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Jocelyn Gorlin
jbgorlin@stkate.edu

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Systemically Treating Autism: A Guide for Empowering Families

Routledge: Brie Turns, Julie Ramisch, and Jason Whiting

Chapter 6: How ASD Influences the Extended Family and Society

Jocelyn Bessette Gorlin PhD, MSN, CPNP

Because families are nestled within the context of the extended families and society, when a child has ASD it affects much more than the nuclear family. This chapter reviews research that illuminates the effect of ASD on those who extend outside the immediate family and how this in turn influences the family. Specific questions include: 1. How do extended family members impact the family of the child with autism; and 2. How does the public including school personnel affect the family of the child with autism?

Theoretical Framework of Autism Family Research: Much of the research on the families of children with autism and related disorders is founded on an ecological and quality of life (QOL) theoretical framework.

The ecological model was first described by Hook and Paolucci (1970) in relation to families, while Bronfenbrenner (1979) described the ecological model in relation to individuals. Development is compared to a Russian doll: the individual is nested within the family and society in a reciprocal relationship in which the individual and family are not only affected by the environment, but also affect the environment in a feedback loop (Bronfenbrenner, 1979).

The QOL theoretical framework is strength-based focusing on satisfaction of a person's life. QOL consists of four domains that work in a synchronistic manner to comprise individual QOL: health and functioning, psychological/spiritual, social/economic, and family (Ferrans, 1996). Because cure is usually not the aim of care, QOL has been described as *the* goal of health care for children with chronic illness (Payot & Barrington, 2011) such as autism.

Family Quality of Life (FQOL) theory is derived from both an ecological and QOL base. It recognizes that the family is altered by the child with autism, extended family, and the public, but the family also experiences new strengths that are reincorporated into the family system. The family becomes

part of a reciprocal, ecological relationship with the child with the disability (Zuna, Summers, Turnbull, Hu, & Xu, 2010). FQOL methodologies are comprised predominantly of quantitative questionnaires. They assess parameters such as financial wellbeing, family relationships and support from others (including extended family and friends), and disability related services, among other parameters.

Extended family members of a child with ASD: A review of the Literature

Few studies directly assess the experience of extended family members who have a relative with ASD. Literature reviews on families of children with autism found that in both quantitative and qualitative studies, those outside the nuclear family such as grandparents or aunts/uncles or friends were rarely included in the research studies (Gorlin, 2015).

For example, of the 12 studies reviewed that assessed FQOL in families of children with autism and other disabilities, usually the mother was the only study participant. Though more than half of the studies did include an extended family member such as grandparents, aunt or “other,” there were usually one to two extended family members in each study, comprising a small fraction of the total sample (Davis & Gavidia-Payne, 2009; Gardiner & Iarocci, 2015).

Of 16 qualitative studies on the family lived experience of raising a child with autism, there was no representation from extended family members such as grandparents or aunts/uncles included in these the studies. Again, the mother was usually the primary study participant (Bultas & Pohlman, 2014; Lutz, Patterson, & Klein, 2012). Some fathers did participate in the studies, but usually represented a small fraction of the study participants (Hoogsteen & Woodgate, 2013; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011).

Overall, from these studies there is some information that can be gleaned. First, from the FQOL literature, it appears that severity and autism-related behaviors correlates with FQOL. Specifically, the more severe the disability, the lower the families rated their overall wellbeing (Gardiner & Iacocca, 2015; Pozo, Sarriá, & Brioso, 2013). Also autism-related behavior inversely correlated with FQOL, e.g., when autism related behaviors escalated, FQOL overall decreased (Davis & Gavidia-Payne, 2009).

Second, there seems to be a dichotomy between internal and external resources. Amongst the families of children with autism and other disabilities, there is a high level of satisfaction reported about relationships within immediate family (Brown, et al. 2010; Rilotta, Kirby, Shearer & Nettlebeck, 2012). There was, however, the least satisfaction reported about support from people outside the nuclear family including extended family and friends. In fact, this dichotomy was found to be true across several countries (Brown et al., 2010; Gardiner and Iarocci, 2012)

Other studies have also revealed extended family who do not seem to fully understand the situation faced by the families raising a child with autism. Bilgin and Kucuk (2010), for example, found that extended family sometimes helped the immediate family financially, but not emotionally. Bultus and Pohlman (2014) and Safe and colleagues (2012) described that parents felt marginalized from extended family members, who did not appear to fully understand autism. Davis and Gavidia-Payne (2009), on the other hand, noted that the support from extended family members was reported to be more important than the support from friends.

The Public and the child with ASD: A review of the Literature

Again, though there is little information that directly assesses those outside the nuclear family of a child with autism about their experience with autism, there is some information to be gleaned about the public's experience.

The public generally holds a stereotype that disabilities are physical, such as a person in a wheelchair. Autism, however, is often invisible, not readily apparent until the child manifests atypical behavior. The invisible nature of autism has been shown to be a factor causing stress for mothers (Bristol, 1984) because the public is more likely to accept poor behavior from a child that is visibly disabled versus one that is invisible.

Farrugia (2009), interviewed 16 parents, mostly mothers, of children and young adults with autism. He described diagnosis as a positive event because it provided a medical explanation of the condition. However, due to the normal physical appearance of the child with autism, parents often felt a

need to inform others outside the home that their child had a disability. This involved constantly teaching others so they could avoid stigmatization.

Hoogsteen and Woodgate (2013) also focused on the concept of invisibility of autism. They interviewed predominantly mothers in an effort to understand families of children with autism in rural Canada. They found that one of the main challenges that families faced was the need to educate the public that their child had autism because the disability is not visible. In this way they were able to help the child and themselves feel less marginalized.

Stigma or humiliation was described directly in reference to the child's behavior. This took the form of judgment by others specifically related to the child's frequent atypical behaviors (Lutz et al., 2012; Safe, Joosten, & Molineux, 2012). The result was feeling like a "bad parent" because the child did not behave as expected.

Lutz and colleagues (2012) interviewed 16 mothers of children and adults with autism, severity not defined. They identified social challenges including feelings of stigma and isolation due to their children's behavior. Again, parents noted the perception that they were not in control or were "bad parents" because of their child's behavior; there was often a desire to remove the child and themselves from the situation, which led to further isolation.

Safe and colleagues (2012) interviewed seven mothers of school-age children to assess the mother's role in caring for the child with autism. The respondents echoed the theme of the community's disapproval of the behavior exhibited by the child with autism. Mothers described the embarrassment of being judged by others because they could not "control their child," referring to the child's inappropriate behavior. Usually they would return home after these encounters stressed and depressed.

Isolation was an issue faced by many families as they raised a child with autism. Several families discussed the difficulty of leaving the home because of the child's behaviors or fears. Bultas and Pohlman (2014) discussed feelings of isolation from extended friends and family who did not understand their situation. Other studies noted isolation from friends and the public who did not understand the child's behaviors (Phelps, Hodgson, McCammon, & Lamson, 2009; Luong, Yoder, & Canham, 2009) and

some described avoiding situations outside the home that were uncomfortable for the child and family (Larson, 2010; Schaaf et al., 2011).

A Recent Study

A recent study was conducted to assess the family lived experience of raising a child with severe autism (Bessette Gorlin, 2016). The aim was to broaden the field to include those that were considered to be family whether related by blood or living in the same home.

Almost half of the mothers (5/11) identified members outside the immediate family and home such as grandparents, an aunt, or a friend as part of their “family.” Twenty two family members from 11 families of children with severe autism were interviewed.

The results were surprising even to the researcher: hybrid families developed over time that included nuclear family, extended and friends that were not all blood related and did not live under the same roof. This blurred the boundaries between nuclear and extended family and provided a unique lens into the experience of extended family members living with autism.

Extended family and ASD. The extended family was often instrumental in helping the families of children with severe autism which occurred not only in the one-parent families, but in two-parent households as well. Usually grandparents, specifically grandmothers, were identified as the individual from the extended family that they depended upon, but aunts were also identified as well. The elder’s role in raising children seemed to be not only a physical, but an emotional, support.

Parents discussed that extended family often helped with cooking, cleaning, and especially with caring for the child so that the parents could run errands, which were difficult to do when the child with autism accompanied them. Extended family members also took care of the child for short periods of time, so the parent could participate in exercise or take a mental health break. Some grandparents described recognizing that they needed to support the parents with a strong relationship so the parents in turn could have the strength to care for the child with autism.

Some grandparents took on the responsibility of planning for the future of the child with autism. One grandfather, for example, helped to organize and plan for the child's future care and finances when they (the grandparents) would no longer be living. One grandmother shared her fear of who would care for the child if the mother were not able, a concern shared by several parents and grandparents:

I'm sorry, (crying) but I'm just – and I'm scared to death because we don't have anybody in our family that can step up and say, 'If anything should happen to [mom], this is what we'll do.'

Several extended family members were adamant that the care that they provided for the child with autism was qualitatively different than the care that could be provided by someone outside the family. For example, an aunt in this study described that her role was to teach the child to love and this was a skill only she possessed as an aunt. She said: "They [the children with autism] learn to love and soften and love to receive, but you don't know how to tell somebody else how to do it." This perception of having a unique role in caring for the child was also evident in a comment by a grandmother who said:

I won't say I get 100% response, but for the most part I can do it. We'll be sitting here, and if he's eating lunch or something, I'll sing to [the child] him a little bit. I always try to talk to him because I just think that it's got to be important for him to hear me, and I do believe that that's one of the things I am. I am Grandma!

Part of the extended relative's unique role seemed to be based on the fact that the relative was older and wiser than most. Several of the grandmothers and aunt mentioned that being older they now had a greater understanding of others and accepted people as they are. This included accepting the child with autism wholly, a refreshing concept that was appreciated by the parents. As one grandmother remarked in describing her relationship to her grandson:

So her [the mom's] goals for him and frustration, I share them, but I have learned in the frustration. He's my darling. There's no shame in my game. I always say I only got one little egg and it's cracked. My one little egg and it's cracked. I love it!

Extended family members and friends worked tirelessly along with the nuclear family instituting positive behavior therapy to try to teach the child acceptable forms of social interaction such as shaking hands or hugging when appropriate. For example, one grandmother wept as she explained that her grandson with autism, who was now 13, had not yet significantly communicated with her daughter. She

said: “No, he doesn’t say ‘Mom.’ It breaks my heart. If he would only say ‘Mom,’ I would be so happy for [her daughter], but he doesn’t”

Some families embraced friends as family. One mother formed a national “underground phone network” to help other mothers raising a child with autism. She also welcomed some friends who helped with her child with autism as “sisters. This mother said, “There's not a blood tie, but there's something that's just as strong, if not stronger, here.”

In one family, a friend actually lived with the mother to help raise her child. She provided direct care to the child and also provided psychological support and respite time for the mother. One mother discussed that she considers her church friends to be her family who helped care for her child with autism, in part because no extended family lived close by.

The friendships seemed stronger if the friends were also raising a child with autism. There was an ease with these particular families because they did not need to explain if their child had “bad behavior.” A grandmother described how precious these friendships were to her son and daughter in law. She said:

[Mom] and [dad] are terrific, as far as building up a social network for him. They have friends over. With those types of families the parents have to come. One parent has to be there as well, but they have kind of a support group for their families. It’s wonderful because I think friends are so important and those families don’t have time to establish friendships, so they don’t get that support from the non-autism families. It just takes too much time.

The public and ASD. There was a general consensus among the families studied that there are public stereotypes or widely held beliefs about autism and the families experienced a stigma or humiliation associated with autism-related behaviors.

Many families found that there is a stereotype that autism is a mild condition. This was probably due to the fact that a form of autism, previously called Asperger’s syndrome, is well known to the public. The stereotype of autism as a mild condition has been perpetuated in popular movies such as *The Rain Man* or *Temple Grandin*. In these movies, the protagonists have high functioning autism and are extremely intelligent. A mother verbalized this sentiment. She said:

TV has created this unrealistic, weird expectation of kids that are autistic... I'm like, 'He has autism; he's not magic.' ...I get this question all the time: 'What's his special thing?' And I'm like, 'What do you mean?' Because they saw *Rain Man*, and they think everybody's a savant...Or they saw *Touch* ...and that was worse, because that kid was like super, super low-function on some things, but then was so smart and mystical on all these other things. I'm like, 'He's a 7-year-old. All he does is bug me for popsicles and cookies.'

Similar to previous research cited, families noted that there is a stereotype or widely held belief by the public, that disabilities are physical or visible, and therefore autism is simply misunderstood because of its invisible nature.

Families discussed that the public cannot understand that their child's behavior could be related to a severe disability and so the child's behaviors such as tantrums, "meltdowns" or tantrums, crying, etc., are interpreted as lack of parental control and "bad parenting." Because of this, the families experienced a sense of stigma or humiliation. One family member discussed her frustration in this regard. She said:

The frustrating thing about autism is that it's invisible, so I've heard more than once, 'Well, he doesn't look like he's disabled.' Would you like me to show you his certificate of disability? Or what can I do to prove it to you?

This family also noted the difference in public opinion when the same child appeared in a department store in a wheelchair. The mother sometimes used a wheelchair to help contain him when they shopped and found, "People seem to be nicer to him when he's in a wheelchair, because it's like the wheelchair carries the connotation of disability".

Several families echoed the concern that they felt stigmatized and ostracized by others because of their child's autism-associated behaviors. One father made the analogy between a person with a heart attack and a person with autism to illustrate the issue. He said:

So if someone's having a heart attack, people aren't ignorant about it, [they think] there's a heart attack happening, what can I do to help out?... They're not ignorant of the fact that this person's in distress, but ignorance about the spectrum disorder thing is a serious issue. That's what we deal with a lot, is that ignorance, because if [the child with autism is] struggling, since they're ignorant of it, all they do, or at least the rude ones, is treat it like you've got an unruly kid that you're not trying to manage.

Because of the invisible nature of autism, families needed to continuously explain that the child had autism. The families described the constant effort to educate others about autism that added to the

fatigue and stigma they already were experiencing. A few parents stated that they felt uncomfortable “making excuses for their child” and pointing out the child’s shortcomings which they didn’t want their child to hear. This is a comment from a family member describing her frustration in generally needing to educate the public about the child’s severe autism:

I guess the thing that really stings ...when people, like cashiers, would try to talk to him, and you have to explain, ‘He doesn’t talk. He doesn’t actually know what you’re saying; he doesn’t really have any concept of language,’ and it feels like it’s become your duty to give everyone a crash course in autism, and that’s exhausting. It’s really not easy to have to – it’s like he gets re-diagnosed every time, because you have to explain. Sometimes you end up telling the statistics, and ‘Yes, he’ll have this for his whole life.’

Many families discussed the challenges of having a child who sometimes manifested aggression to people in public. This resulted in the family being ever watchful of the child and fearful that he or she might hurt someone in public. Several families cited examples of the child hurting others in stores or people at school. Sometimes there were minor offenses, such as, a very young boy who liked to touch the sequins on the seat of women’s jeans, but sometimes it was more severe including psychological assault like rendering a black eye to a teacher. The result was that the families often avoided going into public places with the child.

This resulted in family isolation. Families recounted the numerous times they encountered sneers and stares from others who assumed that the child’s behavior was a reflection of bad parenting practices. Many recalled being publicly rebuked by department store staff because their child was having a meltdown. The following exemplifies one of the many encounters with the public that were discussed. Here the mother describes her interaction in a department store with her daughter with severe autism.

Note that they call the young girl “him” and “that.” The mother shared:

[They say] “What the hell is wrong with [the child]?” Things like that, or, “Get it under control; get *him* out of here! Why do you bring *that* in public?”... The loud speaker [is turned on at the store and they say] “What’s going on?” and “Maybe if you can’t get this under control you should leave!” We have left. Sometimes we haven’t when you have a whole cart of groceries, and you’re like okay, I know what’s happened in the past, I just need to leave now.

Similar experiences were shared by other families. Often families needed to make a choice of explaining that their child indeed had a disability instead of leaving. Some families wanted assistance from others, some wanted to be left to deal with the situation alone. Most said they wished that those in the public would give them positive reinforcement and ask how they could help rather than giving suggestions about how parenting should be done.

Here is another example given from a grandmother about her family's frustration engaging with the public. A grandmother shared her daughter's experience:

She [her daughter] told me a couple of years ago, 'I'm sick and tired of having to explain autism to people in the grocery store who look at you disgusted, as though, "Shame on you for not having control over your child" or "You've got a boy who's 5 foot 6 and trying to crawl into the basket of the grocery cart.'" And it's like, you people, you've never had problems? You've never had anybody in your life with a disability? You certainly are harsh on the ones who do!

Besides the few friends that were identified as a help, there was a general feeling of isolation concerning friends as well. Families discussed the simple logistical challenge of meeting with friends because their schedules were so busy, leaving little free time. It was also difficult to bring their children to other peoples' homes because of the child's behaviors and the need to be vigilant about the child's safety in an unfamiliar space. One mother discusses the challenges they face in trying to meet with family friends. She said:

We've tried to go eat with other people for dinner. They invite us for dinner; we don't get a whole lot of repeat come back.... Just having friends over, it's difficult, sometimes. We have to wait until the kids are asleep and then we can invite friends over, but then their kids are tired and so then they can't come over.... Some people do that [have friends over] for double dates and stuff, but we're not doing it to have fun; we're doing it because we can't come over and play cards. We'd love to come over and play cards....

School was another area in the public realm that resulted in feelings of isolation. Though there were several counts of positive experiences at school, specifically the early intervention programs that often led to diagnosis, there was also the overwhelming theme of isolation experienced by the family at school. Families discussed the child often being separated from other neuro-typical children, and there

were low expectations of their children at school. Lastly, several families described confrontations with school staff that ultimately resulted in the family's expulsion from school.

Several families reported that their child was not included in the classroom like other children. For example, one child did not have an orientation to the school like other students and was not included in special holiday activities like parades. Another father described that his child was taken out of the classroom to wander about the halls because the teacher did not want the child to disrupt classmates. This made the family feel ostracized from the school community in general. As this father astutely pointed out, separating the child with autism from the other school children robbed not only their daughter of the class experience, but it robbed other classmates of the opportunity to learn about disabilities and compassion.

Many of the families described confrontations with school personnel which led to the child being "kicked out" of school. It was unclear why these confrontations occurred, but they appeared to involve the family members advocating for the child in school. A mother described an experience when her child was "kicked out" of her public elementary school. She recounted:

That's when the principal came down that day and told me, and I quote, 'Get the hell out of my school! I'm going to go get [your child].' I said, 'Don't you dare go get [my child], I will get [my child]!' And then we never went back.

Whatever the reason for these confrontations with the school, the families ultimately felt alienated and isolated from the school community, which is typically the hub of a child and family's life.

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