direct opposition to this misconception, this study found that parents are using a parenting style similar to authoritative parenting which is associated with positive child outcomes. This might suggest an issue lies not with poor parenting behaviors but with a lack of understanding on the public’s behalf of the differences and needs of those with autism.

Parents in this study experienced confusion around the medical model’s label of autism, lamenting the lack of understanding of autism and the differences that come with this diagnosis. As disability studies theorist Rosemarie Garland-Thompson writes, people who are differently abled “are expected to look, act, and move in certain ways so we’ll fit into the built and attitudinal environments. If we don’t, we become disabled” (Garland-Tomson, 2005, p. 524). Parents expressed this frustration too, noting that when their child moved differently, say in response to a sensory stimulus, people responded unsympathetically and viewed the incident as bad behavior. This finding illustrates the disconnect between the social model that parents are embracing for their children with autism and the medical model that the public is using to label the same children with autism. Parents expressed feeling judged for their children’s behaviors and then on their parental responses, and ultimately feeling they did not belong for both parents and children due to these misconceptions. This profoundly affected parenting choices surrounding social interactions. Several parents in this study talked about planning trips or outings in lieu of a school related event because they felt their child would not be included, not just by their peers but by parents and educators alike. Overall, this suggests that people within the public sphere are evaluating these children with a medical model label rather than looking at the individual and their needs. This finding is in-line with pervious literature, that parents of
children with autism feel social isolation because of family and bystander judgements on parenting choices (Myers et al, 2009; Neely-Barnes et al., 2011).

These external factors influence the parenting and advocating choices of these parents. This study suggests that parents are incorporating neurodiversity into their families but the public makes this difficult. Not only are the parents in this study moving on to a social model by focusing on symptoms rather than their child’s diagnosis, but they are reevaluating what disability looks like not just in their family but in the public sphere. From this study, an important parallel between the neurodiversity paradigm and disability studies can be seen. This paradigm represents a framework for reimagining disability, as discussed by Garland-Thomson (2005), for families with children with special needs. She explains:

Reimagining disability in this way accomplishes important cultural work. First, it shows disability as a significant human experience that occurs in every society, every family, and most every life. Second, it helps us accept that fact. Third, it helps integrate disability into our knowledge of human experience and history and to integrate disabled people into our culture (Garland-Tomson, 2005, p. 524).

Children with autism often do not behave as their neuro-typical counterparts, making them seem “dis-abled” in the eyes of an unsympathetic environment. However, parents are reimagining disability through their parenting choices. Parents are utilizing strengths related to their child’s autism as traits that will make them successful and removing the stress of extinguishing behaviors traditionally thought of as negative. Finally, parents are creating conducive environments to promote their unique child’s success.

This study suggests that by embracing the neurodiversity paradigm, parents are moving away from the more traditional medical model that labels their child as disabled. Instead, they
are choosing to celebrate their child’s differences in their parenting. Parents who are implementing neurodiverse parenting behavior are laying the framework for reimagining disability within a family system. To reimagine disability in a way that differences are not only tolerated but accommodated within the environments in our society creates a successful model for advantageous neurodiversity. These parents of children with autism are asking the right questions to begin creating an inclusive world, where disability carries no stigma. These parents provide apt models for academics and family practitioners who are looking to move towards a more inclusive world where those with neurodiverse brains are understood as different rather than disabled.

**Limitations**

There are several limitations to the current study, one being the small number of participants. However, the small number of participants allowed me to better understand in-depth the experience of parenting a child with autism. A broader survey or larger sample would allow for a generalization of concepts heard from these participants. As such, I have developed a quantitative survey to reach more parents of children with autism. A second limitation is that parents were not directly asked about the level of functioning of their child. Therefore, future studies should investigate how functioning level might influence parent’s ability to parent under the neurodiversity paradigm. All participants of this study reported an authoritative parenting style. Some may have reported this to please the researcher and to report parenting behavior that is more socially desirable. However, in the interview process, I was able to see parents using an authoritative parenting style through communication patterns with their children and allowing the child to develop autonomy and independence. Lastly, most participants of this study were from high income and high education background which could influence their parenting styles.
Future studies should examine if and how lower income families are embracing the neurodiversity paradigm. Research has found that lower income families have different barriers to overcome to receive services for their child with autism, such as transportation and insurance (Carr & Lord, 2016). Because their ability to advocate for their child may be different, their parenting choices may also be different than those with higher incomes and therefore the response of the professionals should adjust accordingly.

Conclusion

Parents of children with autism offered great insight into parenting behaviors and the experience of having a child with autism. Parents described a parenting style that paralleled neurodiverse parenting and authoritative parenting. Parents are creating a unique parenting style to meet the needs of their child with autism, including accepting their child’s differences, promoting strengths, adjusting environments, and using their autism diagnosis as a functional tool for their child. This study highlights the way parents are embracing the neurodiversity paradigm and beginning to reevaluate disability within their own families. Additionally, this study shows that parents encounter external factors from the public sphere, including misconceptions, judgement, and a lack of understanding surrounding autism. As parents begin to operate under a new paradigm, this study suggests that it could be not only helpful but necessary for professionals to incorporate these aspects into their practice by operating under a more tolerant paradigm. A paradigm that views neurological differences as advantageous and views children as individuals rather than labels to capture all the teachable moments for these children. This shift in thinking also provides a framework for disability studies and family research to examine together what a society without disability might encompass.
REFERENCES


doi:10.1111/jcpp.12703


APPENDICIES
Appendix A

North Carolina State University
Informed Consent Form for Research

Title of Study: Parenting styles, coping strategies, and celebration among parents of children with autism.

Principal Investigator: Catherine Loy (celoy@ncsu.edu or 919-608-0504)
Faculty Sponsor: Dr. Annie Hardison-Moody (amhardis@ncsu.edu or 919-515-8478)

Dear Parents,

As a parent of a child with autism, you are being asked to participate in a research study by Catherine Loy, a master’s student at North Carolina State University.

The purpose of this study is to better understand the parenting styles and coping strategies of parents of a child with autism as well as ways parents celebrate their child.

Here are a few things you should know about research:
Your participation in this study is voluntary.
You have the right to choose not to participate or to stop participating at any time.
You will not receive any compensation for participating in this study.

What will happen if I take part in this study?
If you choose to participate in this study, you will take part in an in-person interview between yourself and one other person. The interview will take between 30 minutes and 1 hour. The interview will focus on your personal experience being a parent of a child with autism.

What are the risks & benefits?
While you will be sharing your parenting behaviors, the information collected will not be paired with any identifying information you choose to provide. If any question makes you uncomfortable or you are unwilling to answer it, simply express that during the interview and the questions will be skipped. This interview will be recorded. The recording and any notes collected will be stored on a private computer that is password protected. Your name will not be stored with any of your interview or survey responses. It will also be kept in a password protected file on a private computer. There may not be direct benefits to you as a participant, but the findings of this study will increase our understanding of parenting styles and celebration of children with autism.

Confidentiality
The information collected in this study will remain confidential. This information will be seen only by the principal investigator and faculty sponsor and not published with any other results of the study. The results of the study will be stored on a private computer in a password protected file. Your contact information will not be paired with any information you provide in the
interview. If results are published your identity will not tie to the information that you have provided.

**Compensation**
You as a participant will not receive any compensation for this survey.

**What if I have questions?**
If you have any questions at any time about the study or procedures, you may contact either Catherine Loy (celoy@ncsu.edu or 919-608-0504) or Dr. Annie Hardison-Moody (amhardis@ncsu.edu or 919-515-8478) at any time. Additionally, if you feel that you have not been treated according to this form or your rights as a participant have been violated during this project, please contact Deb Paxton, Regulatory Compliance Administrator, Box 7514, NCSU Campus (919/515-4514).

*I have read and understand the above information. I agree to participate in this study with the understanding that I can choose not to participate and stop participating at any time.*

Participant Signature: ____________________________  Date: __________________

Investigator’s Signature: __________________________  Date: __________________
Appendix B

Background Information

1. What is your age?___________________

2. What is your gender?___________________

3. What is your race or ethnicity?___________________

4. What state do you live in?_____________

5. How would you categorize the region where you live?
   1. Rural
   2. Urban

6. What is your employment status?
   1. Part time
   2. Full time
   3. Homemaker
   4. Unemployed
   5. Retired
   Other___________________________

7. What is the highest level of education that you have completed?
   _______ Less than high school
   _______ High school diploma or equivalent
   _______ Some college but not degree
   _______ Associate degree
   _______ Bachelor degree
   _______ Graduate degree

8. What is your total household income per year?
   _______ Less than $20,000
   _______ $20,000 - $34,900
   _______ $35,000 - $49,900
   _______ $50,000 - $74,900
   _______ $75,000 - $99,900
   _______ $100,000 - $149,900
   _______ $150,000 or more
**Interview Questions**

1. What do you think is your child’s greatest strength?

2. What type of play activities, toys or games does your child enjoy the most?

3. Tell me about your child’s special interest area(s) or enthusiasm(s)?
   a. Probe: this could be an interests, hobbies, games or topics of interest
   b. Tell me about how your family supports this interest area or enthusiasm?
   c. Tell me about how your child’s school supports this interest area or enthusiasm?

4. Tell me about your child’s IEP plan.
   a. Probe: How do you think your child’s IEP plan aids in your child’s development?
   b. Tell me what you might add or change to improve the plan?

5. “Often big transitions are hard for children with autism.” Tell me about how your child deals with transitions.
   a. When your child is going through a transition, how does your family support him or her?
   b. How about your child’s school?

6. Tell me about any sensory needs or sensitivities your child might have.
   a. How does your family support your child’s sensory needs?
   b. How about your child’s school?

7. How do you think the way you parent might differ for your child with autism? (*if participant has more than one child*)

8. How would you describe your strengths as a parent?
   a. How would you describe the areas where you might struggle?

9. How do you as a parent support your child’s strengths?
   a. Probe: What makes this challenging/difficult?

10. How do you think your local community perceives your child and others with autism?
    a. How has this changed over time?

11. What questions would you want your friends and family to ask to help understand your child or to support you?

12. What do you hope other parents tell their children about children with autism?
Appendix C

**Code: Strengths**
Definition/When to use: Participant’s discussion or experience with viewing or implementing their child’s strengths as resourceful and resilient in the face of their child’s ASD and by allowing their child to be part of his/her own care.

Do not use this code with mention of therapies or interventions, unless they also pertain to parenting behaviors. This code focuses on parenting behaviors.

Example: When AA discussed recognizing her son’s propensity for problem solving and using that skill as a tool to approach other dilemmas.

**Code: Neurodiversity**
Definition/When to use: Participant’s discussion or experience with neurodiversity, even if not explicitly mentioned including promoting the differences and uniqueness of their child with ASD, a lack of desire to remove or diminish autistic characteristics, and advocating for their child and his/her unique care needs.

When not to use with mentioned of strengths or therapies/interventions

Example: When BB discussed the Holland analogy—that a child’s ASD is not a horrible thing but just different.

**Code: Parenting behaviors**
Definition/When to use: Participant’s discussion or experience with specific behaviors for parenting their child with ASD including communication, discipline, or creation of a specific environment that best suits their child.

Do not use with mention of therapies/interventions

Cross Codes: Strengths, Neurodiversity

Example: When CC discussed being able to create an environment at home that works best for her son with ASD—such as keeping the light dim or not watching TV until he is asleep. When BB discussed the challenge of disciplining his son with ASD for a poor choice because he would not understand the antecedent.

**Code: Perceptions (societal & social isolation)**
Definition/When to use: Participant’s experience and discussion of public/societal perception of families and children with ASD, including positive and negative experiences. Also includes aspects of social isolation.

Do not use this code with mention of participant’s feelings or social isolation.
Example: When AA discussed that because her son is high functioning that people might not realize that he has autism

**Code: Diagnosis**
Definition/ When to use: Participant’s experience or discussion of their child’s initial diagnosis with ASD and the discussion of telling their child of their diagnosis

Do not use this code when discussing therapies or interventions

Example: When AA discussed the process of receiving her son’s ASD diagnosis after several evaluations and different diagnoses.
Appendix D

Sally

Sally is in her late fifties and a mother of two children. Her son, the oldest was diagnosed with autism as a young child. Her son who has autism is currently finishing his master’s degree at a local university. She is married. She lives in an urban city where she works full time at a software company. Although she works full time now, she worked part time when her children were younger.

Jeff

Jeff is 45 years old and the father of four children. He has three sons and one daughter. The third child, a son, was diagnosed with autism accompanied with an intellectual disability when he was a young child. His son with autism is currently in middle school. He is married. He lives in an urban city and is a professor at a local university.

Karen

Karen is in her early forties and is the mother of two children, both sons. Her youngest son was diagnosed with autism as a young boy. Her oldest son, who will graduate high school this year, is a great help to her with the care of her youngest son, who is currently sixteen. She is divorced but shares some responsibilities for her son with autism with her ex-husband. She works full time at a local university, where is participates in a support group for parents with children with special needs. She is worried about carrying for her son and working full time once he graduates high school.

Susan

Susan is in her early forties and is a mother of three. Her oldest child, a son, was diagnosed with autism when he was in early elementary school. Her son is currently in middle school. She is currently a homemaker and is active in the local autism community, including support groups and volunteer groups. However, she hopes to go back to school and continue working as her children get older. She is married.

Brenda

Brenda is forty-one and is the mother of one son with autism. She is married and lives in a suburban city. Currently she works part time at a local university assisting with research with new mothers. She is also self employed as a doula.

Jean

Jean is in her early sixties and is the mother of two children. She is married, to her second husband. Her daughter, from her first marriage is about ten years older than her son. Her son was diagnosed with autism when he was entering kindergarten. She works full time as a cardiac
nurse. However, when I met her she was healing from a broken arm and was unemployed at the time.

**Tiffany**

Tiffany is in her late thirties and has two children who have autism. She has a daughter who is six and a son who is four. Both children were diagnosed when they were very young, around two or three. She was a lawyer before she had children but now is a homemaker in a suburban city. She is married. She is also active in the local autism community.
## Appendix E

<table>
<thead>
<tr>
<th>Group</th>
<th>Theme</th>
<th>Participant Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strengths-based parenting</td>
<td>Accepting differences</td>
<td>“I don’t view (child’s name) as being disabled, I view him as being different. I view him as being differently abled.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“But I would like the people of the community to not treat him like he is so far off of the norm.”</td>
</tr>
<tr>
<td></td>
<td>Promoting strengths</td>
<td>“I think he has a lot of strength related to his autism, like when I think through them they are autism traits that happen to be strengths.”</td>
</tr>
<tr>
<td></td>
<td>Specific strategies</td>
<td>“I need to prep- so they do poorly with them (transitions) but I have everything down to a science.”</td>
</tr>
<tr>
<td>Expressing tolerance for differences</td>
<td></td>
<td>“So, they have asked me a lot about his interest and things, same thing. Can we instead of counting animals count ‘bo-bots’ to accomplish the goal that we need to...But at home if I am helping him with this homework I feel like it does help.”</td>
</tr>
<tr>
<td></td>
<td>Encouragement</td>
<td>“But I always felt like if he communicated I could help him. So, I tried not to be ‘you’re just gonna do this’...and encourage him to talk about what it was. I was trying to communicate the idea that if you tell me what is wrong I can help you.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“And I do as a philosophy on parenting that they do know you are there for them.”</td>
</tr>
<tr>
<td></td>
<td>Self-Empowerment</td>
<td>“And that is finally when we got him to talk about it and to listen we really talked about it is a spectrum. There are going to be some people like this and some people that are like that.”</td>
</tr>
</tbody>
</table>
Differences between children

“At first when he didn’t want attention in a way that was comforting because you know my daughter wanted all the attention and he didn’t want any. Then it kind of dawned on me that even though he didn’t want attention he really needed attention. Things really flipped there for her so I wish I would have had more time with her.”

External factors

Judgements

“But I still feel like the general public is going to view those as temper tantrums and like I’m not a good parent because I am not saying you know need to whatever.”

Lack of understanding & unrealistic expectations

“I have had people ask me, and fortunately not in front of him, and of course they used the word retarded. No and he is smarter than you are. Because I can tell because you are using those kinds of words so your IQ isn’t too high-and his is.”

“A lot of people tell me that-my sister tells me ‘he needs to do whatever’- we no, he can’t do that. He is autistic. What are you talking about.”

Lack of inclusion and feelings of not belonging

“Uhh. when you are in a social setting like a class trip, field trip, where other parents act like your child and you are aliens and they have no idea how to treat you. So, they are just going to ignore you. That is the worst thing.”

“He is never going to fit into like a- you know I don’t even know if there are specialized special needs after school programs but he wouldn’t fit in there if there were, and he doesn’t quite fit in in a typical group.”