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Abstract

Autism Spectrum Disorder is the fastest growing developmental disability. Autism is defined as, a bio-neurological developmental disability typically appearing before age three. Characteristics of ASD may include repetitive behavior, withdrawal behavior, and/or misbehavior that make social outings for families difficult. Previous research has indicated the day-to-day level of stress arising from parenting, the parents' lack of confidence in handling the child's behavior, the lack of supportive services to meet the needs of the affected child, and the realization that there is no cure for ASD are a few stressors experienced by parents. The goal of this study is to identify specific resources and other benefits of participating in a support group for parents of children with ASD. The findings of the study emphasize the feeling of community within an autism support group, the use of respite care (temporary or short-term home care of a child that is provided, either for pay or on a voluntary basis) since joining the support group, the type of information shared between members, and the benefits gained from being in an autism support group. The social well-being of individuals caring for a child with ASD has a greater potential to increase when parents involve themselves in external supports. In addition, the overall functioning of a family may be enhanced by support groups as social activity increases through interactions with other group members.
Piecing Autism Together: Families and Support Groups

Autism is defined as, a bio-neurological developmental disability typically appearing before age three. The term “Autism Spectrum Disorder (ASD)” will be used throughout this paper, and should be considered interchangeable with the term “autism,” which is often used in the literature regarding ASD. The term ASD will be used to represent individuals withAutistic Disorder, Asperger’s syndrome, Pervasive Development Disorder, Not Otherwise Specified (PDD-NOS), Rett Syndrome, and Childhood Disintegrative Disorder (CDD).

Characteristics of ASD include impairing a person's ability to communicate, relate to others, and the tendency to engage in rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe and autism may occur in all racial, ethnic, and social groups with it being four times more likely to strike boys than girls. ASD is the fastest growing developmental disability. Today as many as 1.5 million Americans have some form of autism and approximately 67 children are diagnosed per day, which is approximately one child every 20 minutes (Autism Speaks). The forms of autism are thought to have considerable overlap, but the wide variation of symptoms creates a spectrum. Autism is on a spectrum that affects each individual differently.

Asperger’s syndrome and Autistic Disorder are similar in that they are both neurological disorders marked by difficulties in communication and social interaction, which can make it extremely challenging, even impossible, to connect with others. As with Autistic Disorder, individuals with Asperger’s syndrome possess severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests, and activities. In contrast to Autistic Disorder, there are no clinically significant delays or deviance in language acquisition (e.g., single non-echoed words are used communicatively by age 2 years,
and spontaneous communicative phrases are used by age 3 years, although more subtle aspects of social communication (e.g., typical give-and-take in conversation) may be affected (American Psychiatric Association, 2000).

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), is associated with many individuals with autism. However, it is more regularly applied to individuals whose diagnosis is more severe than Asperger’s Syndrome, but not as severe as Autistic Disorder. Experts do not agree on the criteria for PDD-NOS, however, characteristics include impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities. The qualitative impairments that define these conditions are distinctly deviant relative to the individual’s developmental level or mental age (American Psychiatric Association, 2000). The downfall to having no set criteria for PDD-NOS is that if a child seems autistic to professional evaluators, but does not meet all the criteria for autistic disorder, he or she is likely to be labeled with PDD-NOS.

Two rare forms of ASDs include Rett disorder and Childhood Disintegrative Disorder (CDD). Rett’s disorder has been diagnosed only in females and is the development of multiple specific deficits following a period of normal functioning after birth. Rett’s disorder includes normal psychomotor development through the first 5 months of life. Interest in the social environment diminishes in the first few years after the onset of the disorder, although social interaction may often develop later in the course. Problems develop in the coordination of gait or trunk movements. There is also severe impairment in expressive and receptive language development, with severe psychomotor retardation (American Psychiatric Association, 2000).

Childhood Disintegrative Disorder (CDD) is a marked regression in multiple areas of functioning following a period of at least 2 years of apparently normal development. Normal
development is reflected in age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior. Individuals with this disorder exhibit the social and communicative deficits and behavioral features generally observed in Autistic Disorder. There is qualitative impairment in social interaction and in communication, and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. CDD is thought to be diagnosed more in males than in females (American Psychiatric Association, 2000).

The range of ASD makes the importance of receiving a break from time to time in taking care of a child with ASD. Research has indicated that families report the availability of respite care as the critical factor in helping them care for their child at home and avoid institutionalization (Abelson, 1999). The additional support a family utilizes is central to maintaining a sense of well-being within the family.

**Purpose**

The purpose of this study was to identify specific resources and other benefits of participating in a support group for parents of children with ASD. Individuals with a diagnosis on the autism spectrum have an increased need for attention to lessen the likelihood they will injure themselves. Therefore, parents may become isolated from community and family functions. The lack of an effective, coordinated care system for children with autism that provides accurate information combined with the symptoms of the disorder itself can manifest high levels of stress for families, social isolation, negative health outcomes, and marital dissatisfaction (Dunn et al., 2001; Sivberg 2002). Financial strain may increase, because few insurance carriers meet all the medical needs of a child with a developmental disability (Abelson, 1999). A resource for coping when times become challenging in caring for a child with Autism is the utilization of a support group. Support groups become increasingly important places where
information is shared and a sense of comfort is felt among members. Support groups offer members an opportunity to have contact with other individuals in similar situations. The idea of being able to have a shared experience may decrease social isolation, reduce stress, and increase access to information.

Although previous research has indicated that support from one’s spouse, extended family, friends, and support groups can lead to healthy adaptations to “stressful situations;” the purpose of this study was to gather self-reports of life as a parent of a child with ASD. Furthermore, the purpose of the study was to learn about how being part of a support group has impacted the lives of parents with a child diagnosed with an ASD, while allowing them to learn of additional resources and come together as advocates for their children. The functioning of a family with a child on the Autism Spectrum may be increased by involvement in a support group.

*Caring for an individual with an ASD*

Caring for a child with ASD can be challenging and extremely demanding. Parents may find themselves inadequate in dealing with the behaviors commonly exhibited by children with an ASD. Behaviors of an individual with ASD include: repetitive behavior, withdrawal behavior, and/or misbehavior make social outings for family difficult (Higgins, Bailey, & Pearce, 2005). The day-to-day level of stress arising from parenting, the parents’ lack of confidence in handling the child’s behavior, the lack of supportive services to meet the needs of the affected child, and the realization that there is no cure for ASD are a few stressors experienced by parents (Twoy, Connolly, & Novak, 2007).
Stressors and Coping Mechanisms for Families

Unlike other illnesses or events, autism is not short lived, but rather it is a lifetime of multidimensional issues and demands placed upon the family (McCubbin & Figley, 1983). The stresses and challenges of raising a child with ASD are most often associated with the diagnosis of ASD, which include adjusting to ritualistic behaviors, being more involved in education and therapy decision making, increasing contacts with multidisciplinary professionals, dealing with a scarcity of resources, and purchasing and/or using technological supports (Lord & McGee, 2001). These problems are common to many families with special health care needs, but families of children with ASDs may experience these negative outcomes to a greater extent (Dunn et al., 2001; Sivberg 2002).

Families of children with autism confront a host of difficulties in obtaining appropriate care (Knapfl et al., 1995; Krauss et al., 2001; 2003; Smith, 1994). Some of these difficulties include obstacles such as learning where and how to obtain services, negotiating with disconnected service systems, making decisions about treatment options. Krauss et al., (2003) completed a study that involved surveying 2200 families of children with special needs. The results of the survey, as cited in, Mandell & Salzer, 2007, indicated that 35 percent of parents of children with Autism had difficulty in obtaining needed medical services.

Successful adaptation to these issues involves both internal family-coping strategies and external family-coping strategies (Lavee, McCubbin, & Patterson, 1985). Internal coping strategies come from within the family, such as relationship, cognitive, and communication strategies. The goal of internal coping is for family members to become more cohesive and more reliant on one another. Internal coping is less effective when external factors are not part of the picture. Therefore, external family-coping strategies or the use of resources outside of the family
are vital for all family members to adjust and strengthen internal coping. It is likely that a family relying on both internal and external coping strategies will have more success adapting to stressful events within or outside of the families.

Family resources are attributes and supports that are available to the family. Family resources include the individual, the family unit, and the community. The individual resources are one’s knowledge base, personality traits, and physical and emotional health. Family unit resources account for organizational, decision-making, and conflict resolution skills. Community resources are referred to as personal support (friends and family). Research has shown that an individual that displays a balance between these resources and are able to make minor adjustments along the way can achieve a positive adjustment to a difficult situation (Twoy, Connolly, & Novak, 2007).

The Significance of Support Group Usage

Support groups serve as a resource for families to increase their pool of knowledge, which may become particularly important for families of children with autism. Learning about appropriate resources for children with autism is often more difficult than for other childhood conditions since no cure has been developed for ASDs.

The value and impact of support groups are based on a solid foundation of psychological and sociological theories of experiential knowledge, and social support theories (Salzer et al., 2002). Previous research has found that parents of children with developmental disabilities are highly satisfied with the sense of agency and belonging they achieve from participating in groups (Solomon et al., 2001). Parents also report an improvement in parenting skills as a result of participation in support groups, a decrease in their sense of isolation, obtaining more information
about services, and a greater sense of emotional support (Kerr & McIntosh, 2000; Law et al., 2001).

It is likely that support groups will lead to more effective outcomes than those that use the coping strategy outlined in a study by Sivberg (2002), as cited in Twoy, Connolly, & Novak (2007). Sivberg (2002), focused on strain placed on the family system and compared the coping behaviors of parents of children with ASD to those with non-ASD parents. The results supported the hypothesis that there are differences in the types of coping behaviors. Parents of a child with ASD scored higher in coping behaviors of distancing and escape, which is a behavior aimed at withdrawal from a stressful situation. The parents in the control group, scored higher in the use of self-control, social support, and problem solving. The coping style of escape-avoidance corresponds to increased depression, isolation, and spousal relationship problems (Dunn et. al., 2001).

Although the coping strategy of escape-avoidance may be used at times research has indicated that parents of a child with ASD are resilient in adapting to the challenges of caring and raising their child with autism. Using social support systems within the family’s social network is considered a large part of the external family-coping strategies. Parents indicated support from close friends and extended families. Often parents share concerns with close friends and difficulties with extended family members. The stresses for families of children with ASD have the potential to be significant; therefore, it is clear that social support plays a large role in the resiliency factor for these families. Support groups members who have “been there” and shared similar experiences have a greater potential to provide critical information about where and how to obtain services. Members may also band together to advocate for needed resources such as insurance companies covering more of the cost of raising a child with ASD.
Participation in Autism Support Groups

Parents of children with Autism that exhibit self-injurious behavior, sleep problems, severe language deficits, or were referred by their clinician were more likely to belong to support groups. Support group participants are more likely to be middle income, well educated, and less likely to be African American. People with these characteristics may have greater comfort in discussing private feelings and experiences, possibly due to cultural factors. It may also be likely that poor, less educated, urban and rural residents, as well as African American parents do not perceive the use of a support group as beneficial. Parents of older children are also more likely to participate in support groups which may be a result of the time it takes to establish routines and identify resources. (Mandell & Salzer, 2007).

Previous research indicates that parents’ beliefs about receiving adequate social support for themselves and their child have been shown to be important for successful family adaptation (Bristol, 1984; Donovan, 1988; Wolf et al., 1989). Social support, or the perception of social support, can decrease the impact of stress on depression in mothers of children with ASD, indicating that social support plays an important role in maintaining the mental health of these parents (Wolf et al., 1989; Fisman & Wolf, 1991). Mothers of children with ASD who perceive supports to be helpful have been shown to cope more successfully (Donovan, 1988).

The perception of social support and feeling connected are important factors when caring for an individual with ASD. Therefore, this study examines an autism support group and the affect or benefits it has on parents of children with special needs. The social network one is able to create in a support group has the potential to provide an abundance of opportunities for individuals within the group.
Method

Participants

Five parents of children with ASD voluntarily participated in the study. People of all ages, race, ethnicity, and religion were encouraged to participate. All participants were Caucasian mothers of a child with ASD and ranged in age from 32-39 years old. All of the children ranged in age from 6-10 years old.

Materials

The interview consisted of four levels of questions (See Appendix A), which included how one perceived the support groups sense of community, the use or importance of respite care, types of information sharing, and social activity questions. The study was qualitative, but included a demographics questionnaire regarding the participant’s age, sex, race, and relationship to the individual diagnosed with ASD (See Appendix B). The participant was also asked to report the age, sex, race of the individual diagnosed with ASD they were currently caring for.

Procedure

After Institutional Review Board approval was granted, participants were recruited on a volunteer basis from Interlock, an East Central Indiana Autism Support Group. In order to gain interest in the study an e-mail was sent out to the membership by the president of Interlock, which explained the basics of the study and asked individuals to sign-up for interviews. The participants were interviewed for approximately 30-40 minutes on a series of questions ranging from sense of community, respite care, types of information shared at the support group meetings, and social activity questions.
Results

Although many stressors are associated with caring for a child with ASD all is not lost for a family to function well as demonstrated in the responses by the participants. The main reasons for joining Interlock were connecting to other members in the community facing similar issues, while creating a social community (or interacting with others that understand the family dynamics of caring for a child diagnosed with ASD).

*Initial Diagnosis and the “Extra Mile”*

Initially hearing that one’s child has been diagnosed with ASD may be difficult as one participant described an acceptance process.

“I think it’s an acceptance process, although I have to admit there is a grief process that goes with it, which was hard for me to admit for a long time….. I think you kind of have to look at the grief cycle like I’m not going to deny it; I think it follows that pretty closely. The denial of nothing is really wrong and then a little angry, and really kind of a sadness that maybe your kids life maybe isn’t going to be what you expected or that he’s going to struggle. Thankfully I was able to move on, kind of like ok, here’s what we’re going to deal with and I moved pretty quick which was nice once I finally said okay I get what it is… but it’s hard to be effective if you’re not (accepting). I wasn’t accepting of letting other people in at first; I guess because I didn’t want to see people judge him. So, I think that’s part of the Interlock thing—you can go there and know that no one is going to judge and it’s hard to find a group that understands that.” (Kristen, woman, age 33)

“It’s draining to explain everything in detail or for people to feel sorry for you. You can’t express some of the things that happened to your kids because they don’t think they are as funny as our friends that have kids with special needs do. It really does make your life so much easier to not have to explain everything and not have people call you back or say they were crying or felt bad for your kids. We love our kids, we love who they are, I mean our kids are who they are because they are autistic, I wouldn’t know who they were if they weren’t.” (Andrea, woman, age 39)

“Autism isn’t like any disability where you can go in and you can go okay these are the problems we look for and okay these are the solutions to this problem you
don't have that from a physician. It's sort of like your child has autism and I'm so sorry and then that's it because it's such a broad spectrum every child's need is different. ”(Laura, woman, age 38)

The wide spectrum of ASD provides families of children with autism with different social opportunities. The opportunity to be social may be increased or decreased by where the child lies on the autism spectrum.

“We do everything, we don’t have any limitations. I guess with Justin he’s never screamed. He’s always been like the quiet child and for him I tease and call him the little turtle. With his autism it draws him into himself instead of where some of the children it’s an outburst and the whole building knows, well someone is not happy and for him he cries, but he kind of draws up into himself. He’s pretty good now about telling me when it gets to be too much. But yeah, now we go to barbeques, we go to swimming parties, to the movies, out to dinner, and yeah there are no problems.” (Angie, woman, age 32)

“We’ve found that some of our family is more interested in our children and more interested in including them in some family events. We basically feel that we’re not [included] , I think our family wants us there, but they are just overwhelmed and can’t handle what goes on with the two of them. I’ve taken Ben to one movie ever…..working on that for Interlock because I know in Indianapolis they have special movie times for our kids where the lights are up and sound is down and our kids are able to walk around and we’re going to work on that for our kids.” (Andrea, woman, age 39)

Going the extra mile is a common theme among parents of children diagnosed with autism.

Often parents have to help their children continue school work and/or skills learned at home much more than a “typically developing” child. Additionally, parents often coach their children through tough situations in order to achieve a desired outcome such as being able to walk around in a store for an extended period of time.

“He’ll go to school, kind of go through the activities there, and then ride the bus home and then usually when he gets home he’s pretty tired so we’ll usually allow him to have his down time right after he gets home. And then what we often do (he gets home around 3:30) so what we’ll often do is around 4:00 we’ll start what I call school time at home.”(Jessica, woman, age 38)
“I have levels of priority in my life and you have to and there are sometimes you have to let things go because other things are more important. Like Jared going to the grocery is a challenge and I would love to have respite care, but who’s going to love that child enough to sit on the floor of Wal-Mart and coach him through it so that we get to the end result of getting to the store and I go all the way to the back and get milk and toilet paper and get out without a tantrum, which now we can do that, before that was impossible.” (Laura, woman, age 38)

Benefits of a support group:

The understanding one gets from the group plays a large role in being comfortable with a support group. Each support group is unique as described by the following statement.

“Well, Interlock is more than just like a typical support group. It’s not about people coming and going “oh my child has been diagnosed and oh, I feel so bad for myself.” Interlock is more than a support group, it’s a resource center. I mean we are supportive of each other and what other families are going through and you know again, trying to throw a life raft to someone who has no idea, but we also have resources so for me it’s about the other things that we can get out of the group like the Prism Project, Autism Summer camp, Sib Shops, so it’s more than just for the kids with Autism, it’s for the whole family.” (Angie, woman, age 32)

“Being around parents who get it and not having to explain anything and that means a lot so going there and knowing that they (Interlock) will understand and going there and being able to laugh about things that other parents might find horrifying and knowing that the people at Interlock aren’t going to be horrified by something, and we can laugh, which is a coping skill really, just being around other parents and we laugh about it which is a nice relief rather than someone being horrified. …That’s been the biggest thing for me is just connecting with other folks who just understand and not judging…it’s nice just to be able to take your son somewhere where if he screws up it’s not the end of the world and no one is going to be yelling or screaming it’s more of a relaxed environment.” (Kristen, woman, age 33)

“I think that having a speaker come in and educate families on different issues. You start to see there are other people around you that struggle with the same things and you don’t feel so isolated because Autism is sort of a social disability it impacts your home life, your friends, your church, going to church is difficult, going to parties is difficult, even family functions can be difficult and if you have a child that exhibits disruptive behavior. If you’re in a group that experiences that
then it’s kind of second nature to everyone in the group. People are more understanding of that and I think that gives parents more comfort.” (Laura, woman, age 38).

As with joining a support group and being surrounded by people that you come to know and trust strong friendships have a greater opportunity to develop. A member described the aspect of group connectivity by describing the importance of friendship within the group.

”I’ve made a lot of really good friends in the support group that have become my inner circle inside the support group circle like we shop, we try to go out and try to catch a movie or have dinner, or talk about things going on with our children (it’s not all the time). I know one of the mom’s is trying to get respite care so we can go out and have a girl’s night out.” (Angie, woman, age 32)

“We’ve had families over to our house for dinner or went to other people’s houses for dinner or cookouts. We haven’t really gone anywhere in the community because all of our kids have different needs so something that might work well for one family wouldn’t work well for another so it’s mostly going to one another’s houses.” (Jessica, woman, age 38)

“I think people should get more involved [in support groups]. I think people tend to think that they have to give up their lives like we have, but I think that just participating and doing something that you know that you’re helping other people and even if it’s just a little bit of something...you kind of get to be yourself in a way like you get to have your own thoughts even if it’s more about Autism, which kind of takes over your life anyway, that doing something as a community I think is really helpful and a strong message and it feels good. The feeling of helping other people is wonderful, but also again you don’t always have to explain and when you do explain what is going on in your lives they get it you don’t have to go you know, everyone gets it and your learning from someone else what you can do with your own child.” (Andrea, woman, age 39).

Family stresses also have the potential to be relieved through group cohesiveness and social activity outside of the group.

“It eases the stress of the family. Like I said it’s nice to have a girls night out where maybe us mom’s can go to Applebees and have dinner and talk and laugh and not have to worry about correcting behaviors (e.g., the screaming). And the stress of being the mom all the time and I’m not saying being the mom to a
typically developing child isn’t stressful. It’s just from what I’ve seen personally from myself and other mom’s is that it’s a 24/7 job because our children have a harder time understanding things” (Angie, woman, age 32)

Family and Social Activities

The social activities that a family is able to participate in can be limiting and often may entail making many adaptations for a safe social environment. The social aspect of autism is one of the most challenging aspects for families. The social activities for families of a child with autism often have to be less structured and in a less crowded environment to avoid over stimulation.

“Research studies shows mothers of a child with Autism show higher levels of depression and that could be because of the rate of Autism, but it could be because it’s such a socially limiting disability because your child doesn’t look any different than from a typically development child.” (Laura, woman, age 38)

“We go shopping: we don’t go to restaurants because he doesn’t do well in restaurants. We will go to the park, outdoor activities are okay because he’s comfortable outdoors, We do try to go to the zoo or pumpkin patch, but it always has to be things where we are preferably outside. Definitely less structured so he can go through it at his pace and not feel rushed and we have to try and find events that are less crowded because the more kids you add….so like swimming at an indoor pool with a lot of people wouldn’t work or an outdoor one with a lot of people wouldn’t work even though he likes to swim----so it’s extremely limiting.” (Jessica, woman, age 38)

It is likely family outcomes for social activities can suffer by being limited on what activities can and cannot be done as a family. However, persevering through the tough times as a parent proves to be beneficial.

“My husband will go like okay, another great day we went to Wal-Mart and you know that’s sort of lame for a Saturday activity, but we do try to find things, we’re always looking into the community for events that we think he might be able to maintain at.” (Jessica, woman, age 38)
“Between ages 4 and 6-7 was rough for us. People would ask how do you to a restaurant and I would say, “be prepared to ask for a carry out box at any moment we would manage his behavior by letting him take walks while we waited for food, bringing fidget toys along with us, letting him wear a hat and glasses and trying to allow him to adapt to the environment because we can’t change everything for Jared ....Jared has to learn to do what we do and live how we live that’s kind of the point in helping him function in society. We can’t change society for him, but we can help him function within the realm of it. And so we had to go out to eat, we had to go to the store, and now we can go to restaurants and he can order his food and we can go to the grocery.... Where if we had not taken those extra efforts to go through that hell we wouldn’t be on this side of it or he wouldn’t either and it’s important for him to be able to.” (Laura, woman, age 38)

“We do—do movies, it’s important for us to get there early so he can have the seat he wants and it’s important for him to gauge people as they come in, he things sees in pictures so if he can watch everyone come in, he can picture them, if he goes in there are so many people there it’s overwhelming, but if he can watch them come in then he’s fine and he already has his own space and he’s not fighting for space. He does pretty good in movies, socially, we’ll go to the zoo and museum, but it takes a lot of prep work (food that he eats, breaks, family functioning we try to cut in short amounts of time---a few hours and we have to get out of there.” (Kristen, woman, age 33)

Respite Care

When asked about the importance of respite care one participant said, “Caring for a child with a disability and especially one that is behavioral can be very isolating because you can get stuck in a pattern where your evenings and weekends are always at home in your child’s safety zone (Jessica, woman, age 38).” Respite care was unanimously viewed as helpful by all participants. Although some participants did not use it as much, all of them supported the idea of respite care when asked about the importance of it for parents, but some were more reluctant to use it than others.
“I definitely believe they should use it to ease the stress. They can recharge themselves so they can go back and be there for their child. And it (respite care) eases frustration because you know we’re human and we’re tired and if you can go and even drop him (your child) off at someone’s house and even go home and say okay I just want to go home and take a couple hour nap or bubble bath just to recharge yourself. You know spoil yourself a little bit so you can be the person you need to be when your child needs you.” (Angie, woman, age 32)

“Respite is hard, we all want it, but then we are all reluctant to use it. You’ll find a lot of parents saying well yeah, I have the opportunity, but we’re all sort of still reluctant, there is a lot of benefits to it in the sense you can actually get out and have somewhat of a normal outing. You go to the grocery story with your kid it’s a lot different than when you go by yourself or god forbid you go to a movie and those are good benefits from it if you use it.” (Kristen, woman, 33)

Additionally, one participant added this when asked if they felt comfortable asking their family members to care for their child.

“No, I really don’t and it’s because of the lack of education and understanding... as much as she’s just uncomfortable around individuals with disabilities and with some people that’s their nature. And it’s not, that she doesn’t want to be, she just sort of is and Jared knows it and the way he responds to her is different. So, it’s more disruptive, it almost provokes a challenge for him. He feels as uncomfortable as she does and so it just not a good environment.” (Laura, woman, age 38)

Information Sharing and the Fight for Education

The type of information shared at group meetings was also found to relieve some stress of figuring out future plans for one’s child. Helpful information included estate planning, insurance information, connections to speech therapists, occupational therapists, and physical therapist. In addition, to the types of information shared some members have created subgroups of the larger support group by offering services such as Sib Shops or cooking groups that help families cope with the strict dietary needs (gluten free casein free diets) of some children on the
autism spectrum. Sib Shops is a program targeting brothers and sisters of children with special needs by helping them talk through some issues they may be facing.

“I guess, I’m 32 years old, you don’t think about planning a will---it’s not something you think about because you’re like well I’m going to stick around for a long time, but I learned a lot of good information as a parents of a young child and especially one with special needs that it’s important to have someone listed in a will. I’ve been working on doing that and found out that it’s not as expensive, and you can do it online and you don’t have to go to a high priced attorney. So at least he does have a guardian if something happens so he doesn’t have to go into an institution or something like that.” (Angie, woman, age 32)

“The Medicaid waiver, and people were like you have to do this, there is a 10 year waiting list, so we went ahead and got that started, because that’s more of when he is an adult, but if you wait until he’s adult and there is a 10 year waiting list, then you’re kind of out of luck for 10 years.” (Jessica, woman, age 38)

The battle between main stream and special education classrooms can sometimes become a difficult debate for parents. The debate becomes difficult because the school tries to manage what is “best” for the child, while protecting their resources (e.g., money for hiring additional specialized teachers or therapists). While a school tries to protect their resources a parent may see those resources as essential to their child’s educational experience.

“You hit something of a brick wall when it comes to schools, not that they’re not willing to work with you, but because their resources are limited. I think the thing that Interlock does best is to let families know what else is out there because you have to do some of the work on your own and be willing to go the extra mile.” (Kristen, woman, age 33)
“IEP’s (Individualize Education Programs) are hard because you go in and sit around with about 7 other professionals who are really about guarding their schools and their resources. You have to respect that, but it’s kind of intimidating because you want to set up the best thing for your child. They do too in the sense that they don’t want it to interfere with anyone else’s education, but they don’t want to provide the funding to do what they need to do to help Dave be successful. We struggle in that he has a full time aid (I had to insist on that) for him to be in a regular classroom otherwise they would be happy with him being in a high functioning special needs classroom…. I’ve offered to go with parents to their IEP meetings because it is really hard to go in and sit to hear people say really negative things about your child and tell you that you really don’t understand even…and that happens quite frequently actually. ” (Kristen, woman, age 33)

Discussion

In the early years parents may find themselves in stressful situations as they may have to adapt their entire routines to best care for their child. Parents may experience stressful situations such finding sufficient medical care, finding the means to pay for medical care, finding social opportunities as a family, and making sure routines stay steady.

The coping mechanisms used by families affected by autism are imperative to a family coping with negative societal outcomes, the rate of familial social activity, individual happiness, and overall well-being as a cohesive familial unit. Individuals possessing any of the common factors that are associated with ASD make the experience of internal support (within the family) or external support (outside of the family) an important ingredient for the emotional and social well-being of parents. However, external coping may be increasingly difficult as families with children with an ASD often has a restricted level of contacts with the community because family, friends, teachers, and community members often do not understand the behavioral characteristics of a child with ASD (Twoy, Connolly, & Novak, 2007). However, if a family is able to utilize resources (e.g., support groups or trained members of the community) it is likely to increase the family’s overall well-being.
The findings of this study confirm that social support, specifically individuals outside of the family (external) is valuable in providing positive outcomes for families of children with ASD. It is likely that the support surrounding the parents is a motivator to advocate for educational opportunities (e.g., being mainstreamed in school) and for social opportunities (e.g., special movie times for children with ASD).

Support groups for families of children with ASD provide opportunities for parents to connect with other members, share resources, and share sense of commonality. The commonality factor comes from being around individuals that understand the experiences of a child with ASD better than individuals of “typically developing” children. The social well-being of individuals caring for a child with ASD has a greater potential to increase when parents involve themselves in external supports. In addition, the overall functioning of a family may be enhanced by support groups as social activity increases through interactions with other group members or respite care is found through programs such as autism day camps or general connections within the group. However, it is important to realize that every situation is different and it may take many attempts at adapting to situations to find the “right” fit for a family of a child with ASD.

As one parent noted, music therapy into a child’s behavior plan, tends to be a calming technique. It is likely music therapy is effective because of its repetitive nature. It is likely that an individual with autism will feel a sense of relief to have a chance to be creative because they know when the music is going to start and stop. Routine for an individual with ASD is extremely important and can lead to decreased stress levels for the family as a whole. All changes produce stress; it is important for an individual with ASD to be prepared well ahead of time as they have a more difficult time adjusting to sudden change.
In addition, one parent noted that an emphasis on physical activity may be beneficial as parents can often get caught up in the mental aspect of raising a child with ASD. Although routine is important, slowly implementing new strategies and carrying back-up plans are important to raising a child with ASD. One parent said, “Carry a back-up plan, we used to have a baseball hat, sunglasses, and music, and headphone set and now the iPod is a beautiful thing because he can watch a movie or listen to a book, or he loves classical music which is great because it’s relaxing for him, um, those are kind of our strategies, but b/w the ages of 5-6 we have to take a chewy tube and sour lemonade…he would get a lot of oral motor stimulation and that was a calming effect on him (Laura, woman, age 38).”

Although a lot of trial and error may cause stresses for parents of children with ASD such as finding a diet that works for their child, educational opportunities, and social opportunities; they are resilient and loving parents. However, it is encouraging to see businesses such as local movie theatres work with Autism support groups to provide opportunities for their children to see movies like a “typically developing” child would be able to do. Movie theaters have set up special movie times where children with ASD can come into a comfortable environment (e.g., lights up, sound down, and if behaviors common to ASD occur then they will not be interrupting common theatre etiquette.

It is possible that a religious affiliation is more likely for parents of children with a disability as one parent described her coping mechanism by saying, “I guess I just have strong faith and pray my way through it when I have to and go “Oh, Lord, give me grace” because that’s kind of my thing when I’m stressed out.”
Limitations and Additional Research

The limitations of this study include a lack of diversity as all participants were Caucasian mothers in their 30’s from the same support group. It may be beneficial to conduct more research on parents and support groups for individuals with disabilities, but more specifically fathers and siblings of individuals with disabilities. The understanding of both siblings and fathers may aide in bringing entire communities together as a cohesive unit where more information or opportunities could become available. In addition, it would be useful if more support groups for parents of children with ASD or special needs were created due to the nature of support that is felt in these groups.
References


Appendix A

Interview Questions:

Sense of community questions:

How did you hear about Interlock or get connected to the group?

How long have you been coming to Interlock?

What was your main reason for joining Interlock?

What do you believe is the major benefit(s) of coming to a group such as Interlock?

How did you adapt to having a child diagnosed with Autism Spectrum Disorder before joining Interlock? How have your adaptation strategies changed since joining Interlock?

How has Interlock enhanced your life or impacted your family?

How do you feel Interlock provides group members with a sense of community or connectivity?

Respite care questions:

Have you ever used respite care?

What do you feel the importance of respite care is, why?

Have you ever called on another member of the support group for respite care? Please describe the experience.

Do you feel comfortable asking relatives of the family to help care for your child? Why or why not?

When do you feel the greatest need for respite care? (e.g. over the summer when school is out or during the holidays)?

What brings on the feelings for respite care?

How do you cope if respite care isn’t available?
Types of information sharing questions:

What type of information has been shared with you at group meetings?

What type of information do you feel has the greatest impact on your family or things you are doing for your child?

Have the meetings led to any successful changes in your own life or your child’s life? If yes, what have the changes been?

Social activity questions:

What types of activities do you do as a family (e.g. shopping, going out to eat at restaurants, attending movies)? How does your child deal with these types of social activities? Are you able to participate in these activities as a family effectively? If so, what are some common strategies you use to provide a safe social environment for your child?

What type of social activities have you participated in with other members of Interlock?

How often do you participate in social activities with other group members (daily, weekly, monthly, yearly)?

Do you feel you have an adequate amount of time for yourself or to participate in activities you find enjoyable on a weekly basis?

Do you have a sense of worry when you are not with your child and participating in some of your favorite activities?

Can you think of anything else that you believe to be important in participating in a support group for families that have children with Autism?
Appendix B

Demographics Questionnaire:

Participant’s Age:

Participant’s Sex:

Participant’s Race:

Employment Status:

Relationship to child:

Age of child:

Sex of child:

Race of child: