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**Parents of Children with ASD: The Effects that Having a Child with Autism Spectrum  
Disorder has on Parents and Families**

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**Author Note**

I have no known conflict of interest to disclose.

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### **Abstract**

Autism spectrum disorder (ASD) is a largely prevalent disorder that is typically first diagnosed at a young age. This diagnosis can have extreme effects on the family members of these children with the parents or guardians receiving the greatest impact of these effects. Having a child with ASD can be detrimental to a parent's mental health as well as to the family's functioning capabilities. This literature review found and reviewed 11 articles to interpret the psychological effects that having a child with ASD has on parents. Additionally, this article aimed to determine the effectiveness of intervention programs that have been implemented in these families and if they would be helpful in the future. It was found that there is a significant amount of parental stress as well as large amounts of anxious and depressive symptoms present in the parents of children with ASD. Furthermore, the evidence suggests that the intervention programs implemented in these specific studies decreased the negative symptomology of parents of children with ASD as well as improved overall family functioning.

*Keywords:* autism spectrum disorder, parental stress, family functioning, intervention programs

## **Parents of Children with ASD: The Effects that Having a Child with Autism Spectrum Disorder has on Parents and Families**

Autism Spectrum Disorder (ASD) is a developmental disorder that impacts the nervous system and impairs one's ability to interact and communicate with others as well as some motor skills (American Autism Association, 2020). ASD is typically manifest in the first three years of life and is a common disorder that affects 1 in 54 children worldwide, with symptoms varying between each person (National Autism Association, 2020).

There have been some findings that reveal that there is a high correlation between parents of children with ASD and an increase in parental stress levels (Feinberg et al., 2014; Khanna et al., 2010; McStay et al., 2013; Pattini et al., 2019). Along with this, there have also been correlations found between significant behavioral problems in children—particularly young boys—with ASD and an increase in psychologically depressive symptoms in their parents (Bromley et al., 2004). As ASD is generally found in the first few years of life, the parents have a large amount of responsibility put on them as they raise their child. Because of this increase in responsibility, there are more concerns about the psychological stress manifested in these parents. Due to the increase in the parents' psychological stress, there are some parents that need therapy or other resources and are not receiving them.

While not all families are significantly impacted, trends illustrate that there could be more need for assistance in these parents' lives than what is being offered. For these reasons, this literature review will examine empirical literature on the psychological effects that children with ASD have on their parents or guardians. This review will specifically examine the psychological symptoms of parents, the effect that having a child with ASD has on family functioning, and the

effectiveness of previously implemented intervention programs, as well as some possible implications for future research.

### **Methods**

This search was done to find the effects of having a child with autism has on parental stress levels, as well as the effectiveness of intervention programs in the lives of parents of children with ASD. The three databases used in this search were PsychInfo, Web of Science, and PUBMED. To find the correct articles relative to the question at hand, the search items included: ‘autism’ OR ‘ASD’ OR ‘autism spectrum disorder’ AND ‘mental health’ AND ‘family stress’ OR ‘parental stress’ AND ‘United States’. There were also filters used to narrow the search results.

This search gave 111 articles and therefore, to narrow the results, the search excluded 1) non-empirical articles, and 2) articles conducted before the year of 1990. Specific items such as ‘United States’ and the keywords of ‘family stress’ were added to this search to narrow the results. This then gave 37 results which were then analyzed. The 11 articles that were used in this study were those that passed the criteria of 1) pertaining to the appropriate topic, 2) written in the English language, and 3) pertaining to the parents and other family members of children with ASD and not pertaining to the children themselves.

### **Results**

The information regarding parents of children with ASD was similar across all the articles found. However here, they will be summated within three subgroups which include the psychological symptomology of parents of children with ASD, the impact ASD has on parental family functioning, and intervention programs and the degree of helpfulness in their targeted areas.

### **The Psychological Symptomology of Parents**

Each study touched on the manifestations of different psychological symptoms from parents of children with ASD with parental stress being the most highly mentioned. Pattini et al. (2019) specifically discusses the major differences between mothers of children with ASD and mothers of typically developing children and their levels of anxiety and parental stress. They did so by administering a psychological stress test to 15 mothers of children with ASD (M-ASD), and 15 mothers of typically developing children (M-TD). They then measured the differences in heart rate and cortisol levels; the participants were also interviewed and given stress tasks. Each of these measurements were purposed towards analyzing the differences between the reactions of M-ASD and M-TD. Their results illustrated that M-ASD experience heightened levels of anxiety, lower social motivation, and an increase in avoidance strategies compared to M-TD. They also found that there were significant stress-induced rises in cortisol levels that were only present in M-ASD. There were some limitations that were presented within this article, one of which was that the sample size for each group tested was not extremely large and therefore could affect the validity of these findings. However, this study still offers a unique view of these mothers' lives and the effects that having a child with ASD has on them.

Khanna et al. (2010) illustrated similar results to those demonstrated in the study performed by Pattani et al. 2019. They did so by administering a wide variety of self-assessments that examined different areas in the parents' lives such as parental stress levels, quality of life, coping strategies, etc. Something that is of importance to note is that of the 1,039 self-assessments sent out, only 304 were returned, therefore creating a sample size that was smaller than the desired amount. This also effects the demographics that are tested here as the researchers could not choose who responded. However, as this number does meet the standards

for statistical significance the findings show validity. The results from the responses received indicated that high levels of anxiety exhibited in the parents are correlated to lower amounts of support offered to them by their community or family. The results also revealed that the parents who reported a larger extent of behavioral problems and functional impairment in their children scored significantly lower on the quality-of-life assessment than those parents who did not. This study also compares the scores they received from parents of children with ASD to those of the general US population. Their comparison showed that parents who have children with ASD scored much lower in physical health, general health, social functioning, mental health, emotional role, and in their mental component summary than the general population.

Another study took a different approach in trying to determine what factors of having a child with ASD causes the most parental stress (McStay et al., 2013). They measured the child with ASD's age, behavioral disorders, and quality of life to see if these may be large contributing factors to parental stress. Like Pattini et al. (2019) they compared the scores received by children with ASD and their parents to typically developing children and their parents. Unlike the limitations of Pattini et al., (2019) they had 204 participating parents. Though one limitation that can be seen here is that a large portion of the children tested in this study were male with a significantly smaller female population. However, they saw that young males often caused more stress in parents than did young females (McStay et al., 2014). Their findings showed that age and verbal ability did not have a significant impact on parental stress, however there were significant correlations found between autism severity and increased parental stress. Parental stress also tended to increase if the child was less proficient in attention and social skills as well as if they demonstrated a large amount of behavioral opposition and hyperactivity. However parenting stress levels went down if the child's quality of life was better (McStay et al., 2013).

Nevertheless, if the child demonstrated higher degrees of behavioral problems, then the parents' quality of life decreased (Khanna et al., 2010; McStay et al., 2013).

As described in each of the studies above and several others, there is a significant amount of parental stress present in parents of children with ASD that is not typically present in parents of typically developing children (Khanna et al., 2010; Pattini et al., 2019; Schiltz et al., 2017). As represented by the data, there are certain aspects of ASD and its symptoms that cause greater psychological symptomology within parents. Behavioral difficulties and social impairment are both common factors that have correlated to higher levels of parental stress than other ASD symptoms (Feinberg et al., 2014; Khanna et al., 2010; McStay et al., 2013; Pattini et al., 2019; Schiltz et al., 2017).

### **Children with ASD and Family Functioning**

Along with looking into what specific aspects of ASD cause parental stress and other symptomology, some of these studies investigated how the symptoms exhibited by the parents effect the family and its systems. Di Renzo et al. (2021) did so through a cross-sectional study across 61 families of children with ASD. They aimed to test the children with ASD and their differentiated qualities and abilities as well as the family and their reactions to certain behaviors or actions shown by the child. They did this to see if the children had a significant impact on the family interactions and family systems within. A questionnaire was used as the main method for testing their hypothesis. This testing strategy could be a limitation due to other methods such as interviews being substantially more in depth. However, from the information gathered, it was found that the parents who had good quality of relationships with their spouse were associated with better parental competence and therefore had lower stress levels in caring for their children (Di Renzo et al., 2021). This was evident even if their children presented the typically stressful

characteristics mentioned by McStay et al. 2013. Di Renzo et al. (2021) also saw that the families who were more balanced and had healthier interactions tended to have less stress in their lives than those who reported an unbalanced and problematic functioning family with unhealthy interactions.

Similarly, another study explored parent-child interactions and parental attitude in rearing children with ASD as both are integral in understanding the growth and development of children (Ozturk et al., 2014). This was done by examining questionnaire responses given by 99 participating parents of children with ASD. They found that the parenting attitudes differed between mothers and fathers. The mothers were more prone to feel as if they must take on more of the responsibility for interacting with and caring for their child(ren) with ASD than the fathers did. This study also noted that the parents who experienced heightened stress directly relating to their parental role often felt that a large amount of their stress came from the interactions they had with their child(ren) (Ozturk et al., 2014). To add, the parents that received less support (familial, social, therapeutic, etc.) were more likely to experience greater levels of psychological stress than the parents that had more access to or were already receiving more support (Bromley et al., 2004) This was also seen in the study done by Khanna et al. (2010). The parents that struggled with balancing the differentiating roles that they held without additional support from outside sources also showed increased signs of stress related parental functioning as well as depressive symptoms (Bromley et al., 2004; Ozturk et al., 2014).

While Ozturk et al. (2014) performed the testing process through implementation of questionnaires, Bromley et al., (2004) instead used an interview process. There was some similarity in the number of parents participating as one had 99 (Ozturk et al., 2014) and the other had 71 (Bromley et al., 2004) which both reach the amount sufficient for statistical significance.

However, there are differing limitations present in each of these studies. Ozturk et al. (2014) tested both mothers and fathers of children with ASD whereas Bromley et al. (2004) only tested mothers of children with ASD. This presents a possible constraint in the comparison of these two studies and their findings as one has a less generalized population than the other. Nevertheless Ozturk et al. (2014) does mention that there was a sparse number of fathers that were willing to participate in this study, so the comparison made previously is still valid.

Another study by Rodrigue et al. (1993) took a different approach in examining the effects that children with ASD had on family processes by instead looking at the siblings and their perspectives. They administered different scales that measured social and behavioral adjustment in the children as well as a scale that measured satisfaction for the parents. There was a total of 59 siblings of children with either ASD or typically developing children to offer a comparison between the different perspectives. A limitation in the research could be that Rodrigue et al. (1993) did not examine the size of the family and if that had a greater impact on the siblings and the expectations forced upon them. Rao & Beidel (2009) performed an extremely similar study of the siblings and the parents of children with ASD and their adjustment and stress levels. Here, the biggest limitation is that their sample size is quite small ( $n=29$ ) and does not reach statistical significance like other studies do.

From the results of these two studies, it was determined that a significant number of siblings of children with ASD felt that they received less parental attention than their sibling with ASD. They also noticed that a degree of the increased parental stress had a residual effect on the siblings of children with ASD. It was also found that if the parents' marital satisfaction was higher, then both the parents and the siblings adjusted better to having a child with ASD in the home (Rodrigue et al., 1993). However, having a child with ASD also showed some negative

effects on marital relationships and job-related stressors, which in turn effected time for family activities and family flexibility (Rao & Beidel, 2009). The parents felt that they were limited in career paths because they needed to stay home and care for their child with ASD. The families also reported having less time or resources available for family vacations or general family outings (Rao & Beidel, 2009). This then took a toll on the amount of time they were able to spend together as a family, which therefore weakens family processes.

### **Intervention Programs and Their Effectiveness**

As the studies previously mentioned have shown, there is high correlation between parental stress and other symptomology and having children with ASD. Because of this, there have been many intervention programs put into place to try and help with these issues. One such program is a cognitive behavioral intervention called Problem-Solving Education (PSE). PSE's goal is to treat depression through six sessions of intervention with mothers and their children with ASD. Feinberg et al. (2014) performed a randomized clinical trial to compare different sessions of 59 parents receiving PSE and 63 parents receiving smaller amounts of care or support from outside sources. Through this they found evidence that PSE showed efficacy in decreasing parental stress and depressive symptoms. It was also noted that the mothers that received PSE treatment had an increase in social coping skills in comparison to the mothers that received smaller amounts of care from outside sources. They also saw that the mothers receiving PSE tended to implicate what they were learning it into situations where they addressed problems either directly related to or that were made more difficult by their child with ASD. There were 122 participants in this study so a larger sample size than previously mentioned studies, however, there was a limited demographic here as there was only a small section of a certain area that was

interviewed. Though their findings are still promising and pointed towards PSE as likely being successful in future implications and testing.

Another approach taken within studying the effectiveness of interventions was comparing two different programs of intervention to each other, rather than studying just one. Iadarola et al. (2017) uses this method by comparing the outcomes of 180 children with ASD and their parents participating in a randomized clinical trial of parent training. They then split the participants into two groups and assigned them to the different intervention programs. The first of which is the parent training program (PT) which aims to teach new skills, decrease disruptive behavior and aid in areas where participants had skill deficits through classes and role plays with parents. The psychoeducation program (PEP) had the same goals but addressed them through scheduled therapy and scheduled sessions that offered the parents information on how to help their children.

Like the process used in the study done by Feinberg et al. (2014) Iadarola et al. (2017) then analyzed the parents' stress levels, caregiver strain and sense of competence post intervention process. The results here reported that both groups showed improvement, however PT illustrated an increase in sense of parental competence as well as reduction in parental strain and stress in comparison to PEP. Nevertheless, it took varying amounts of time for these significant differences to appear in the data from PEP. Some differences appeared at 12 weeks while others appeared at up to 24 weeks which could present a limitation in the validity of the results as they did not all come together and were measured at different times. It was also found that there was an increase in child disruptive behavior from those that were a part of the PT program. This finding was consistent within non-ASD populations as well. And, as the sample size was larger, this could be an appropriate representation of other ASD populations worldwide.

There are presently a large quantity of intervention programs functioning worldwide; many of which are implemented to target certain areas of the parents' or the children's lives (i.e., parental stress, anxious and/or depressive symptoms, quality of life, social skills, family processes, coping mechanisms, etc.). Like the PSE (Feinberg et al., 2014), PT, and PEP programs (Iadorola et al., 2017), the program for the education and enrichment of relational skills (PEERS) aims to improve the social skills, knowledge, and frequency of peer interactions, as well as decrease ASD symptomology in children (Schiltz et al., 2017). PEERS also works with parents in discussing the success of the treatments. PEERS has been seen to improve family functioning by increasing parental self-efficacy as well as decreasing familial disruption, and parental anxious and depressive symptoms (Schiltz et al., 2017). The biggest limitation of this study done on PEERS is that it does not necessarily test the efficacy of the program but rather the changes seen in the families after the intervention process. However, even with this specific limitation, the information gathered from the data still points toward promising outcomes in the PEERS program and the positive impact it has on improving the social skills of children with ASD (Schiltz et al., 2017). Along with this, the PT, PEP (Iadorola et al., 2017), PSE (Feinberg et al., 2014), and PEERS (Schiltz et al., 2017) all showed promising evidence that these interventions strongly related to an increase in the quality of life and other positive impacts on the parents and families of children with ASD, even if some had a stronger correlation than others.

### **Discussion**

The research presented in this literature review shows evidence that having a child with ASD in the home has a significant impact on the psychological well-being of the parents in addition to family functionality. The research also suggests that there is a substantial difference

in families of children with ASD compared to the general population and families of typically developing children, especially pertaining to the physical and emotional health and well-being of the parental figures in these families. The studies highlighted here also exhibit indications of the efficacy of implemented intervention programs in families of children with ASD. These programs, though differing in their targeted areas of improvement, were seen to decrease parent stress levels as well as reduce caregiver strain. Intervention programs also aided in increasing the social and coping skills of both the children with ASD and their parents—particularly the mothers.

The greatest limitation of the research reviewed is the smaller sample sizes. There are a few studies represented here that exceed 100 participants which then weakens the validity of the results presented in the articles with less participants, as well as lessens the probability for generalizability within these articles. Another limitation within the articles is the methodology used within each study as a most of them were not longitudinal and relied largely on self-reported data. There needs to be future research in this area to gain a more reliable analyzation of how these findings occur across multiple populations and whether future implementation of intervention programs should be considered. However, the current findings presented in these studies provide substantial evidence to suggest that there is a large amount of parental stress and other psychological symptoms exhibited in the parents of children with ASD. Additionally, the data here has shown that intervention programs have been helpful in reducing these negative symptoms in parents and improving their quality of life and overall mental health. Therefore, this issue and possible interventions need to be looked at more in depth to further improve the lives of parents of children with ASD.

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### **Changes Made from the Writing Lab**

After attending the FHSS writing lab for my introduction I extended my introduction greatly. I also reworded many different things to make my writing much clearer especially around my explanations and definitions for different terms and aspects of my paper. They also advised me to add more citations to my introduction, so I did my best to do so. Lastly, they helped me to figure out the funnel in my introduction and how I could better transition the different aspects there. My second visit to the FHSS writing lab for my full paper was less productive. The biggest piece of advice I was given during this visit was to reword my explanations of studies and how they performed their analyses. They also recommended that I make my citations clearer. By this they meant that it was a little difficult to determine which part of the information my citations were referring to. So, I did my best to adjust according to information and directions they gave me.

### **Changes Suggested for Classmates**

The biggest thing I found myself recommending in my peer reviews was more coherency and clarity in their thoughts. There were many sentences that I read that I could find out what the meaning was, but it took several times reading over it to figure out what they were trying to say. When this happened, I would comment, "I think I understand what you are trying to say here but it is not completely clear. Maybe try rewording this sentence to make sure you get your full purpose across." Or I would ask specific questions so that they could see what was missing in their thought. In some papers, there was some missing pieces such as lack of synthesis, summary, or analysis, so I would remind them that it was something that needed to be added. I would also suggest minor grammatical changes or possible ways that they could reword their sentences so that it made more sense or flowed better. It was also convenient to have a rubric to

follow as I reviewed their papers as it gave me a good sense of what I needed to focus on in my comments.