



**EDUCATE, EMPOWER, AND ENLIGHTEN A COMMUNITY ON  
AUTISM**

**By: Lori Goss-Reaves**

**Presented at:  
NACSW Convention 2015  
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**Abstract:** *Parents raising children with autism face many challenges. Research has reported a need for formal and informal services to assist parents with the challenges they face. This article will focus on the results of a participatory action research study aimed at exploring how formal and informal services impact parental stress. The participants in the study identified their unmet needs and created an action plan for community change.*

**Key Words:** autism, parents, participatory action, research

## Educate, Empower, and Enlighten a Community on Autism

“Seek the peace and prosperity of the city to which I have carried you into exile. Pray to the Lord for it, because if it prospers, you too will prosper” (Jeremiah 29:7, New International Version). Social workers are trained to embrace their communities by working collaboratively to invoke change. Participatory action research (PAR) is a collaborative approach to research that seeks to engage those most impacted by the problem being studied. It is through the research process that individuals, organizations and communities become empowered and change occurs (Stringer, 1999). As communities thrive, individuals in the community are positively impacted.

Autism spectrum disorder, otherwise known as ASD, is a complex neurodevelopmental disorder for which there is no known cause or cure. Research has found that parents of children with autism report increased levels of depression, anxiety and stress (White & Nay, 2009). These parents often rely on formal and informal supports to cope with the stressors they face (Bishop, Richler, Cain, & Lord, 2007). This study expands the literature regarding how formal and informal services impact parental stress. Recent reports indicate that one in every sixty-eight children is diagnosed with autism. This shows the ever-increasing number of families who are being impacted by ASD.

### **Methodology**

The research question that drove this study was: How do formal and informal services impact the stress level of parents raising children with autism? A participatory action research

approach was used to elicit participation from those who were formally and informally involved in the problem being studied. A participatory action research approach was selected because it is built on the assumption that when stakeholders share their diverse knowledge and experiences with each other, they can create solutions to the problems they face (Stringer & Dwyer, 2005). This is done through a cycle of looking, thinking, and acting.

During the look phase, qualitative data was collected from the participants. This included eleven primary stakeholders who were all raising a child with autism. Three secondary stakeholders also participated in the study; these individuals were professionals who worked in the field of autism. Participatory action research is a process that is cyclical in nature. It allows the participants to become active members in the research process. Through observation, reflection, and action, a well-designed action research study can result in community change and social action (Greenwood & Levin, 1998). That was the overarching goal of this research project.

During the analysis phase of the project, all of the gathered information was reviewed, the transcribed data was coded, and categories were identified. As converging and diverging perspectives were analyzed, themes emerged (Stringer, 1999). The information was presented to the primary and secondary stakeholders during the first focus group, and a joint account of their experiences was created. During the second focus group, the stakeholders assisted in the data analysis by prioritizing the themes that had emerged. This information was used to develop the action plan.

### **Summary of the Findings**

One finding from the study was that parents in the ABC community did rely on formal services to help their child with autism. These services however, did not always result in a

reduction of parental stress. By enumerating the data, the researcher found that 91% of the primary stakeholders were utilizing formal support services. The formal services that were being utilized included: First Steps, speech therapy, occupational therapy, physical therapy, public school IEP services, special needs preschool, applied behavior analysis, family counseling, career counseling, Medicaid waiver services, and special activities organized by the autism coordinator in the public school system.

### **Factors That Increase Parental Stress**

The formal services were found to increase parental stress when they were not evidence-based, not available in the community, not stable, or not accessible to the parents due to finances or eligibility. The parents described their experiences this way:

#### **Evidence based.**

- Probably what increased our stress the most is that there were so many non-researched based programs on the Internet and we would go after most of those and there was not only no funding to support that, but there wasn't really anyone to help you do it.

#### **Community availability.**

- It was stressful to drive [child] to services.
- We see a specialist in [town 40 miles away] for [child's] dentist and we have [child's] neuropsychologist in (town 50 miles away). The only thing [child] sees in [the ABC community] is [child's] pediatrician.

#### **Stability.**

- They [the formal services] were not stable. It seems like there was always somebody new, someone changing, and this is really hard for kids like my daughter. Because the same person, they understand her but you know it takes months sometimes, at an hour a week to try and get to know your child.
- It seems like there was always somebody new, someone changing, and this is really hard for kids like my [child].

### **Finances and eligibility.**

- They [formal services] impacted my stress because there are some financial restraints that go with it.
- Not being able to provide for my child what [child] needs because I make too much money that has been very frustrating. On paper it may look good but you can't pay for the therapy yourself.
- Sometimes I feel like there are a lot of organizations that say that they can help them [child with autism] but when you call them up they'll say, 'Oh well, you are not in that category.'
- If it [ABA services] had been less of a financial strain, we probably would have done it longer because I think it was helping. We were not seeing leaps and bounds of major improvements, but we were seeing some.

**Skill and empathy level of the provider.** The formal services were also reported to increase parental stress when they were given by a provider who did not understand the needs of the parents, were not specifically trained in autism spectrum disorders, were not careful with their words, and were not familiar to the provider. This was demonstrated by the following comments by primary stakeholders:

### **Understand the needs of the parents.**

- When you have a child with autism you really want the hands-on, you want someone right there that you can talk with and you can say, 'Okay, that's fine,' but what to do in this situation and we didn't feel that we had that. Everyone was just—kind of, you know—the information was there but not the hands on emotional support that we needed at the time and that's kind of frustrating.
- I think sometimes the workers don't realize their words, when we are so desperately hanging on and every day is a battle.
- When someone says, 'Well, be thankful that [child] is on the spectrum,' that totally dismisses everything we go through because it's like—you're not home with [child], you don't see the tantrums, you don't see the frustration when he is being bullied. It just almost tries to dismiss what we are thinking or feeling or the challenges that we face daily.

### **Trained in autism spectrum disorders.**

- [Agency] encouraged us to get counseling there for the behavior therapy but when we met with the therapist there it just did us no good. They were actually giving us parenting information, but it was so general that it wasn't being applied to his behaviors. We really struggled with that—we gave that up.
- It wasn't a counselor who specifically knows autism, so I feel like maybe by him not having a specific awareness of Asperger's that it maybe wasn't as effective as it could have been.
- We are still battling the [general education] teachers.

### **Careful with their words.**

- The ABA therapist told me that we need to prepare him to live in a group home and I thought, 'No, we are going to prepare my child for college.' We are setting the bar that high, and I will lower it if he can't go there. But how can you set your bar so low for a child? We have no idea what they are capable of.
- When you meet that negative person who takes your hope away.
- I had someone tell me one time, 'Well your son is retarded' and that just rocks you to the core because I am thinking, 'Well, he is probably smarter than both of us combined,' because you know they are aware of things we just don't even realize.

### **Familiar to the parents.**

- The occupational therapist changes every few months it seems like. [Child] gets comfortable and gets into a routine, he's making great progress and then I pick him up and, 'Oh my gosh, I don't know who you are and I just left my kid with you for an hour.'
- I would not be comfortable leaving my child in respite if I did not know the provider and know that they were trained to deal with my [child].

### **Factors That Decrease Parental Stress**

Formal services were also found to have a decrease on parental stress. The factors that impacted this were the impact on the family system, location of the services, amount of support



and relief from care the service provided to the parents, impact on the child's development, and services given by a provider who advocated for the child and understood the needs of the parent.

**Impact on the family system.**

- Something we are able to do as a family that really relieves our stress [referring to the autism friendly movies].
- The Valentine's Dinner was wonderful because we were able to sit down and go face-to-face, my husband and I, because the kids were off in another room.

**Location of the services.**

- The services in the home have been very valuable.

**Amount of support and relief from care provided to the parents.**

- They've given me a break, which is amazing sometimes.
- You know it's like you have someone on your team.
- The special needs teacher and her group is absolutely wonderful. She advocates for my son and that is her main focus.

**Impact of the service on the child's development.**

- It has actually made my stress better because I felt like [child] was getting some kind of help from people that know about it [autism].
- I think they helped in the speech aspect of it. My stress is much less because he speaks.
- Special health insurance covers ABA even though it's only two hours a week; those are two golden hours because it is another person coming into his life.
- I think it is hard when you are a parent to know that there is all this good information out there, but you don't know yet what to use. Sometimes you get a lot of people coming at you just wanting your money, you know and you are so desperate—you want your baby back—and if you had the money you're willing to try it, but sometimes—I know this will sound cold—but sometimes it seems like people give lip service and nothing comes from it.

- A lot of times you hear the same agency saying over and over again, ‘Here are the signs of autism, and how to get them diagnosed,’ but then there is nothing about how to take care of a child every day.

### **Provider who advocated for the child and understood the needs of the parent.**

- The special needs preschool staffs are like family because every triumph we had they celebrated with us like [child] was their child or grandchild.
- When the teacher says, ‘He’ll get it in time; he’ll get it,’ and it kind of eases you down and lets you know it will be okay, you’re going to make it through, it is just a rough spot.

### **Informal Services**

While formal services were found to have both a positive and negative impact on parental stress, informal services were only found to have a decrease on parental stress. The primary stakeholders expressed the impact of informal services in these ways:

- Sometimes it is just another parent that has a child with special needs, they understand too. Even though the problems are different, they still understand.
- It’s good to know that I’m not the only one going crazy sometimes and experiencing the stressors I am facing. It is stress relief to be able to rant to someone who understands.
- It’s almost like we have battle scars and they know what you mean.
- And I don’t know where we would be without the friend’s support that has honestly been our biggest support.
- Having someone to communicate with has been the biggest thing.
- They have helped you realize that you are not alone.

**Help from immediate family.** Sixty-three percent of the primary stakeholders also listed immediate family as being an informal support. The amount of support was dependent upon the location of the extended family, their understanding of autism, and their age.

### **Location of extended family.**

- Our family is very supportive and we are very appreciative. Unfortunately my parents live in [another state]. They come up three to four times a year.

### **Their understanding of autism spectrum disorders.**

- Family has definitely helped with the stress by giving me a break and trying to learn as much as they can too. To know how to handle him and things he does.
- From my extended family there is a huge lack of understanding, a lot of them are older and autism, of course, wasn't huge back then.

### **Their age.**

- My [adult] daughter is very supportive.
- The sibling is two so she really hasn't—I mean she has sort of added to the stress.

**Church.** Fifty-five percent of the primary stakeholders reported that they stopped going to church due to the challenges of taking their child with autism. Four of the primary stakeholders reported that they received support at church, but that there was no formal program in place for their child. The support received and unmet needs are reflected in the following statements from primary stakeholders:

### **Church support.**

- This [new] church has just reached out and been amazing towards us. They never really provided any support except for love when we are at church.
- Our church has really been supportive. I think partly because we have other kids in the program so there is this awareness that they work with families. The director is very good at communicating with me; like if he had a bad day or days where he wouldn't go in and he would hide under a table, [she was] just very encouraging that he'd be fine.

### **The unmet needs at church.**

- The church has really been a big issue with us in the past. We started out when he was younger going to church; he never warmed up to the classrooms or anything. It was hard for him to sit with us, you know, with the rest of the congregation, and the loud noises. Even the microphone, the pastor talking and it has been way too hard so we have really stopped going basically.
- At that point, I felt like I could not leave him at the church in that setting, so we started taking turns having someone stay with him or we paid someone to be at home with him.
- I would go to church every week, but then I just kind of stopped.
- We would like to go as a family again someday.
- We have not been, we tried one Sunday and there was a meltdown. It was a change of routine; there were a lot of people so we just stayed home. My husband will go one week and maybe I will go in a couple of weeks.
- I've gone to churches before, like one church I went to and the lady was like, 'Put him in the nursery.' Well then he wanted to roam and she came back out and she was like, 'We won't take care of your child like that,' so I stopped attending. I try to teach my baby about God, we watch programs on TV and stuff.
- We really like church, but I had to take on two part-time jobs so a lot of weekends I was working and I couldn't go and my wife struggled with trying to take him by herself and everything. So we probably haven't been to church in about four to five years.

### **Unmet Needs That Became the Focus of the Action Plan**

During the second focus group, the stakeholders worked together to identify their unmet needs. They created a joint account of services they would like to see made available in the ABC community. This became the focus of the action plan. The identified services were:

1. A program to provide emotional support to families and link them to services
2. A mentoring program for parents
3. A support group
4. More things in the community to increase awareness of autism

5. Respite care
6. Overnight respite care
7. ABA for children with autism without the financial burden to their family
8. More options in therapy (e.g., counseling, ABA, speech, occupational therapy, physical therapy).
9. A hub or centralized place for information about services and activities in the community
10. A newsletter
11. Extended Junior Face Place
12. Something organized through the university in the ABC community
13. Someone to help parents deal with loss, grief, and acceptance
14. More autistic friendly things to do in the community
15. An organized time (with volunteers or students) for parents to have a evening free from the care of the child with autism
16. Daycare that is equipped to meet the needs of children with autism
17. Additional speech therapy, outside of what is provided by the public school system, without the financial burden to the family.

### **The Action Plan**

The primary and secondary stakeholders were very involved in the action plan phase of this research project. They collaborated to prioritize their identified unmet needs, which directed the focus of the action plan. Six themes emerged and five were addressed in the action plan.

These themes were: (1) emotional support at time of diagnosis; (2) a hub or a centralized location

to learn about community events/resources specifically geared towards parents and children; (3) emotional support from providers who understood ASD and the needs of the parent; (4) a break from the daily care of the child; and (5) ongoing emotional support for the parents.

### **Emotional Support at Time of Diagnosis**

The first action was to find a way to help parents of children with autism at the time of the diagnosis. As a collective group, the stakeholders made a list of the emotions they felt at the time their child was diagnosed with autism. The emotions were: anger, fear, nervousness, anxiety, sadness, joy (to know what they were dealing with), and feelings of being overwhelmed. To assist others who are going through the same experience, the group decided to make a “First Aid Kit for Autism.” The host agency produced 100 kits, all of which were distributed. The stakeholders were passionate about their desire to do something to help other parents who were facing the issues they had faced. They became empowered by their ability to make a difference in the lives of other parents who were embarking on the journey of raising a child with autism.

### **A Hub or Centralized Location**

The second action addressed the need for a hub or a centralized location for parents to receive information about autism related services or activities in the ABC community. A meeting was held with community leaders who had hosted an event in the past to serve this population. At this meeting, the community leaders learned about a community calendar, which had recently been created to inform parents of events that were occurring. This calendar also allowed individuals to search by topic and find services within a 120-mile radius of their community.

Each agency representative that was present was given the opportunity to partner with this project so events could be posted. Every agency that was present chose to create an account and made a commitment to post their events on this online community calendar. This web-based

calendar will serve as a hub and centralized location in the community where parents can access information about events that are being held that promote autism awareness or support for parents who are raising children with autism. Another option given was for organizations to link their web site or Facebook page to the community calendar. One stakeholder was granted permission to have Facebook unblocked for the purpose of informing parents about upcoming activities.

### **Emotional Support from Providers**

The third action focused on providing parents with emotional support from professionals who understood the needs of the parents who were providing care to a child with autism. A presentation of the research findings was made to the administrative staff of the host agency. The agency director was interested in learning how the host agency could become a source of counseling support to parents who are raising children with autism. The researcher made a presentation to all clinical staff of the host agency. This training equipped the clinicians to better serve parents of children with autism. The training was also used to inform the parenting programs at the agency.

### **A Break from the Daily Care**

The fourth action was in regard to respite care. According to the results of the data analysis, respite care was an unmet need of parents who were raising children with autism in the ABC community. A meeting was held with the regional director of the Department of Child Services (DCS). The researcher presented the results of the study to the director and found that respite dollars would soon become available. Although these dollars were not earmarked for parents who were raising children with autism, they were able to utilize them. The researcher also sought options for respite care that allowed the parents to be familiar with their provider. A

state-funded service called Caregiver Support was found. Primary and secondary stakeholders were made aware of this new program and how to access the service.

### **Ongoing Emotional Support for the Parents**

The fifth action that resulted from the study was that the behavior support group, which began as a pilot in February of 2013, was expanded to meet the needs of additional parents. The original group was capped at ten members. The autism coordinator, after learning of the primary stakeholders' needs for emotional support and desire for a support group, stated that she would add another behavior support group so that ten more parents could join.

The results of the study were also used to create changes in the content being presented at this behavior support group. This was done to better meet the needs of parents who were raising children with autism. After hearing about the parents' need to better understand how to advocate for their children, the leaders invited a speaker who specialized in advocacy for special needs children to come to their next meeting. This speaker was able to share with the parents the options they have for advocacy training and their right and opportunity to have an advocate with them at all case conferences where the IEP's are developed. One secondary stakeholder stated:

- The discussions we have had do have an impact on the future as we work together. It helps to hear what parents face and about their needs as parents. It will impact how we conduct our next parents support meetings.

Another secondary stakeholder stated that she was going to make some changes to an event she had planned as a result of hearing the needs of parents during the three focus groups.

She stated:

- We are good at throwing things at you. It is time to take you step by step.



## **Discussion of the Results**

This study revealed that parents who are raising children with autism rely on a variety of formal and informal services to cope with the stressors they face. These services, however, were not always found to decrease parental stress. A participatory action research approach was found to be an effective way to bring together primary and secondary stakeholders who had an interest in the problem being studied. The primary stakeholders were able to collectively find their voice. Their voice was heard by secondary stakeholders who were in the position to make changes in the services delivered. The stakeholders worked together to create a “First Aid Kit for Autism” that was distributed in the community. One primary stakeholder stated,

- This (focus) group might not change everything, but it might be a catalyst for change. Coming together creates synergy that can continue from here.

## **Recommendations for Future Research**

This study pointed to the need for future research in the area of church programming aimed at supporting parents raising children with autism. The data revealed that 55% of the participants stopped attending church after their child was diagnosed with autism. Research aimed at gaining insight into this phenomenon is needed, along with solutions to the problem. The participatory action research approach used in this study was found to be effective at empowering stakeholders, improving practice, and facilitating community change.

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