5-2015

Understanding the Role of Support Groups in the Lives of Parents of Children with Autism Spectrum Disorders

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Understanding the role of support groups in the lives of parents of children with Autism Spectrum Disorders

An honors thesis presented to the Department of Anthropology University at Albany, State University Of New York in partial fulfillment of the requirements for graduation with Honors in Anthropology and graduation from The Honors College.

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April 2015
Abstract

The birth of a child with disabilities forces parents to rewrite narratives of family and what it means to raise a child with disabilities. Parents of children with Autism Spectrum Disorders (ASD) often find that their child’s behavior and development makes it difficult to relate with parents of typically developing children, and so support groups become a place to find parents who share similar experiences. This study examines the role of support groups in the lives of parents of children with ASD. It asks how the support group differs from other sources of support and relationships, what information is sought from the support group, and how the support group itself has helped parents as they rewrite their narratives of themselves and their children. Although only three mothers participated in the study, their responses indicate that the support group they belong to has had a significant impact on how they view their child with ASD, their ability to connect with parents who understand their challenges and concerns, and how they are moving forward in crafting their narratives as mothers of children with ASD.
Acknowledgments

I would like to thank Dr. Elise Andaya for her invaluable support throughout this process. She has taught me so much about conducting a study and crafting a narrative, and I truly appreciate all that she has done. I have been lucky enough to have taken classes with her since my first semester in college, and throughout that time she has fostered my love for cultural anthropology and taught me new ways of viewing the world around me. I am so happy that I had the chance to work with her on my thesis.

I would also like to thank Dr. Jeffery Haugaard. He has given me so many amazing opportunities as part of the Honors College, and his support this past year has been particularly meaningful to me.

I would like to thank the children with ASD that I have cared for, who inspired me to look into this topic. Their needs and abilities, and how they interacted with the world around them, opened my eyes to both the challenges and joys of working with children with special needs. I would also like to thank the mothers who took the time to participate in my study and who were willing to speak about difficult and at times sad topics.

Finally, I would like to thank my parents for their love and support. My love of learning started at a very young age, and they have always been there to encourage me to keep exploring, which I think played a huge role in my interest in anthropology today. Words will never be able to express how much they mean to me, but I want to tell them that their belief in me and the love they have shown has encouraged me to imagine, to explore, to learn, and to help others.
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INTRODUCTION

It’s another busy day at the local children’s museum. Children don construction helmets and wield plastic hammers as they build a house. The play kitchen is bustling. Nearby, several kids and their parents work together figuring out how to get a ship down a canal using a series of locks. The rice table is, as always, a popular destination. Children dress in the traditional outfits of different cultures (sometimes at the same time as they put on their construction gear). It’s noisy, but that’s normal for Explore & More. This is a museum that believes play is just as important as learning, and that the two can go hand-in-hand. The kids at the museum are figuring things out, whether it’s how a pulley system works, looking at fossils, finding out about a new culture, or just learning how to share as they harvest vegetables and go fishing.

This could be any day at Explore & More, except for a few things. For one, a happy Golden Retriever is here, making his way through the museum with his handler. He’s a therapy dog, and a huge hit with the kids. When an older child has a meltdown that’s more reminiscent of a toddler’s outburst, none of the other parents shoot disapproving glances towards the child’s parents for his behavior. Instead, their expressions are full of understanding and sympathy – they know too well what it’s like to experience a child’s outburst in a public place. The families here right now all share one very important aspect of their lives – they are all families of children with Autism Spectrum Disorders (ASD). Tonight is what the museum calls “Au-Some Evening”, a night where the museum opens for the families of children with ASD. It’s an opportunity for families to relax, for children to play in an environment that isn’t quite as chaotic as a typical day at Explore & More, and for siblings of children with ASD to meet other kids
who share similar experiences. Most of all, it’s a chance for children with ASD, their siblings, and their parents to enjoy being a family without parents having to explain their child’s behavior to people who don’t understand what it means to have a child with ASD.

The opportunities that Au-Some Evenings provide piqued my interest. I wanted to discover how parents found out about this and other ASD-friendly events. Explore & More is about twenty minutes from the city of Buffalo, and further from the more populated area north of the city. Although parents who frequented the museum would find out about Au-Some Evenings through their visits, I was curious how other parents found out about it. As I learned more about the event, I found out that a leader of a local support group for parents of children with ASD had been closely involved in the development of Au-Some Evenings. From there, my interest turned to understanding what role support groups play in the lives of parents of children with ASD.

Children with ASD face a number of challenges in their emotional, social, and academic development. Their parents often bear the brunt of the difficulties their children experience. Having a child who acts differently than others their age, and whose future is often uncertain, places many of these parents in a position where they feel isolated from parents of typical children. Support groups for parents of children with ASD give these parents an outlet where they can discuss both the challenges of raising a child with ASD and their own feelings regarding coping with a diagnosis of ASD and the associated feeling of isolation. They create a safe environment where admitting feelings of hopelessness or speaking of the challenges parents face on a daily basis can be done without fear of judgment or criticism. These support groups come to play an important
role in allowing parents of children with ASD to talk about their parenting experiences with others who have had similar experiences.

OBJECTIVES

The goal of this project was to look at the role support groups played in the lives of parents of children with ASD. The current anthropological research on this topic is limited. However, the unique challenges presented by ASD, for those diagnosed with ASD as well as their families and communities, have recently become topics of interest for anthropologists. One of the defining characteristics of autism is an individual’s inability or difficulty relating themselves to everyday situations, as well as impaired communication (Sterponi and Fasulo 2009). However, as ASD has been researched further, it becomes clear that children with ASD can and do communicate and interact with the world around them, albeit not always in the ways used by typically developing children (Sirota 2010).

Other research examines how individuals with ASD have sought to create communities of their own in which they can resist biomedicine’s negative view of disability, and have instead looked to transform the notion of what being an individual with ASD means (Bagtell 2010). This research, as a whole, is important to take into consideration when looking at the challenges faced by parents of children with ASD. In particular, it can illustrate how dominant societal views on what it means to have ASD can make it difficult for parents to accept and understand their child’s diagnosis. It is
here that support groups play an important role in connecting parents and allowing them to share challenges, experiences, and concerns.

In speaking with members of the Buffalo Parent Group for Parents of Children with Autism Spectrum Disorders, I hoped to discover: (1) why parents sought out support groups; (2) their experiences prior to and following joining these group; and (3) what resources they seek out through the group. Focusing on a single support group allows for multiple perspectives on what that particular group offers parents. Although I was only able to hold a few interviews, the findings show how important the Buffalo support group was in the lives of parents with children with ASD. While this research did provide insight into the original objectives, the concern, challenges, and successes expressed by parents pushed me to expand this project beyond its original scope.

LITERATURE REVIEW

PARENTING THE ‘IMPERFECT’ CHILD

With the rise of technology that allows for advanced pre-natal screening and extensive care following birth, the narrative of being a parent to a disabled child has changed dramatically in recent years. Prenatal screening is presented to parents as an invention that allows them to make more choices about their reproduction themselves, without large amounts of interference from health care professionals (Gammeltoft 2014:109). Rapp (1999) focuses on the increasingly routine nature of pre-natal screening. While screening allows doctors and parents to learn a great deal of information about their child’s genetic health, a positive result for a fetal problem can mean that parents have to make a difficult decision about whether or not to abort the
pregnancy. This in turn creates a view of disabilities that is relatively new. Now, parents have the choice of whether or not they want to bring a child with disabilities into the world. Rapp found that the majority of the women she interviewed about pre-natal testing had decided, prior to getting the test results, that they would abort the pregnancy should they be given a diagnosis of Down’s syndrome (1999:129).

Pre-natal screening, therefore, holds the promise that having a “perfect” child, defined as not having a disability, is both possible and desirable. Having this perfect child means fewer concerns about the financial and emotional burden of raising a child with a disability. Although not necessarily true, the idea of a perfect, non-disabled child seems to suggest that life will be easier and that both parents and child will face fewer obstacles in the child’s development. A number of parents expressed an unwillingness to have a child with Down’s syndrome due to what they felt would be a lack of a relationship with their child. One participant said, “I would feel grief, not having what I consider a normal family.” Another said, “I have an image of how I want to interact with my child, and that’s not the kind of interaction I want, not the kind I could maintain.” A third stated, “I’m sorry to say I couldn’t think of raising a child with Down’s. I’m something of a perfectionist” (Rapp 1999:134). Each of these parents wanted a perfect child in the sense of a child without disabilities, and pre-natal screening allowed them to make the decision to not give birth to a child with disabilities. Not wanting to have a child with disabilities was explained through a narrative of loss in terms of the extent of the interactions and relationships parents could form with a child with disabilities and the time and effort that would go into raising a child with disabilities (Rapp 1999:135).
The growing belief in the possibility and desirability of having a perfect, non-disabled child thanks to advances in medical technology and testing is at direct odds with another growing movement. Increasingly, people with disabilities, their families, and their friends and communities are calling for an acceptance of disabilities and for people to see that being disabled is not inherently a bad thing (Bagtell 2010). They wish for people to see them in terms of what they are able to do, rather than what they cannot. While this movement is present within many disabilities, in terms of this paper it is important to focus on how people with ASD are challenging what it means to be disabled.

ASD, unlike Down’s syndrome and other conditions that can be diagnosed during pregnancy, cannot usually be screened for accurately until a child is 18 months or older (Rutter 2011:398), although some parents recognize signs of atypical development in their child before then. Therefore, there is no way for parents of children with ASD to decide if they want to continue the pregnancy. The choice of having a perfect child is taken away from them. While some parents are heavily influenced by the fact they do not have a perfect child, other parents and their children have begun to view disability as something that is socially constructed, rather than as something that lies wholly within the individual (Bagtell 2010:33). Rather than seeing disability as inherently bad, they emphasize the face that disability is produced through stigmatizing social interactions that frame the disability as negative. Technology and the rise of online communication has fostered this narrative, as it allows for individuals with ASD, as well as their families, to connect with others who share the same view (Bagtell 2010:36). For parents, constructing this alternate view of disability allows them to create a new narrative, one based on their child’s accomplishments and interactions with the world rather than what
they are unable to do. Likewise, it allows individuals with ASD, in particular those who fall on the high-functioning end of the spectrum, to express how they view themselves in regard to the world around them and to call for people to recognize their capabilities. In many senses, this is less of a movement, as generally defined, and more of a growth of a like-minded community in which ASD does not hold the same negative connotation as it does outside this community.

There are thus two very different views emerging on what disability means, and parents are faced with a choice as early as the middle of their pregnancy or, conversely, well after their child is born about what view they are going to take and how they are going to construct their story regarding disability. As Rayna Rapp and Faye Ginsburg note, the birth of a disabled child is “an occasion for meaning-making, whether through the acceptance of ‘God’s special angels’ or the infanticide of offspring deemed unacceptable” (2001:536). New technology has made it possible to create that meaning prior to birth in some cases, thanks to pre-natal screening and the choice of whether to abort a child with a disability. Parents are unquestionably put under significant stress in decisions about abortion. However, it is important to understand that the wish for a perfect, non-disabled child is not one that comes solely from a fear of having a disabled child, but also stems from fears about the effect a disabled child will have on the family. One of the few parents to speak out about aborting her pregnancy because of a diagnosed disability said she did it so her daughter would not end up being the caretaker for her younger, disabled sibling when her parents died. This mother characterized her abortion as “an act of love” (Rapp and Ginsburg 2001:539) for her other children, and her daughter in particular. It is clear that disabilities have a profound effect on how parents
craft narratives about their families and their futures, even if the child with disabilities is never born.

When a child does have a disability, however, whether diagnosed prior to birth or later on, families face having to craft a narrative that goes against an underlying negative view of disabilities in society. Often, the composition of this narrative is forced upon parents well before they are prepared to undertake such a radical shift in how they construct who they are and who their child is (Rapp and Ginsburg 2001:547). The narrative is thus ongoing and ever-changing as families encounter new challenges and experiences that shape how they want to tell their story of being a family with a disabled child. It is only when parents feel comfortable with how they are constructing their narrative – about their child, and about themselves as parents of a child with disabilities - that they are really able to confront public opinion of what it means to be disabled. As technological advances allow children and parents to share and connect with others with the same disability, stepping out into the public sphere becomes less daunting and more focused on the representation and acceptance of individuals with disabilities (Rapp and Ginsburg 2001:550). Technology thus plays two very different roles with regard to disability. In one role, it allows for the screening and potential termination of a pregnancy when the child would be disabled. In its other role, it serves to connect people with disabilities and allows them to share their narratives of what they are capable of doing, rather than only focusing on what they cannot do.

Landsman (1998) examines the choices parents of disabled children face both prior to and following birth, as well as their experiences as mothers of disabled children and how they frame their and their child’s story. Landsman begins with a discussion of
how she tells the story of her daughter’s disability, writing that she usually chooses to tell it as “a story of triumph over adversity, of the victory of the human spirit against all odds” (1998:70). At the same time, however, Landsman acknowledges that there are many ways she could frame her daughter’s story: as a victim, as a tragedy for both mother and child. Her research focuses on how mothers construct their stories of motherhood. She found that the women who participated in the study felt that society viewed them as responsible for their child’s disability. Some of the women took this sense of responsibility further and accepted a level of blame (1998:82). At the same time, however, many of these mothers actively rejected this narrative that society was forcing upon them. Landsman found that many of these women portrayed themselves as “real mothers,” which Landsman describes in this context as “the person who knows better than anyone else the needs and characteristics of her child and is the prime mover taking action on the child’s behalf” (1998:82). In this way, mothers were able to rewrite the stories of mothering a child with disabilities. They could take responsibility not for the disabilities of their child, but of the extensive action they took to ensure their child was being treated in the best way possible. In doing so, they portray their child as a victim not of their disability, but of the lack of action of incompetent or inattentive medical staff, and themselves as the heroic mother who knew instinctively what was wrong with their child (1998:82-83).

In rewriting their stories, mothers are taking charge of a situation that might otherwise make them feel as though they have lost all control. Although doing so may allow parents to proceed in a more positive manner, it also serves to set them further apart from both parents of children without disabilities and from the medical
professionals that they have cast as the antagonists in their stories of motherhood. One parent said that “just because professional is saying this is what the case is, that doesn’t necessarily mean that I have to go with that” (Landsman 1998:84). The perceived and actual failures of medical professionals in the diagnosis process results in many parents no longer trusting that system, or the professionals in it.

The study also revealed that mothers of disabled children redefine what it means to be a mother and what it means to have a perfect child. Mothers of disabled children “not only insert features such as anger and advocacy into their definitions of motherhood, but they also derive their identities as mothers in part from what they interpret as newly acquired knowledge of what should really matter in life” (Landsman 1998:87). Motherhood becomes for these women not about the perfect child, but about focusing on different celebrations of milestones that their child reaches. In doing so, they challenge the definition of normal, and its use in describing the delays and deficiencies of children with disabilities. As one mother in the study put it, “there is no normal” (Landsman 1998:91). Every child develops and grows and succeeds in different ways and at different times, and by rejecting the concept of normal, mothers of disabled children are saying that while their child may not be typical, their life should not be deemed abnormal. Landsman found that, ultimately, mothers decided that it was “the child’s ability to give and receive love” (1998:93) that became the defining feature of their child’s humanity. While each mother still struggled with guilt, with societal pressure, and with the heartbreaking ‘what if’ thoughts, they reshaped how their child’s narrative was told by embracing who their child was.
The changing narrative of what it means to be a parent of a child with a disability has led to the development of activism on a more personal level. Rapp and Ginsburg (2011) found that this activism took shape as parents realized how their child’s disability was going to affect their lives long-term. Families with a child with a disability often find that the typical paths that American families take through life no longer apply to them. Instead, they found themselves “reimagining everything – from household budgets to school careers to sibling relations to models of humanity” (2011:383). Families thus have to remap their lives in relation to their child’s needs, as well as their own experiences as family members of someone with a disability. Their stories “collectively constitute a ‘new kinship imaginary’ with temporal and social implications” (2011:383). This new kinship imaginary allows for a broader understanding of what it means to be a family and what it means to be human, and how differences from the expected norm affect families as a whole.

The temporal and social implications Rapp and Ginsburg (2011) mention are closely related to each other and to why families with a child with a disability each face a unique path. Disabilities range in severity, levels of stigma or acceptance, and at what age they are most often diagnosed. This, in turn, affects when children receive treatment or intervention, and what those treatments and interventions mean for the family. Rapp and Ginsburg found that “parents who help intensively – usually, but not always, mothers – are themselves slower to progress through their own life-cycle as their child ‘stays young’ in relation to demands usually surpassed at a conventionally much younger age by typically-developing kids” (2011:386). Due to their child’s needs, families find themselves turning down invitations of friends and other families, which eventually leads
to an isolation of sorts for the family of a child with a disability. Their lives become more home-centered (2011:386), which can in turn make it difficult to find support. Parents must also come to terms with the realization that their child’s future in terms of a job, relationships, and involvement in their community is unknown (2011:386). The future parents and family members imagined for their child prior to a diagnosis of a disability is very different from the future they must plan for following such a diagnosis.

Rapp and Ginsburg address a key aspect of this changing narrative of kinship in how parents respond professionally to their child’s disability. They found that parents “redesigned their work descriptions or forged new employment opportunities to focus on specific disabilities in the wake of their own child’s impairment” (2011:389), which allows for parents to become much more involved and knowledgeable regarding their child’s disability. It also lends them a more authoritative voice when discussing treatment options and interventions with medical and educational professionals. As more and more parents enter fields that assist children with disabilities, those fields are being advanced quickly due to the personal nature of the work. One father interviewed took a job at a foundation for a rare disability because “he felt no ‘outsider’ would give the same energy and passion to fundraising, scientific research, and the support for this orphan disease” (2011:389). Parents become more than just parents in these cases. They become professionals in various fields, they become advocates for their child and other children who share the same disability, and they portray activism on a personal level. Their voices are not those of huge foundations or experts in certain fields, but of concerned and invested parents who can tell their stories on both personal and professional levels.
At the same time, however, Rapp and Ginsburg (2011) found that some parents are less willing to discuss their child’s disability in a more public setting and have a difficult time rewriting themselves as advocates or activists. This comes not necessarily out of a denial of their child’s disability but rather from the episodic nature of their journey and the time it took for them to rewrite their stories of parenthood. One parent of a child with a disability interviewed “struggled to come to terms with this ‘impediment’ to her fast rising career and her assumptions that she could ‘have it all’, including a ‘perfect family’” (2011:393). She, like many other parents of children with disabilities, struggled with rewriting her personal identity in the face of her child being diagnosed with a disability. It is not just about the disability itself, but what it means in terms of being a parent and what effect it will have on the family’s life, such as new financial burdens and other more logistical issues that come up. In this way, families are forced into reimagining and rewriting both their stories and their child’s story. Although eventually most of these parents embrace their new idea of family and kinship, doing so takes time and can be difficult without support.

Seeking out various forms of support is a key component in many parents’ journeys to construct a new narrative about their child and their child’s disability. Rapp and Ginsburg explore this support coming in the way of books written by parents of children with disabilities and special needs (2011:395-396). Such books normalize the very much non-typical everyday lives of families with a child with a disability, giving parents the knowledge they are not alone in what they are facing and allowing for both the ups and downs of raising a child with a disability to be shared honestly. Rapp and Ginsburg also explored books written by those who have the disability they are writing
about (2001:546), which serve not only to prove that having a disability does not mean a person is incapable of achievement, but also to provide comfort to families of children with disabilities. Adults with ASD have also contributed to a growing community of support for individuals with disabilities by leading a self-advocacy movement, where the voices of individuals on the higher-functioning end of the spectrum can speak for both themselves and those who are on the lower-functioning end of the spectrum (Bagtell 2010). The visibility of disabled individuals on talk shows and in online groups and websites has also helped bring about more areas of acceptance for both individuals with disabilities and their families (Rapp and Ginsburg 2001). The positive presence of disability in the media and online makes it easier for parents to find sources of support.

A child’s diagnosis is usually the first time a family must dramatically change how they view themselves and their relation to the world around them. It is the start of a rewriting of their stories. While there are other points in these families’ lives where they come up against new challenges that force them to make more changes, one of the most significant is what happens when a child with disabilities is no longer a child. Rapp and Ginsburg state that “it is in the transition to life after high school that families may experience a cultural free fall in attempting to establish a future path for their young adults with disabilities” (2011:401). Their child’s future, which at one point seemed so far off given all the daily challenges these families face, suddenly becomes a huge, looming unknown where once again those who do not follow the typical path of young adults tend to be viewed as failures by society (2011:401). Rapp and Ginsburg believe it is important that the future that parents once imagined for their child and no longer exists should be acknowledged and mourned, because “kids and their families face the loss of
dreams for the future, before they can come up with alternatives” (2011:403). Like any form of mourning and grief, it takes time and space to process this loss and to establish a new normal in its place.

**PARENT-RESEARCHERS: ANTHROPOLOGISTS ENGAGE WITH PERSONAL EXPERIENCES OF PARENTING CHILDREN WITH ASD**

One of the particularly interesting aspects about the anthropological research on ASD is that many of the researchers are themselves parents of children with ASD. Although many anthropologists acknowledge that their own experiences affect the way they view their research, the personal nature of the research of anthropologists who are parents of children with ASD allows for a much closer look at what it truly means to have a child with ASD, without a filter that may otherwise be present between anthropologists and their research participants. In these cases, anthropologists become both a researcher on ASD and a subject of their own research. These perspectives are particularly valuable within anthropology because they give a firsthand account of what it means to be a parent of a child with ASD. Crawford and Haldane frame their own experience through what they call a “discourse of lack” (2010:24) that accompanies their daughter and her diagnosis. This discourse of lack frames the diagnosis of ASD and its impact by explaining what is missing in the behaviors of a child with ASD. Their daughter lacked the characteristics and behaviors of a typical child. Crawford and Haldane found that this discourse of lack enabled them to explain their daughter’s “entire being with three words: she – has – autism” (2010:24). Although what their daughter lacked was not all that
Crawford and Haldane focused on as parents, it was what enabled them to explain why their daughter was behaving differently to others and allowed them to “play by a different set of rules” (2010:24) than families who did not have a child with ASD. Crawford and Haldane found that while people did not place responsibility upon them as parents for their daughter’s behavior, the diagnosis also served as a way for people to remove themselves from part of the family.

Friends will volunteer to babysit Calum, her brother, but not Lula. Family will say: “I’m comfortable taking Calum to this or that place, but I don’t think Lula will want to go.” This is a way of avoiding the admission that they don’t want her, don’t understand her. Lula is officially special and thus requires a specialist. People can deal with weirdness, but not with a diagnosis of weirdness. Normal adults are responsible for the behaviour of normal children in our society, but how could any non-specialist be expected to take responsibility for Lula? Autism gives others a free pass as well, a way to disengage (Crawford and Haldane 2010:24).

While Crawford and Haldane use the discourse of lack to their daughter’s advantage by removing any responsibility for her actions, by doing so they also give others permission to put her in a separate category. They are no longer just parents, but parents of a child with ASD. As a result of this discourse, however, Crawford and Haldane found that they had unintentionally given those around them an excuse to isolate both their daughter and themselves.

The narratives that emerge from the experiences of parents of children with ASD are similar to those that Landsman (1998) discusses. However, since a diagnosis of ASD does not occur at birth but later on, it is often parents who first notice signs that their
child is not developing typically (Chamak and Bonniau 2013). This means there is a period of time where parents must start crafting a narrative of their child being different without knowing a diagnosis to include in their narrative. However, once there is a diagnosis of ASD, the narratives constructed go beyond explaining a “different” child to “seek[ing] to advocate for something beyond the story itself, whether that is a specific theory about what causes autism, a new understanding of autistic people, or a new type of therapy or treatment program” (Jack 2014:2). The diagnosis of ASD gives parents one narrative, of being a parent of a child with ASD, and their path following that diagnosis allows them to create a complementary narrative of the meaning they have taken out of their experiences with and beliefs about ASD.

GENDERED CARE AND SYSTEMS OF SUPPORT FOR PARENTS OF CHILDREN WITH ASD

The need for support systems for parents, and in particular mothers, of children with ASD has been widely identified. Although both mothers and fathers are affected by their child’s diagnosis, it is often mothers who take the majority of the daily childcare. Altiere and von Kluge (2009) found in their study of parents of children with ASD that for nearly every couple who participated, it was the mother who stopped working in order to care for their child with ASD. This places a huge amount of physical and emotional stress onto mothers, who are more likely than their husbands to suffer from problems resulting from this stress (Boyd 2002). They are not only dealing with the normal sense of loss that accompanies the diagnosis of a disability in their child (Nealy et al.
2012:188), but coping with the everyday toll of raising and caring for a child with a
disability. Likely because mothers are involved more closely in caring for their children
on a daily basis, their voices dominate in many of the studies of parenting a child with a
disability (Boyd 2002; Clifford and Minnes 2013; Landsman 1998; Nealy et al. 2010).

The immense amount of stress experienced by parents of children with disabilities
can be reduced by the presence of support systems for parents. Boyd (2002) found that
the three biggest stressors for parents of children with ASD were “(a) concern over the
permanency of the condition; (b) poor acceptance of autistic behaviors by society and,
often, by other family members; and (c) the very low levels of social support received by
parents” (2002:208). Research has also found that the stress levels of parents of children
with ASD are significantly higher than the stress levels of parents of children with other
developmental disabilities, leading to more reports of anxiety and depression in parents
(Boyd 2002:209). Stress levels have been found to relate to the personality of the
mother, the type and availability of support systems, and the characteristics of her child.
The characteristic that most affected stress levels was how dependent children were on
caregivers, especially for assistance with self-help skills (Boyd 2002:210). Formal
methods of support, such as respite services and interventions by professionals, were
most often sought by mothers whose children had more challenging characteristics and
who had a small support network within their family and friends (Boyd 2002). The
sources of support that influenced lower levels of stress were relatives of the mother, the
spouse, and other parents of children with disabilities (Boyd 2002:210). These sources of
support are all considered informal systems of support. Informal support systems seem to
be more effective in addressing stress levels than formal supports, since mothers can
share their concerns with people they view as their peers, rather than with a professional with whom they might not feel comfortable. However, research on both formal and informal systems of support shows that mothers greatly benefited from joining parent support groups where they could share their worries with other parents with similar concerns (Boyd 2002:212).

Parent support groups do appear to have an important impact in lowering the stress levels of parents of children with ASD, and tend to be a cost-effective way of providing support. However, there has been an overall lack of research on the use of support groups, which is surprising given the apparent popularity of such groups with parents (Clifford and Minnes 2013:1663), as well as the positive results demonstrated by the limited available research. There is evidence of significant positive changes in parents’ perceptions of ASD (Clifford and Minnes 2013) following involvement in a support group. Parents attending support groups, which are generally seen as an informal meeting with a professional helping to run the meeting or answer questions other parents are unable to answer, “reported an increased sense of control in the world, an increased sense of belonging or being part of a community, and positive changes in their relationship with and perception of their child” (Clifford and Minnes 2013:1663).

Clifford and Minnes (2013) conducted a study on the usefulness of an online support group for parents of children with ASD, which held online chat sessions in real time, structured by a facilitator and recommended topics. Although a range of topics was covered in each session, most often the sessions “focused on providing mutual support and a sense of belonging among participants” (2013:1667). Even though the study initially focused on the relationship between stress levels and symptoms of anxiety and
depression in parents before and after the support group, a significant relationship between these was not found (2013:1670). However, the participants reported being satisfied with support they received and the topics discussed as part of the group, and saw the group as useful. Clifford and Minnes found that the most useful aspects of the group, as reported by participants, were the ability of the group to connect parents and to obtain information regarding resources, while the least useful aspects were the online format of the group, the difficulty of discussing certain topics, and too great a difference in experience from other parents (2013:1670). Clifford and Minnes found that they ran into many of the same problems as previous studies on support groups, such as sample size and attendance, but overall the study revealed the importance of community, if not for reducing stress levels then for sharing experiences and gaining information and resources.

**RESEARCH METHODS AND QUESTIONS**

As my introduction relates, I first became interested in this topic after a local children’s museum began holding “Au-some Evenings” for children with ASD and their families. I wanted to look at how families discovered resources such as this one, and my research topic expanded into the role of support groups. I contacted the two leaders of the Buffalo support group, who were both heavily involved in the implementation of the program at the children’s museum. Due to concerns about confidentiality and the privacy of group members, the leaders offered to share the information about this project at their meetings so that people interested in participating could contact me.
I designed an interview protocol targeted at uncovering: (1) why parents sought out support groups; (2) their experiences prior to and following joining these group; and (3) what resources they seek out through the group (See Appendix A for list of questions). The questions were designed to be open-ended in order to leave room for parents to bring up their own experiences and concepts that I may not have considered or even known about when the objectives were laid out. The interviews were carried out either over email or in person. All names used in this paper are pseudonyms, and IRB approval was granted prior to carrying out the research.

In the end, only three mothers completed the interview, and I speculate on the reasons for low response rates below. The three mothers I interviewed each had different experiences and backgrounds, although each of them has two children. Crystal is a single mother of two sons ages 18 and 13. Her youngest son has ASD. Rachel, who is married, also has two sons. Her oldest son, who is 6, has ASD. Her other son is 3 years old. Grace and her husband have a 10 year old daughter with ASD and a 7 year old son.

There were a number of limitations to the research, the primary being that only three participants were interviewed. When I initially reached out to the leaders of the Buffalo support group, I was told that membership was confidential and so they would pass along information about my project but could not allow me personally to contact parents first. This is entirely understandable given that the research covers a sensitive subject area. However, it did limit my ability to talk to parents personally prior to the interviews. A number of parents did contact me wanting to participate in the project, but many then decided not to, for a variety of reasons. I was warned by the leaders of the support groups and by some of the parents themselves that many parents of children with
ASD simply do not have the free time in their day to go somewhere for the interview or even to hold one over the phone. Only one of the three people I interviewed wanted to do the interview face-to-face, while the other two both opted to do it via e-mail, where they could look over the answers and take some time to reply. While I did tell all parents who originally were willing to participate in the project that they could take several weeks to respond to the questions, some felt that it was too much of a commitment and so opted not to continue. I think the number and the open-endedness of the questions seemed to be a bigger commitment when parents were interviewed by email than they were when done in person; however, the quality of the email interviews was better because parents had longer to respond and could take as much time as they needed to think about what they wanted to say and how they wanted to say it. Now that I have conducted the interviews and seen how parents responded, I think creating a simplified version of the interview questions might have resulted in higher participation rates. However, I also feel that a simplified version would not have given me the quality of answers I received, at least not without follow-up questions that participants may or may not have been willing to answer.

Besides the issue of recruiting and the free time needed to participate in the project, I think the research may have been somewhat limited in the sense that I am very much an outsider to the ASD community. While I have worked with children with ASD, my experiences can obviously not compare to what these parents go through each day. Furthermore, many parents were extremely concerned about confidentiality, even after reading the informed consent forms. One of the people who participated stressed after sending me her interview questions that she was concerned about confidentiality given
how blunt and critical she had been in the interview with respect to the actions and reactions of friends and family. The concerns about confidentiality seemed to be more focused on the experiences of the parents than on concerns about their child’s confidentiality, as all three mothers made it clear through their responses that those around them knew of their child’s diagnosis. Confidentiality became a worry for participants because despite some bad or difficult experiences with family members and friends regarding their child’s diagnosis and behavior, they all still depended on those forms of support and were concerned about offending the people closest to them. Family and friends become both a source of tension and a source of support, and so it is understandable that confidentiality would be a concern for the mothers who participated.

Finally, I think this project was limited by its very subject. Raising a child with a disability is extremely difficult, both mentally and physically. By asking for specifics in how the support group worked and what parents got out of it, I was asking parents to share some of their experiences, both good and bad, as the parent of a child with ASD. Some parents may not have felt comfortable sharing that information, while others may have felt that I, as someone who was not a parent of a child with ASD, could not understand their position. My age could have also played a role in this, with parents possibly feeling that my own life experiences were not comparable to their own, and so I would not fully understand their experiences, especially with regard to being a parent. Looking back, I think that giving potential participants more information about my background as a caregiver for young children and my experiences working with children with disabilities might have resulted in a few more participants.
DISCUSSION AND ANALYSIS OF RESEARCH

CRAFTING STORIES OF MOTHERHOOD

While my research was originally focused on how support groups enabled parents to find new resources and opportunities, the interviews quickly revealed that the support group itself was an incredibly important resource itself. I thus turned my attention on how the mothers I interviewed crafted their stories of motherhood. As my questions did not ask about how each mother rewrote her story as a parent of a child with ASD, how each mother chose to narrate and tell her story to me revealed how they wanted their experiences to be seen by an outsider. Whether or not they realized it, each mother had decided upon a story to tell to describe their own emotions and experiences in parenting a child with ASD. Their stories varied, but the support group featured prominently in each interview, and so clearly played an important role in how each mother went about rewriting her story of motherhood.

EXPERIENCES AS A PARENT PRIOR TO AND/OR OUTSIDE THE SUPPORT GROUP

In order to understand the importance of the Buffalo support group in the lives of parents of children with ASD, it was first essential to understand the experiences these parents have had prior to joining the support group and outside of the group. Participants described two major experiences: (1) a lack of understanding of what ASD was and how to cope with their child’s diagnosis; and (2) feeling isolated as a consequence of feeling constantly judged and criticized by family members and parents of typical children.
Coping with a child’s diagnosis of a lifelong disability is a difficult and challenging experience for parents. One mother interviewed, Rachel, wrote “I had a very difficult time and felt a lot of guilt for not noticing his symptoms earlier/getting him evaluated sooner”. Her guilt became an obstacle to her even considering seeking out other families with children with ASD for “more than six months”. Another mother, Grace, spoke of the long journey it took for her daughter to be diagnosed with ASD. Her daughter was originally diagnosed with Turner’s Syndrome, and it was not until Grace demanded her daughter be tested for ASD at age five did they receive the diagnosis. Unlike Rachel’s feelings of guilt, Grace wrote

We were relieved. We were glad to finally have an answer, something that explained why she didn’t talk, why she became so aggressive when she was upset, why she was obsessed with her daily schedule, why she perseverated on certain things, why she jumped when she was excited. So much of what confused us finally made sense. We were almost happy to get the diagnosis because we felt like we belonged somewhere.

It is important to understand that Grace was not relieved because her daughter had been diagnosed with ASD, but because it gave her a map to move forward. A diagnosis means that there are other people out there who are having similar experiences.

Crystal had a vastly different experience with her son’s diagnosis, mainly because she, unlike Grace and Rachel, did not know what ASD was when her son was diagnosed. Nor did she receive much information about it when her son was first diagnosed. She said that at the time she thought that “I don’t know…people wouldn’t make children be
like that on purpose. I hope not”. It was not until Crystal joined a support group that she received accurate information regarding her son’s diagnosis. Prior to joining, she expressed feeling “so scared I was going to do the wrong thing” for her son. However, her sense of isolation lessened when she moved away from the city where her son was born and came to Buffalo. She reported that there was a “noticeable way her son’s disability was dealt with” in Buffalo as compared to where they had lived before, and that she found the Buffalo area in general to be more accepting of her son. Although Crystal did not offer any information as to why the Buffalo area was more accepting, the fact that there are several ASD support groups in the region and the resources listed by other participants suggests that many people are making an effort to make sure children with ASD and other disabilities, as well as their parents, feel welcome in their community.

Even joining a support group did not take away the isolation parents felt outside of the support group. Rachel remembers how “playdates ended horribly and I would normally leave bitter. It hurt to watch kids treat my son differently. I didn't blame them, but it still hurt to watch my son not develop and interact with children like his same age peers.” It was not just her child who was being isolated, but she as the parent of that child. Her child was not acting the way other children were, and that was undoubtedly noticed not just by other children, but by their parents as well. Rachel turned to online groups as well, but they were filled with posts about typical children. “I left it because I felt I couldn't relate to the other parents. I still find it difficult to read posts from parents with typically developing children at times,” Rachel wrote.

Grace also discovered quickly how other parents could be judgmental regarding her daughter’s diagnosis.
At our PTA meetings, we don’t share personal, challenging stories about our children. I almost feel like to admit that parenting is anything less than idyllic would be blasphemous. The other parents would look at me like I am a terrible parent who doesn’t love her children. Most of our meetings revolve around telling funny stories about our children, or sharing cute things that our kids have done. So I don’t feel comfortable sharing stories about my challenges with the PTA moms.

For Grace, the isolation she felt was extreme. At the PTA meetings she attended, she felt like she could not possibly tell parents of typical children what her experience of parenting was, especially after hearing the stories that these parents shared. She did not have the same experience with her daughter as they did with their children, and so even though the parents were not actively excluding or isolating her from the group, Grace did not feel comfortable or welcomed. Her isolation went beyond those meetings as well.

I felt isolated CONSTANTLY. None of my friends could understand what I was going through. Either they were too busy with their own families, or they didn’t want to take the time to truly understand my challenges. My family was also little help. I remember one time when I was complaining to my mom about the fact that my daughter still wasn’t talking at 2 years old. She said to me, “Well, do you talk to her?” As if that was the problem! What kind of question is that? No one understood, not even us at that point, so we were constantly fending off inappropriate, judgmental questions, comments and suggestions.
In Grace’s case, her family’s judgment made her isolation that much more extreme. She was not only isolated from her friends and family because of her daughter’s diagnosis, but faced judgment from people she had previously seen as centers of support. Facing criticism over her daughter’s development was particularly hurtful given that Grace was doing everything she could to get the proper diagnosis and therefore treatments and interventions for her daughter. The criticism from her family turned the blame on Grace, whether or not that was their intent. This blame isolated her further from her family.

EXPERIENCES AS A PARENT WITHIN THE SUPPORT GROUP

All three mothers interviewed reported entirely positive experiences as a member of the Buffalo support group. While it was expected that this feedback would be mostly positive, it shows just how important this group is in welcoming parents of children with ASD that none of them reported a time when they felt the group had failed them in some way.

The ways in which each mother became a member of the support group relate to the experiences they had previously. Crystal learned about it through a flyer given to her by a Medicaid coordinator. She had not been actively seeking a support group. In fact, Crystal said it was “when I started going to support groups” that she started actively seeking out the parents of children with ASD. However, she also said that the support group interested her because she wanted to “be able to tell what to do to be a better advocate for my son.” Rachel said she learned about the group “in a class I attended
about autism.” Grace’s path was a bit different. Following the diagnosis of her daughter, she originally felt like she finally belonged somewhere. She soon discovered otherwise.

What I didn’t realize at that time was that just having the diagnosis doesn’t mean you “belong” anywhere. You need to involve yourself in the community in order to feel a part of it. So, about a year after her diagnosis, I started looking for a support group. I found this Autism Support Group through the Children’s Guild Foundation online, and I started going. I’ve been going ever since.

While Crystal and Rachel had both been given information about the support group through other community resources they used, Grace recognized her need to belong to a support group. These different experiences in finding the support group may relate to the experiences each mother had prior to joining the support group. Although Crystal and Rachel both felt somewhat isolated, the feeling of isolation reported by Grace was much higher than that reported by the other two mothers.

All three mothers found that the support group provided them with exactly the sort of atmosphere and support they had been looking for. When asked what the most important part of being a part of the support group was, Crystal offered several reasons: “Feeling like you belong,” “Knowing that they stand for the right thing,” “They don’t discriminate. They’re accepting of all people,” and “They don’t turn you away because you’re different.” For Crystal, the idea of inclusion and belonging within the group was extremely important, especially because following her son’s diagnosis she was being kept “out of the loop” by her son’s doctor. She described the support group as “a way to keep me from being isolated…to let me know I wasn’t alone.”
Rachel confirms that belonging to a group with other parents who understood her experiences as a parent of a child with ASD was the most important aspect of the support group for her. She wrote that for her, the most appreciated aspect of the group was “feeling that there are other people I can talk to about what we are going through because as nice and supportive as family and friends can be, few people truly understand how difficult life can be sometimes”. In the support group, she found other parents who understood exactly her feelings and the challenges she faced. Rachel added, “Now, I feel like there is hope and I can celebrate small victories with people who understand.”

Grace, too, felt that the sense of group inclusion was important.

The most important part of belonging to this group is the empathy I feel and receive from others who struggle as I do with a child with autism. I know that I can share anything that has happened, or anything that I’m worried about, and the others in the group either have experienced the same thing, or they understand completely how I feel, and why I feel the way I do. Sometimes just having others listen and understand, can make a world of difference in my outlook. And I am happy to empathize with others through their struggles and feelings. It’s a give and take that fulfills me and helps me to face the challenges of my life head-on, with a more positive attitude and mindset.

For these three mothers, the support group connected them with people who shared the same struggles as they did, and who needed a safe place to share those struggles and voice fears and ask for advice. When their traditional sources of support, such as family and close friends, failed to provide the support and understanding that
these mothers were seeking, the support group created a new community for parents where a system of support and understanding was a basic component. For Grace, although the diagnosis itself provided her with some relief because “we finally felt like we belonged somewhere”, it took time for her to realize that the diagnosis was not what gave her a sense of belonging. By joining the support group and sharing her experiences, both good and bad, she became part of this community. She says that with the support group, “I never feel alone in our journey anymore. I have people that I know understand me, my daughter and my family. They care about us as I care about them”. This shows the strong sense of community and family that the support group fosters. It is clear that the support group these mothers are a part of has grown into this community because of the members themselves and the willingness of members who have been in the group longer to share their own experiences in order for the new members to become more comfortable.

While all three participants offered reasons why the support group was important, Grace offered considerable insight into her experience as a member of the support group.

I joined this support group 4 years ago when I really felt like I had no one to talk to about the issues I was having with my daughter. No one that I tried to explain things to had any understanding of what I was going through. Not only that, most of my friends and family had a lot of sympathy for my daughter, but none for me. As a result, I was often judged harshly when sharing information about my experiences and my feelings. I needed to find a group of people that were going through the same things that I was, so that I could share my challenges without being judged or criticized.
During the very first meeting, I was nervous about how others would accept me since I hadn’t had much luck with acceptance in my own circles. I remember not sharing much and just listening to others. To my surprise, even the listening was cathartic. I left that meeting feeling so much lighter, calm and dare I say, happy. Just hearing others’ stories helped me to feel like I wasn’t alone, like there were others out there going through the same things that I was.

After a few meetings, I finally felt comfortable enough to start sharing my own stories. My daughter has severe violent tantrums when she doesn’t get her way, or when things don’t happen as she expects they should. She bites, scratches, pinches and pushes. She screams and stomps and just melts down overall. I consistently have a cycle of scars and bruises on my arms and face due to these tantrums. I remember when I first shared that with the group. I started crying because I felt so embarrassed and overwhelmed. I just didn’t know how to handle this. As I looked around at the other faces in the group, I noticed a few nodding heads and sympathetic eyes. I wasn’t alone. Other people had experienced the same things and felt just as hopeless as I did. This gave me the strength to keep going, to fight through 1 more day, to try to make things better for my family and to seek help.

Grace’s experience with the support group illustrates just how welcoming and safe the support group is for parents. In a society where the illusion of being a perfect parent with perfect children is held as such an ideal, admitting to other parents or opening up on the challenges of raising a child with ASD was difficult for Grace, especially because she did not have the support of those around her. One of the most important
parts of Grace’s experience with the support group was that she received sympathy for her challenges as a parent, which she had not gotten up until that point.

One of the themes evident throughout Grace’s interview is her struggle to portray herself as a “perfect” parent to parents of typical children, and the transformation that took place after she joined the support group. Unlike the mothers Landsman (1998) interviewed, who rewrote the concept of what being a “perfect” mother was, Grace, both willingly and unwillingly, spent a long time holding on to this portrayal of herself as the traditional perfect mother. As mentioned, she felt uncomfortable about sharing stories of the daily challenges she faced with other members of the PTA, because the stories of parenting told at those meetings were “around telling funny stories about our children, or sharing cute things that our kids have done.” While Grace struggled to keep up this image of being a perfect mother that she wanted parents of typical children to see her as, she also struggled with the idea that in doing so, she was not being a perfect mother to her daughter. She wanted to cast herself as the heroic mother of a child with ASD, and to her that meant not sharing or allowing others to see her struggles. Her isolation from family and friends, as well as her discomfort in situations with parents of typical children, initially made her feel that she had failed to be a “perfect” mother. It was not until she joined the support group and became comfortable with the community that she was able to begin rewriting her own story. Once she joined the support group and found other parents who faced the same challenges she did, Grace found herself able to share stories about her daughter, even ones that she would have found embarrassing to share elsewhere. In sharing her experiences and struggles with other members of the support group, Grace was eventually able to recast herself not as a failing “perfect” mother but as
a loving parent of a child with ASD. Through the shared experiences of support group members, Grace realized she was not alone in her struggles and that she was now a member of a community where struggling and dealing with aspects of parenting that parents of typical children would never even think about was not a sign of failure.

Sympathy and understanding are key components of the experience of being a member of a support group for all three mothers interviewed. However, the support group does more than just provide a place to discuss the challenges of raising a child with ASD. It also helps to keep parents focused on the positive and on the accomplishments of their child. Rachel says that each meeting, “we are all asked to share a celebration...I love that focus on the positive.” Grace, too, finds the positive focus an important part of the support group.

We try to keep the meetings positive, and focus on achievements that our children have had from the previous month. This is pivotal in keeping us all in a positive frame of mind. We all share a “celebration;” something that our child did that surprised us, or fascinated us or delighted us or relieved us. It reminds us that although our children may not achieve at the same rate, or to the same height that their typical peers do, their achievements are just as grand and important, and we appreciate them so much more.

This focus on the positive is an important part of the atmosphere of the support group. It allows parents to share challenges, but to also share things that their child achieved. As Grace says, sharing these celebrations allows parents to share an accomplishment that is big and important for their child, even if parents of typical
children would not necessarily see that as an accomplishment. While a child with ASD may not reach the same milestones at the same age as their typical peers, or even reach those milestones altogether, sharing what they have accomplished with parents who understand exactly how big that accomplishment is for a child with ASD allows parents to celebrate their child in a way that they may not otherwise be able to.

**INFORMATION AND OPPORTUNITIES PROVIDED BY THE SUPPORT GROUP**

One of the initial objectives of this research project was to learn how parents of children with ASD accessed resources. Once the focus shifted to the role support groups play in the lives of parents of children with ASD, it became clear that the support group was the main way that parents both looked for answers and information and discovered opportunities for families of children with ASD. The interviews reveal a wide range of information that parents were seeking as well as the opportunities that the support group provided. Although some of the examples given by the mothers were expected, they also brought up examples that I had not even thought about prior to the interviews.

Finding the right resources and specialists can be a difficult task, and all three mothers interviewed expressed how much the support group had helped them find such resources when they asked. Rachel’s son has dealt with gastrointestinal problems, and she turned to the support group to learn if any other parents had experienced similar issues with their children. Rachel was able to get an answer to her question, saying “I was given positive and negative feedback…and have the name of a specialist I plan to see
if his struggles continue”. Through the group, Rachel says, she also has “access to a directory to find activities and professionals that can work for my son”.

Crystal spoke of how the support group helped her by explaining some strategies to deal with her son’s behavior. The support group, she said, helped her understand that “it’s okay that he does what he does”. The support group also fostered discussions regarding wills and trusts, the steps parents need to follow for Medicare, how to sign up for respite services, and information about “how to prepare for IEP meetings”.

Crystal identified opportunities provided by the group that she found both positive and negative. One of the positive opportunities the support group gave her was the chance to meet with parents of adult children with ASD. This was an uplifting experience for Crystal, because it gave her the chance to see what the adults with ASD were capable of doing and “what they’ve accomplished”, as well as how they were integrated into the community. However, Crystal did find one opportunity provided by the group to be negative, mainly because it was not what she wants for her son. She met with a group of parents who had adult children who were unable to live on their own, and so either lived with their parents or in a group home. Crystal expressed a desire for something more for her son. “I don’t want to stifle him. I want him to be independent, which I know he can be”. Although meeting with this second group might have been helpful for other parents, for Crystal it was a negative experience because she fully believes that her son belongs in first group she met, and that he will be able to one day live independently.
Grace spoke about a time when the support group as a whole identified a need for a resource and then worked together in order to address this need.

Approximately 1 year ago we started talking about how neat it would be if we had a list of fun activities and places to visit that are ASD family-friendly. It could be activities that we would register for, like camps or classes, or it could be activities that we would save for a rainy day, like a trip to the Science Museum. One of our leaders, together with another parent and a lot of feedback from the group, created what they call the “Summer A-list.” It’s a comprehensive, complete list of autism friendly places to visit and things to do. I LOVE it! I refer to it often and have dog-eared many of the pages.

Like Rachel, Grace also talked about the specialists and professionals that she found through the support group. One of the challenges that parents of children with ASD face is that events outside their child’s routine can be extremely upsetting for their child, and so finding services that understand their child’s needs and behaviors can be difficult. Grace said that the group spent a large amount of time discussing this, and sharing their experiences with various services. Grace said, “Our current dentist was also a referral from a group member. We often talk about medical providers and which are the most sensitive to our children. We are so lucky to have found her!”

Grace also spoke about several of the same services that Crystal did, and was especially focused on sharing experiences and support regarding schooling. “All of us share our experiences with school and transitions from home-based programs to school programs. Although our children attend different schools in different types of programs,
we share the same anxieties and worries about socialization, teachers, curriculum, services offered, etc.”

The resources, opportunities, and information shared and provided by the support group gave each mother what she was looking for and also further confirmed the importance of the support group for them. Both Rachel and Grace spoke about seeking resources that were “autism friendly”, whether it was a specialist or swimming lessons. Crystal identified more information, rather than opportunities, that she learned from the group, although the two opportunities she did speak about were revealing in her hopes for the future. Crystal very much fits the role of the heroic mother, from her portrayal of her son’s doctor as not doing enough to explain to her what was happening with her son to her portrayal of herself as deeply invested in her son’s future, as evidenced by the information and resources she spoke about.

LOOKING TOWARDS THE FUTURE

One of the aspects of a diagnosis of ASD that parents must face is the fact their child will have autism for their entire lives. Parents of children with ASD therefore must not only face the daily challenges that ASD poses as their child grows up, but also plan for their child’s future. This includes planning both for transition services as their child becomes an adult and for who will support their child when they are unable to do so.

In Grace’s words,
Having a child with ASD is really hard. First you realize that your child will never grow up to be your friend, or your child will never have a career or goals that you can brag about. Then you understand that your child will never really talk to you in a meaningful way, or look at you straight in the eyes out of anger or love. You wonder if your child will ever be able to use the toilet appropriately to have a bowel movement and clean herself by herself...You know that your child will never be able to take care of herself by herself, and she will always live in your home or an institution as she gets older. Even as an older adult, you wonder if you will ever be able to travel as your parents do, or take vacations. We will always be taking care of her in a very necessary capacity, and it is a thankless task.

Grace sums up what many parents of children with ASD must learn to understand and cope with when looking towards the future, while at the same time having to deal with the challenges their child presents in daily life. For Grace, a large part of her struggle to rewrite her story can be seen through what she expressed here. Her worries about her daughter’s future parallel her own journey of first discovering her daughter’s diagnosis and then struggling to find the support she needed and was not getting from extended family or friends. Although she has become more comfortable with her narrative of parenting a child with ASD in the present, she has not yet come to terms with what that will mean in the future. Graces recognizes that as both she and her daughter grow older, they will need to seek new systems of support, possibly in the form of admitting her daughter to an institution or group home. However, she is not yet
comfortable with that idea and what it means in her identity as a parent of an adult daughter.

Although Rachel spoke very little about her son’s future, Crystal was outspoken and confident in what she saw in her son’s future. She said, “Even though he has a disability, he has a lot to offer,” and expressed her desire to see him “be a productive member of society”. She was also very clear about what she wanted for her son in terms of employment, saying that she did not want him to “have jobs where he is expected to clean” because she firmly believes that he is “capable to be in a job where he is making change to his community”. What is interesting about Crystal’s hopes for her son’s future is that she is so focused on making sure he is a part of his larger community. The future Crystal wants for her son shows how the sense of community and understanding from the support group has affected how she views both her role as a mother of a child with ASD and what her son is capable of doing. Like Grace, Crystal was empowered through the support group, although in a different way. Grace became able to see herself as a good mother, while Crystal finally found the support she believed necessary for her son to succeed.

Crystal was the most open about what she saw happening in the future. Grace was more focused on coming to terms with what a diagnosis of ASD meant moving forward, while Rachel spent very little time focusing on the future, saying only that “when my younger son is old enough, I will have him attend a sibling support group if he would like to”. Her expressed concern for the future is about her typical child, not her child with ASD, although those concerns stem from worries about how having a brother with ASD will affect her younger son. Grace also expressed a desire for her son to attend
these sibling support groups, saying, “when my son is old enough to attend, I want him to have a safe place to talk about his feelings just as I have found in my support group.”

She also spoke about her son’s future in terms of how he views and treats others. “I just want to teach him something that I never learned growing up...tolerance and acceptance and even love for those that are different from us. My hope for him is that he learns how to interact with people with special needs, and to have a kind, understanding heart for all people.”

All discussions of the future came unprompted by the interview questions, which may explain why each of the mothers approached it differently and varied in how much time they spent addressing it. I felt that the interview questions left room for parents to expand into more sensitive topics if they wished, and I believe that the future is one such topic. One of the key aspects of ASD is that it is a spectrum disorder, meaning that children with that diagnosis will vary greatly in how they behave and what they are capable of doing, depending on how severe their case is. Although the severity of a child’s ASD could be a factor in how participants used the support group, I felt that it was too sensitive and invasive a question to ask. While I did not ask specifically about either the severity of the diagnosis or their child’s future, I think each mother made a choice, conscious or not, of how they were going to address these topics within the interview.

CONCLUSION

Each of the mothers interviewed shared deeply personal experiences and thoughts as the parents of children with ASD and as members of a support group. What is
particularly interesting about the three interviews is that although the mothers shared similar experiences both outside and in the support group, the way they presented their stories differed greatly.

Grace’s story is filled with challenges and roadblocks, both from the outside world and from her own beliefs. She marked the support group as a turning point in her life, but it is still clear that she struggles with her daughter’s diagnosis. When asked how having a child with ASD has affected her life, her reply was much more open than I expected. “If I’m being completely honest, I have to say that having a child with ASD has completely changed the person that I was into someone that I wish I wasn’t. Before having my daughter, I was not cynical or depressed or angry or atheist or anxious...as I am now.” Although the support group is a turning point in Grace’s story, her struggles of accepting herself as a mother and as a person are far from over. However, Grace has learned new ways to approach life through the support group.

I wish I could say that having a child with ASD has made me stronger or more fulfilled, but I would be lying. Most of the time I feel plain defeated, which is why the support group is so important to me. It gives me hope, forces me to be more positive and makes me look at my daughter in a different way. I see her achievements and celebrate them, no matter how small. I find love in her expression even if it’s just tolerance. My group gives me the support I need to keep going, to fight for my daughter, to experience joy within the ASD world. It makes me forget about how having a daughter affects me, and makes me think about what I can do to help her. Because in the end, it’s not about me. I didn’t birth my daughter to fulfill me; I didn’t decide to have children because of what
she could do for me. It’s about her. How can I be the best mother in the world for her. The support group reminds me monthly of this most important little detail, which can make all the difference in my daughter’s life.

Grace has learned how to rewrite her story. It is a story of loss and sadness, of anger and frustration, but it is also the story of realizing that there are others out there whose stories are similar, and who can sympathize and offer support in ways others cannot. For her, the support group allowed her the space to redefine motherhood in an environment where there was no judgement, only understanding and acceptance. Grace’s journey to do so is still ongoing, but what she shared about the support group and about how her life has changed paints a very vivid picture of what it means to be a parent of a child with ASD.

Crystal did not struggle to redefine her view of motherhood after her son’s diagnosis. Instead, her challenges lay in the fact that she perceived a lack of care and resources for her son and for herself following her son’s diagnosis. She fits the role of the heroic mother determined to do what is best for her child, but with a very important twist. Her experience before the support group was marked with healthcare professionals, including the ones who diagnosed her son with ASD, who did a poor job of explaining what ASD is in terms that Crystal could understand. She therefore was unable to seek out resources early in her son’s life, and said she “sometimes used to think something was done” to her son to make him behave the way he did. She placed the blame on the doctors who diagnosed her son for not giving her access to resources her son needed, and believes she knows better than those doctors what is best for her son.
Joining the support group allowed Crystal to seek a better explanation of ASD, which changed her focus from the doctors she believed had wronged her and her son to gaining access to resources and specialists who could help her son in the way Crystal wanted. Crystal says she believes with “the right people working with me, he [her son] could soar.” Crystal’s story turns from a negative focus on what she lacked and how her son’s options had been limited to a positive focus on what she as a mother can do to support her child. For Crystal, the support group gave her the validation she was looking for and made her feel more informed, which in turn made her more confident in making decisions going forward.

While Grace’s story is about her struggle to accept herself as a good mother, and Crystal’s story is about overcoming challenges and seeking resources for her son as a heroic mother, Rachel’s narrative bridged the two. Rachel found herself isolated from friends and the mothers of her son’s peers because of her son’s diagnosis. However, she says, “I am lucky that my husband and family ARE supportive” regarding both her son’s needs and her own need for support in being a mother of a child with ASD. Rachel did not offer any suggestion in her interview that she struggled with redefining her sense of motherhood following her son’s diagnosis, but both her feeling of isolation and her feeling that she is lucky to have the support of her husband and family suggest that she faced challenges in accepting what it meant to others for her to be a mother of a child with ASD. In effect, Rachel felt pressure from the outside to redefine her sense of motherhood, even though she was more focused on finding the right specialists and resources for her son. Doing what is right for her son and her family is very much what
Rachel sees as the definition of motherhood, and so that did not significantly change how she defined motherhood, at least in her narration.

The support group gave Rachel a place where her definition of motherhood was not questioned. She could seek out the resources and specialists she was looking for from the group, and she could celebrate her son’s successes rather than feel that her son was being compared to his typical peers. It also gave Rachel the community she needed to fully support her son’s needs, as well as a venue in which she could express difficulties and challenges.

The interviews with Grace, Crystal, and Rachel reveal the central role that the support group plays in their lives and the lives of their children and families. The support group provides a community where both understanding and knowledge was requested and provided. It speaks to the strength of the support group’s sense of community that although each mother came into the support group with different experiences and varying emotions and beliefs about their child’s diagnosis, and although they each were seeking different aspects and levels of support, all three mothers reported only positive experiences with the support group.

The mothers of children with a disability face enormous challenges as they recreate their definition of motherhood and face a world that is largely uninformed or uninterested in the daily struggles of raising a child with a disability. The three interviewed mothers all spoke of the isolation and lack of understanding by friends and family that they faced while raising a child with ASD. The support group, in providing a safe atmosphere to discuss challenges and to celebrate successes, allows these mothers to
find others who have faced similar challenges. The support group comes to act as more than just a network, but as a second family of sorts, upon whom parents can rely on as a source of support, understanding, and advice.
APPENDIX A

Interview Questions

1. How old is/are your child/children with ASD?
2. Do you have any other children, and if so, how old are they?
3. What have your experiences been as a member of this support group?
4. If you belong to more than one group or community, which ones are most important to you? Why? Are there certain groups you turn to for specific reasons?
5. Are these groups in-person or virtual?
6. Do you belong to any communities of parents without ASD? If so, which community do you feel more of a member of?
7. How did you learn about these communities?
8. Do you ever feel that these groups or communities have failed you in some way? Have you ever turned to the group for information and not been able to get feedback? Can you tell me about this experience?
9. Can you speak about a time where the group provided you with information you were looking for?
10. At what point following your child’s diagnosis did you seek out other families of children with ASD?
11. Before becoming a member of a group, did you ever feel isolated? Can you speak of how you feel in comparison now?
12. What sort of resources have been made available to you or brought to your attention through these groups?
13. What community resources or events for children of ASD do you use or participate in?

14. What’s the most important part of belonging to a group for you? Why?

15. Do you view yourself as an active member of these groups? How often do you attend meetings or use services made available by the group?

16. What topics are discussed within the groups? What comes up most frequently? Do you think these topics are important? Is there anything you wish would be focused on more?

17. How does having a child with ASD affect your other children? Do you seek out resources for them? How does having a child with ASD affect your own life?
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