

# Parental Stress, Behavioral Strategies, and Child Development in Autism Spectrum Disorder (ASD)

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Autism Spectrum Disorder (ASD) is a developmental disorder that includes difficulties in communicating and interacting socially with others. People with ASD exist on a wide spectrum of symptom severity and exhibit large variability in developmental outcomes, which can be influenced by many factors such as age of diagnosis, genetic factors, and more. In this review, we focus on the role of parental experience and behavior and how it may influence development, specifically examining the role of parental stress and the use of behavioral strategies that may decrease stress and improve parent-child communication. We also summarize multiple longitudinal and cross-sectional studies employing a range of observational and interventional methods. First, we find evidence that parents of children with ASD may be up to three times as likely to experience stress as parents of children with other developmental disorders. When these parents experience greater stress, they are more likely to be critical of their children, and their children are more likely to experience worse developmental trajectories. We next reviewed strategies aiming to improve parent-child communication and decrease parental stress, specifically educational strategies such as synchronization and specific structured behavioral interventions like Transitioning Together. Overall, we have found positive evidence suggesting that these strategies may improve outcomes for children with ASD both in school and home environments. We conclude by recommending further research into behavioral and educational strategies for parents centering the role of parental stress while noting the many ethical considerations in ASD research including privacy and power dynamics between healthcare providers, parents, and children with ASD.

## Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that affects about 1% of the world's population<sup>1</sup>. A diagnosis of ASD can be made for children as young as 15-20 months old<sup>2</sup> and the average age of diagnosis is 4 and a half years<sup>3</sup>. To be diagnosed with ASD, a person must hold persistent deficits in three areas of social communication, including those in social-emotional reciprocity, nonverbal communicative behaviors, and developing, maintaining, and understanding relationships. The person must also showcase at least two of the four types of restricted, repetitive behaviors, which include stereotyped or repetitive motor movements, use of objects, or speech, insisting on sticking to routines, having fixated interests that are abnormal in intensity, and abnormal reactivity to sensory input<sup>4</sup>. ASD is also associated with comorbidities including tics, sleeping issues, learning disabilities, rigid food choices, and epilepsy as well as psychiatric conditions such as ADHD, anxiety, and aggression<sup>5</sup>.

ASD is a wide spectrum and can range from very mild to severe<sup>5</sup>. For example, about 44% of children with ASD report to have average or above-average intellectual ability, suggesting that they experience milder symptoms while about 24% of children with ASD report to have severe symptoms<sup>6</sup>. For example,

individuals with mild ASD may have relatively intact language skills but may experience some difficulties in maintaining conversations or understanding non-literal language. However, individuals with severe ASD may have significant language delays such as limited use of verbal communication and difficulty understanding and interacting in social situations. Individuals with mild ASD may have specific interests that they feel inclined to do, but individuals with severe ASD may have highly specific interests and show rigid adherence to those practices in a way that hinders their daily functioning. It is important to note that both individuals with mild and severe ASD experience sensory sensitivities such as lights, sounds, or textures. However, those with severe ASD may be more sensitive to these factors. Additionally, developmental trajectories throughout life can vary significantly within the ASD population. A child's developmental trajectory describes the progression of a particular behavior as the child ages. 26.7% of adults with ASD have relatively extreme symptoms—they are restricted to simple phrases, have IQs in the range of intellectual disability, and will require life-long support<sup>7-9</sup>. By contrast, 17.5% of adults with ASD are able to live independently<sup>10</sup> and there are many intermediate outcomes with partial support.

The explanation for the wide variety in symptom severity and developmental trajectory is not completely understood but

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has both genetic and environmental components. From the genetic and biological side, it is known that early altered brain development and neural reorganization are associated with the development of ASD<sup>11,12</sup>. Additionally, prenatal and perinatal factors as well as maternal dietary and lifestyle factors are associated with an increased risk of ASD<sup>13</sup>. Furthermore, the usage of specific maternal medications during pregnancy has been associated with an increased risk of ASD<sup>14</sup>. However, these relationships are all correlational. While the field has made great strides in understanding ASD, much work remains to untangle the genetic contributions and the causal mechanisms of ASD and its development.

Simultaneously, much research has been done on the environmental and behavioral contributions to ASD and to the development of children with ASD including the roles of social environment, educational environment, family environment, and therapeutic environment. In this review, we will focus on the family environment and on the role that parental stress and parental behavior play in the development of children with ASD. Raising a child with ASD can have a profound impact on the entire family and all of the child's caregivers, adding time and financial pressure and increasing parental stress<sup>15</sup>. There is some evidence that these can cause family effects which may reciprocally negatively affect the diagnosed child<sup>15</sup>. Of course, there is wide variability in the family environment, leading to different stress responses. In the first half of this review, we will thoroughly explore this issue, investigating how ASD impacts parental stress, how parental stress impacts parenting behaviors, and how parental behaviors affect child development in the context of ASD. In the second half, we will investigate possible behavioral interventions - strategies that parents can implement that may alleviate the reciprocal relationship described in the first half. We explore several types of interventions and compare and contrast their reported effects on parental stress, parent-child communication, and a child's developmental outcomes. We will finally discuss the limitations of the research reviewed in this work including the representativeness of participant pools, the personalization of treatments, and the accuracy of self-report measures.

## Parents of Children with ASD Experience Increased Stress

Raising children with ASD is associated with high parental stress. Through an 8-day examination of the everyday experience of 96 mothers living with their child with ASD and a control group of 230 mothers living with a child without ASD, it was found that the mothers of children with ASD in this study were 3 times as likely to experience a stressful event than mothers of children with other disabilities such as Down syndrome, fragile X syndrome, cerebral palsy, etc.<sup>16</sup> This number was

found by calculating the Odds Ratio (OR) of parents reporting a stressful event on a given day. Further, the mothers of children with ASD reported having arguments twice as many days as the mothers in the comparison group (25% of days vs 13% of days) and experiencing more than twice as many days of stress as mothers in the comparison group (28% of days vs 11% of days).

This examination, conducted by the Survey Research Center at Penn State University involved a 15-25-minute phone interview each evening where each mother was asked about their daily experiences in the previous 24 hours, including stressors, positive events, mood, and physical symptoms. Stress was assessed using the Daily Inventory of Stressful Events survey<sup>17</sup>. In addition to increased stress, these mothers experienced less leisure time. It was reported that mothers of children with ASD spent around 5 hours each day participating in childcare activities and household chores. On the other hand, mothers of children without any disabilities only spent around 3 hours each day. The surplus of parenting responsibilities that come with caring for a child with ASD leaves many parents with very little leisure time, which is associated with greater stress<sup>16</sup>. Both groups of mothers were similar in terms of ethnicity, income level, marital status, and number of children. Participants' positive and negative emotions were measured each day by using an adapted version of the Non-Specific Psychological Distress and Positive Emotions Scale<sup>18</sup>.

In another study, mothers of children and adults with ASD were reported to have a "biological signature" of chronic stress - hypoactivation of morning cortisol<sup>19</sup>. Stress is categorized as chronic when it lasts for weeks and months and can impact one's long-term health and hypoactivation refers to an abnormally low level of the mothers' morning levels of cortisol, a hormone involved in the stress response. Low morning cortisol levels are correlated with a variety of negative symptoms in women such as emotional distancing, fatigue, intrusive thoughts, numbing, and attentional problems, which can further contribute to psychological distress<sup>20</sup>. For participants to qualify for entry into the study, families needed to have a child of at least 10 years old who was diagnosed with ASD, and the child's score on the Autism Diagnostic-Revised (ADI-R) must match up with the parent's report of ASD. The study consisted of 86 mothers who lived with their child with ASD and a comparison group of 171 mothers who lived with their child without disabilities. The mothers' cortisol levels were measured 4 times a day using an at-home saliva collection kit that was issued to them 1 week before the study began. The mothers were instructed to measure their cortisol once after waking up, a second 30 minutes after waking up, a third before lunch, and a final sample before bedtime. It was found that mothers of children with ASD had much lower cortisol levels at all 4-time points when compared to mothers of children without any disabilities, further showing the biological signature of stress in mothers of children with

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ASD. The heightened stress levels and stunted hormone activity may contribute to fatigue and low attention issues, which can negatively affect both the child with ASD as well as the parent; this will be discussed later in the paper.

Furthermore, the strain on parents can shift as the child with ASD gets older. In one study, the coping mechanisms and general well-being of 153 mothers of toddlers and 201 mothers of adolescents with ASD were studied<sup>21</sup>. It was found that mothers of adolescents in this study reported significantly higher levels of anger than mothers of toddlers<sup>21</sup>. Anger was measured using the Profile of Mood States (POMS) survey<sup>22</sup>. They also investigated the coping mechanisms of these participants using the Coping Orientations to Problems Experienced survey<sup>23</sup>. These results load onto two theoretical constructs of coping—emotion-focused coping (consisting of denial, venting, and behavioral disengagement) and problem-focused coping (consisting of active coping, planning, and positive reinterpretation). It was found that there was a significant difference between the groups on behavioral disengagement, an emotion-focused coping mechanism<sup>21</sup>. In this study, mothers of adolescents displayed significantly higher levels of behavioral disengagement than mothers of toddlers (with mean scores of 1.90 vs 1.46, respectively). They also found that the use of problem-focused coping mechanisms positively predicted maternal well-being. The authors framed these results as supporting a theory of “wear and tear” in which caregivers who have been in the role for a long time experience a cumulative toll and that the use of problem-focused coping could act as a “buffer” to wear and tear. Additionally, they suggest that the use of emotion-focused coping could be associated with the mothers of adolescents feeling less in control of their role as a parent; other research has found that emotion-focused coping strategies are often used when uncertainty is paired with a stressor and when a person is unable to change the stressful event<sup>24</sup>.

Additional studies investigated if increases in stress over time occurred at particular moments in life. One study found when their children graduated from high school, parents tended to become more critical of them<sup>25</sup>. In this study, the criticism and behavior problems of 118 mothers who lived with their child with ASD were examined over 7 years. The mother’s criticism was measured through five-minute speech samples (FMSS) where they were asked to speak about their child for 5 consecutive minutes. These speech samples were recorded and then analyzed based on whether the parent opened with a negative remark, described their relationship with their child negatively, or made multiple criticisms about their child during five minutes. The researchers found that when children graduated from high school, mothers became significantly more critical ( $p < 0.05$ ,  $d = 0.66$ ). The researcher’s posited that this could relate to the loss of services associated with high school exit for the participants in this study.

In all cases, it is important to consider the limitations of the

studies described in this section. In each study, the sample sizes were relatively small and the participants were fairly homogeneous in regards to race and socioeconomic status. Furthermore, the participants were all mothers. Although the primary caregivers are usually mothers, it is important to consider the role a father’s stress plays in a child’s behavior as well.

Overall, we found that raising a child with ASD is associated with high parental stress levels as measured by survey and biological signature (hypoactivation of morning cortisol). We also found evidence that this stress is not constant over development. In one study, mothers of adolescents with ASD reported higher anger and behavioral disengagement than did mothers of toddlers with ASD. Finally, we reviewed results that suggest that this stress increases particularly at times of life transition such as a child’s graduation from high school, and that this is associated with increased maternal criticism towards the child. We also reviewed some evidence that particular parental coping techniques such as problem-focused coping may buffer parents from the wear and tear of long-term caregiving. In the next section, we will explore how changes in parental behavior, such as increases in criticism seen in this section, relate to changes in development for children with ASD.

## **The Effects of the Parent’s Behavior on the Child’s Behavior**

It has been suggested that when a child has ASD, there are family effects that reciprocally affect the child. In the previous section, we reviewed some of these family effects—parents of children with ASD may experience greater stress, especially at critical times during development, and during such times, parental behaviors like criticism may increase. In this section, we tackle the question of how changes in parental behavior, like criticism, may impact the child’s development and contribute to the family dynamics. Of course, in all cases, it is important to keep in mind that complex measures of child development will be affected by many variables beyond parental behavior, including home environment, school environment, therapeutic environment, and genetic factors.

First, we review a longitudinal study exploring the relationship between parents’ expressed emotions and the externalizing behaviors of their children with ASD<sup>26</sup>. Externalizing behaviors refer to such activities as tantrums, aggression, property destruction, and not following instructions<sup>27</sup>. The severity of the child’s ASD symptoms and behavioral and emotional problems were measured. Afterward, the parents were asked to rate the validity of specific statements that pertained to their levels of criticism, hostility, and emotional overinvolvement. This data was collected at two different times over two years. Patterns of parental distress were then measured and analyzed. It was found that criticism and hostility were significantly positively correlated

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to increases in the severity of the child's externalizing behavior over 2 years ( $p = 0.002$ )<sup>26</sup>. Furthermore, 5.8% of the variance in the change in the child's externalizing behavior over the two year period was accounted for by the parents' criticism/hostility. This study provides some evidence that children's externalizing behaviors can be affected by the levels of parental criticism and hostility that they experience.

In another study, the interactions between criticism and the child's electrodermal activity (EDA) were examined, focusing on EDA as a measure of children's emotional reactivity<sup>28</sup>. EDA is a marker of multiple systems that are often referred to as the "fight or flight" response. These systems help increase attention to help individuals assess risk and inhibit impulsive behaviors in situations that are threatening<sup>29</sup>. Furthermore, EDA has been linked to autism symptom severity<sup>30</sup> and externalizing behavior problems<sup>28</sup>. 40 children with ASD between ages 4 and 11 years and their caregivers participated in this study. The visit took place in a university laboratory that was set at 74 degrees Fahrenheit and the EDA sensors were placed on the outer right wrist of each child. The families then participated in five laboratory tasks. These tasks were grouped into three categories: parent-child compliance, goal-oriented problem-solving (regulatory tasks), and parent-child free play. EDA data from the two regulatory tasks were assessed in this study. To measure parental criticism and warmth, the parents completed the Autism Five-Minute Speech Sample (AFMSS) while their child participated in independent tasks. Criticism was marked by the frequency of times the parents criticized or found fault in their children. These comments include present-tense negative descriptions of their child's personality as well as harshly worded comments on their child's problematic behavior. Warmth was marked by the intensity of the feeling that was expressed by the parent when talking about their child. This was represented by a positive/enthusiastic tone; and spontaneous expressions of affection, love, and appreciation. Both externalizing and internalizing behavior problems were reported by the primary caregivers using the Child Behavior Checklist<sup>31</sup>. It was found that criticism and warmth were significantly correlated with externalizing problems—parental criticism was positively correlated while parental warmth acted as a buffer. Criticism significantly correlated with externalizing problems under average and high EDA ( $p = 0.02$ ,  $p < 0.01$ ), but not when the children had low EDA ( $p = 0.98$ ). Although warmth was correlated with the child's externalizing behavior, it was not uniquely related to child behavior problems beyond its association with criticism. Furthermore, neither criticism or warmth were significantly associated with internalizing problems. Although both AFMSS variables were correlated with externalizing behaviors, only criticism was a significant predictor in the regression; warmth was only predicted at the level of the trend. Together, the predictors accounted for 29% of the variance in externalizing behaviors. Overall, it was found that criticism positively predicted externalizing behaviors under

conditions of average and high EDA, but not low EDA. This suggests that children with ASD who are more reactive to psychophysiological arousal may be more vulnerable to parental criticism than other children. Therefore, it can be hypothesized that children who have lower EDA are more resilient than others against parental criticism.

Thus far, we have seen that some parental behaviors such as criticism may account for some variance in poorer child outcomes and that this may depend on vulnerabilities related to psychophysiological arousal. Next, we will examine parental behaviors which are related to improved child outcomes.

First, we review a study that aimed to observe the relationship between parents' behaviors while interacting with their children with ASD and changes in children's language abilities. The study included 61 participants: 25 children with ASD, 18 children with developmental delays, and 18 children with no developmental delays<sup>32</sup>. The children were assessed during 2 individual sessions where their communication behavior was assessed over 25 minutes of interaction with the experimenter. Afterward, the parents were asked to interact with their child in the confines of a university laboratory—this was recorded. After observing the recordings, the researchers grouped the behaviors into 2 groups. The first group was the child's invitation for joint attention (when the child directs the experimenter's attention to an event or object). The second group was the child's responses to offers for joint attention, which was measured by the percentage of times the child used their eyes to follow where the experimenter pointed. The children were assessed again after one, ten, and sixteen years to distinguish short (one year) from long-term (ten, sixteen year) gains. Using the Spearman's nonparametric test, it was found that the frequency of synchronized verbalizations significantly predicted the child's future gain in language skills ( $p < 0.04$ ). In other words, children with ASD whose parents focused on the child's interests during play interactions (e.g used synchronization) developed superior communication skills throughout 1, 10, and 16 years than children whose caregivers attempted to establish new points of interest during playtime. The children's communication development was measured using a battery of language scales. At the first follow up, year one, the Reynell Developmental Language Scales<sup>33</sup> were used to assess the children's language skills. This was selected because it was the only standardized language measure that could be used with the entire sample when the study first began. Then during the second and third follow ups, year ten and sixteen, the Reynell Scales were given to children who could not obtain a base score on the Childhood Evaluation of Language Fundamentals-Revised<sup>34</sup>. During the sixteen year follow up, one child's language ability was assessed using the Mullen Scales of Early Learning<sup>35</sup>. For another child, the Childhood Evaluation of Language Fundamentals-Preschool<sup>36</sup> was used to assess language ability. All measures provided age-equivalent scores for the child's language skills. This study suggests that a

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child's language development may be related to the engagement behaviors of their parents. In an expansion of this study, 28 additional children with ASD were gathered and the patterns of longitudinal changes in their language abilities were evaluated<sup>37</sup>. During wave 1, the participants were assessed during three individual sessions where the child participated in an evaluation of nonverbal communication, a test of cognitive development, and a standardized language assessment. In addition to those tests, interactions between the mother and the child were recorded during a 14-minute home visit. Through stepwise model development, the addition of the joint attention variable as a predictor of intercept and slope improved the model fit significantly ( $p < 0.001$ ). Therefore, joint attention was found to play a substantial role in a child's language development; preschoolers with ASD who were more responsive to joint attention developed language skills faster than less responsive children.

In one last example, a recent study investigated the effects of three different approach styles in the mothers of 24 children with ASD and 24 children without any disabilities<sup>38</sup>. Each mother and child pairing was asked to play in a laboratory playroom setting for 10 minutes and was videotaped. The mother's behaviors were separated into 3 groups: Social, Physical, and Object. A social approach involved the mother using social cues to engage the child (ie. facial gestures or vocal cues). A physical approach involves physically moving toward the child and or making contact with the child. An object approach involves the use of an object to engage the child. The child's behavior was then separated into 2 groups: approach and withdrawal. Approach responses were a sign of continuing the interaction whereas withdrawal responses did not continue the interaction. After analyzing the video, the total number of approaches made by the mother, the number and intensity of approach and withdrawal behaviors, and the contingency of the child's response to each type as well as the intensity of the mother's approach behavior were recorded. The 28 children in this study were more amenable (responded/engaged more) to physical approaches by the mother (57%), and they were less receptive to object and social approaches respectively (45% and 34%).

This data suggests that within this group of children, particular styles of parental behavior (physical approaches versus object or social approaches) may be more successful than others.

In this section, we have reviewed a series of evidence that show how changes in parental behavior correlate with behavior and development of children with ASD. Some behaviors such as parental criticism have been related with increases in externalizing behaviors. Other behaviors like physical approaches and synchronization were associated with improvements in cognitive abilities and parent-child relationships. Of course, we have only reviewed a few of many possible parental behaviors, these studies enrolled relatively few people who were not representative of the worldwide ASD population, and there are individual differences between different children with ASD and what works best

for one child may not work well for another. Additionally, there are many other factors which influence a child's development besides parental behavior including genetic factors, educational environment, and therapeutic environment. Our main takeaway from this section is that the developmental trajectory of children with ASD can be impacted by parental behavior. When taken in concert with our first section which found parents with ASD may experience greater stress and that this stress is associated with changes in parental behavior, such as increases in criticism, this points to a potential opportunity to improve child development outcomes—by intervening in parental stress and parental behavior. In our final section, we will review studies of specific structured parental interventions and their effects on parent and child outcomes.

## Interventions for Families

Behavioral interventions are structured strategies aimed to improve some aspect of parent or child outcomes within the context of ASD. We will review five strategies here, three interventions which focus on either child behavior or parent-child interaction, and then two strategies which directly address parental stress and coping. In all cases, it is important to keep in mind that all families and children are unique and it is likely that no intervention will be optimal for all situations. Further, each situation is multifactorial and context dependent - many things will affect child and parent outcomes besides structured behavioral interventions such as educational context, family environment, family history and genetic factors. Finally, not all families and children have equal access to behavioral interventions due to a variety of factors including geography, socioeconomic status, language barriers, and many others. Still, as we will review below, in the populations in which they have been studied, there is evidence that interventions may improve both parent and child outcomes in a variety of environments. We will first review the three interventions which directly address child development or parent-child interaction.

First, we review an 8-week multi-family group psychoeducation intervention called Transitioning Together<sup>39,40</sup> which reported parents being happier and having greater problem-solving skills and children becoming more social and engaged<sup>41</sup>. 41 families with adolescents with ASD were recruited to participate in this study. The participants were then randomly assigned to either the intervention group or the control group—those in the intervention group participated in the intervention (described below) whereas those in the control group did not participate in any intervention. The data was collected at Time 1 (pre-intervention) and Time 2 (post-intervention). During both time points, parents were required to participate in a standardized interview as well as a questionnaire regarding their well-being and the behaviors of their child with ASD, and the adolescents were asked to answer questions regarding their friendships and social activities.

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This intervention consisted of 2 individual sessions with the family and 8 weekly group sessions that put the parents and their child into two separate intervention groups. The parents in the intervention group spent time learning about topics related to ASD and participated in problem-solving methods, which was led by one PhD-level psychologist and one graduate student. The adolescents participated in educational activities and were led by Masters-level psychologist or social worker and one or more graduate students.

Throughout the study, the parents' depressive symptoms and problem-solving skills were measured. To measure the quality of the parent-child relationship, the parents were asked to rate their feelings towards their child as well as the child's feelings towards them. Using the CES-D to measure parental depression, it was found that before the intervention, the mean score for the parent's in the intervention group was 19.90, which was well above the clinical cut point for depressive symptoms. However, after the intervention, the mean for the parents was 14.46, which was in the typical range and reflected both clinical and statistical significance. Furthermore, parents in the intervention group had significantly increased scores on the Family Empowerment that measured their problem-solving skills ( $p < 0.05$ ). In contrast, parents in the control group showed no differences ( $p = 0.60$ ). Furthermore, there was a statistically significant increase in the frequency of the children's social interactions ( $p < 0.05$ ), but there was no change in the control group ( $p = 0.82$ ). In addition, the mean social engagement was 2.43 at Week 1 and 2.93 at Week 8, which reflects a statistically significant increase across the weeks ( $p < 0.05$ ). While the results of this intervention were positive, it is important to consider the long-term effects of interventions. The authors noted that parents must practice the concepts they learned during the intervention over time in order for them to remain effective, especially when their child shows relapses in negative behavior.

Next, we will evaluate a 3-year randomized clinical trial of the Focused Playtime Intervention (FPI), with 70 participants aimed at increasing the mother's synchronization with her child and in turn, the child's expressive language skills - a common problem area for kids with ASD<sup>42</sup>. Of the 70 participants, 64 were boys and 6 were girls. The participants were randomly assigned to either the experimental group or the control group ( $n = 36$  and  $n = 34$ , respectively). Both groups participated in the Parent Advocacy Coaching (PAC) program that aims to help parents become active participants in the planning of their child's treatment and educational programs. However, the experimental group only participated in 3 sessions of the PAC and also completed the FPI program. The control group was not included in the FPI program so they only participated in 4 sessions of the PAC program. The mean age of the children in the experimental group and control group was 4.86 years and 4.66 years, respectively. The mean age of the children's mothers in the experimental and control group was 36.0 years and 35.7

years, respectively.

FPI involved 12 weekly in-home training sessions that aimed to coordinate toy play between the parent and their child. Every session was videotaped and consisted of two parts. During the first part, the parent and interventionist took turns interacting with the child. During this time, the interventionist showed the parents strategies, commented on the child's response, and gave specific feedback on the parents' interactions which helped emphasize the mother's positive contributions. During the second part, the parents learned about each intervention topic through a number of strategies including reviewing specific moments in the videotapes that showcased both the adult's behavior and the child's responses. Mothers were asked what their child was thinking and feeling, what the video clip made her feel, and if the behavior displayed by the child was typical. Based on what the mother said, their responses were classified as Positively Insightful, One-Sided, or Disengaged—the latter two were categorized as Uninsightful. It was found that the parents who participated in the FPI were significantly more synchronized in their responsive behaviors after the intervention ( $p < 0.05$ ) than parents in the control group. Additionally, parents who were categorized as insightful were found to have benefited the most from participating in the intervention. Maternal insightfulness is categorized as the mothers' capacity to describe her child's "thoughts, feelings and behaviors, in a rich, nuanced, and accepting way"<sup>43,44</sup>. In the experimental and control group, 13 mothers (39.4%) and 11 mothers (33.3%) were categorized as positively insightful. Mothers that were classified as insightful had a significant treatment effect ( $p < 0.01$ ) whereas mothers who were classified as non-insightful did not ( $p = 0.58$ ). The results in this study failed to show a significant main effect on the entire treatment group. However, children who entered the study with expressive language skills below 12 months ( $n = 24$ ) showed significant language gains ( $p < 0.05$ ) whereas children with expressive language skills above 20 months ( $n = 18$ ) did not gain as much ( $p = 0.23$ ). This study shows the nuance of interventions - while FPI was effective overall, it was much more effective for some groups ("insightful" mothers and children with language deficits) and it may not be helpful to every family.

The third intervention we will review is "Social Stories". It has been found that when a caregiver depicts an anticipated or previously experienced event to their child with ASD in cartoons followed by a discussion between the parent and child, it can help reduce disruptive behavior<sup>45</sup>. This process is known as Social Stories, which aim to inform, advise, and reflect upon social situations, and are primarily used to teach new routines, increase desired behaviors, and reduce problematic behaviors<sup>46</sup>. This specific Social Stories intervention recruited twenty children between 4-12 years old. Leading up to the intervention, parents were interviewed and asked about their child's behavioral, social, and communicative challenges. Parents were asked to define a problem behavior and a communication impairment in order to

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form a story that can best decrease the problematic behavior and enhance the child's communication, respectively. Each sentence in the Social Stories was accompanied by an illustration, which was shown to be beneficial in helping the children process written and spoken information<sup>47</sup>. A total of 36 Social Stories were used in this study; 17 focused on behavior and 19 focused on communication. Each child was issued two stories and participated in two or three half hour sessions per week. This study did not have any controls. Researchers obtained daily parental ratings (10-point Likert Scale) for measures of behavior and communication skills identified on a per child basis. These questions were designed specifically for each child based on their own behavioral challenges. It was found that across the children in the study, 65% of behavior stories were correlated with statistically significant improvements in the targeted behavior ( $p < 0.05$ ), while 53% of communication stories were correlated with statistically significant improvements in the targeted behavior ( $p < 0.05$ ). However, an important limitation to consider is that the parents were not blinded to their children's treatment status and many were home during the intervention. Therefore, the feedback given by the parents could potentially be influenced by demand characteristics. Even so, this is unlikely as parents often provide examples of their children's successes. It is also important to recognize that the parents could have prompted their child to showcase the desired target behavior, which could have influenced the results. As with other interventions, it is important to note that Social Stories need to be repeated in order to produce optimal outcomes. Furthermore, it should be made aware that the use of the Social Stories intervention will not produce uniform results for every child due to differences in the severity of symptoms each child experiences<sup>48</sup>. It is also essential to note the potential confounding variables that might provide an alternative explanation for the observed improvements such as the child's home environment, physical well-being, affinity for stories, etc.

Thus far we have reviewed three interventions which largely focused on either child's skill development or parent-child interaction. Next, in line with our previous sections, we will review a study which contrasted two interventions that focus specifically on parental stress.

A study of 35 families was conducted to assess the impact of two interventions - Parent Education and Behavior Management Intervention (PEBM) and Parent Education and Counseling (PEC) on a parent's mental health and adjustment to raising a child with ASD<sup>49</sup>.

In this study, the parents' mental health was measured as well as the child's ASD symptoms and the symptoms' severity at two times: pre-treatment and at a 6-month follow-up. Changes in parental well-being were measured using the General Health Questionnaire<sup>50</sup>. Child symptoms were mainly measured using the Developmental Behavior Checklist (DBC)<sup>51,52</sup>. The families were then randomly split into three groups: PEBM,

PEC, and a control group where none of the participants with ASD participated in either of the interventions. The PEBM group mainly focused on parent education and skills training through the use of workbooks, homework tasks, and feedback. Throughout the sessions, parents learned the principles of managing behavior and change as well as how to improve social interaction and communication. They also learned about the services available to their child and how to manage parental stress, grief, and mental health problems. Parents in the PEC group participated in the same discussion sessions as those in the PEBM group. However, during the individual sessions, parents in the PEC group did not participate in skills training or homework tasks. Instead, the PEC put an emphasis on parent education and counseling. Both PEBM and PEC were delivered by special educators or psychologists who had experience with children with ASD and their parents. Both groups went through ten 90 minute small group (4-5 families) sessions that alternated with ten 60 minute individual family sessions over a span of 20 weeks. The control group consisted of children with ASD and their parents who received early childhood services but no PEBM or PEC intervention. They were, however, a part of a follow-up study of autism and received three 6-month assessments. Participants in all groups went through reassessments after the intervention program and 6 months after the program using all the pretreatment measures of child and parent/family functioning (the control group was reassessed 20 weeks after the initial assessment). Using the General Health Questionnaire and some of its subscales [somatic symptoms, anxiety, and insomnia]<sup>50</sup>, it was found that after the intervention, participants with more severe somatic symptoms significantly benefited from the PEBM treatment rather than no treatment ( $p = 0.005$ ). Furthermore, both the PEBM and PEC interventions were found to be effective in significantly reducing symptoms of anxiety and insomnia ( $p = 0.001$  and  $p = 0.004$ , respectively).

In conclusion, in this section we reviewed five distinct interventions focused on improving outcomes for children with ASD and their parents - Transitioning Together, Focused Playtime, Social Stories, Parent Education and Behavior Management, and Parent Education and Counseling. It is important to note that these are a small selection of the many existing structured interventions including Applied Behavior Analysis (ABA), Speech and Language Therapy, Occupational Therapy, Sensory Integration Therapy, Relationship Development Intervention, Social Skills Groups, Cognitive-Behavioral Therapy, etc. Each intervention brings unique strengths and weaknesses. Still, the five reviewed here span a wide variety of strategies and focuses. Our takeaway from this brief review is that a diverse set structured intervention can be successful at improving parent and child outcomes and that choosing the best intervention for a particular family involves understanding the characteristics of the parent and child. We conclude optimistically by noting that each of these strategies was successful in improving both parental and

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child outcomes.

## Discussion and Conclusion

Autism Spectrum Disorder (ASD) is becoming increasingly prevalent<sup>7</sup>. People with ASD show wide variability in symptoms in childhood and in developmental outcomes throughout life<sup>53</sup>. This variability is driven by a wide set of factors including genetics, education, socioeconomic status, lifestyle behaviors, therapeutic strategies, and family environment. In this review, we examined the role of one particular factor—parental stress and parental behavior. In the literature there is a description of a so-called “family effect”—a reciprocal relationship between parental stress and children’s behavioral problems within the context of ASD<sup>25</sup>. We reviewed evidence related to this hypothesis as well as to behavioral interventions focused on improving outcomes for children and parents.

In the first section, we reviewed parents’ relationship to stress and how this stress relates to their parenting behavior. We found evidence that mothers of children with ASD reported higher stress than mothers of children with other developmental disabilities<sup>16</sup>. This was expressed in self-report questionnaires and tracked with a biomarker of chronic stress - lower levels of morning cortisol<sup>19</sup>. We also found that this stress changes over time. Studies showed that mothers of adolescents with ASD reported higher stress levels than mothers of toddlers and that their stress tended to increase at times of big transitions such as high school graduation<sup>25</sup>. The authors of the study speculated that an increase in stress could be attributed to the loss of the resources that had been provided to them through their child’s education system. Further, they suggested a “wear and tear” model of caregiver stress throughout childhood, although it should be noted that such a model likely applies differently depending on the individual stressors of each family. We concluded that section with evidence that increased stress is associated with increases in certain parental behaviors like criticism<sup>25</sup>.

In the second section, we asked how changes in parenting behavior are associated with changes in child behavior and development in the context of ASD. We reviewed several studies which showed evidence of significant relationships between particular parental behaviors and child behaviors. Across several studies, increased parental criticism was associated with increased externalizing behaviors in children with ASD<sup>26</sup>. Interestingly, we also found evidence that children with higher scores on a biomarker related to physiological arousal (EDA) experienced this to a greater effect than children with low EDA, providing evidence of individual differences between people with ASD. We next reviewed several examples of parental behaviors that resulted in positive changes in a child’s behavior or development. In these studies, researchers observed parent’s behavior with their child in particular situations and looked for associations between a parent’s behavior and their children’s

behavior and future development. It was found that particular behaviors (those reviewed here included a “physical approach” and “synchronization”) tended to be associated with positive child outcomes including increased language skill and higher levels of parent-child communication<sup>38</sup>. Of course, these are just two of many types of parental behavior and the takeaway for us here is that within the context of ASD, there are relationships between parental behavior and child behavior both in the short term and in long term development.

In the final section, we reviewed the effect of formal behavioral interventions on child development. While in the second section, we reviewed studies in which researchers categorized relatively unconstrained parental behavior, we here reviewed studies in which parents and children underwent formal and structured training from experts in an effort to improve a particular aspect of their parent-child relationship, their child’s development, or their own stress levels. We selected a variety of studies with the following interventions: Transitioning Together, Focused Playtime, Social Stories, Parental Education and Behavior Management, and Parental Education and Counseling<sup>39,40,42,45,49</sup>. It was found that in the case of all five studies, the interventions were associated with a significantly positive effect in at least one of their desired outcome metrics including decreases in parental mental health symptoms (Transitioning Together, Parental Education and Behavior Management, Parental Education and Counseling), increases in parental problem solving ability (Transitioning Together), increases in prosocial child behavior (Social Stories, Transitioning Together) and increases in parent-child communication synchronization (Focused Playtime).

Taken as a whole, we find support for the idea that there may be a “reciprocal family effect” as previously hypothesized<sup>25</sup>. For example, in the Transitioning Together intervention, it was found that parent-specific measures (like depressive symptoms) improved along with child-specific outcome measures (social behavior)<sup>39,40</sup>. This does not imply a causal relationship between a parent’s depressive symptoms and child’s social behavior but does provide evidence that these measures may be interrelated. On this basis, we recommend that future ASD research centers include not only child outcomes but also parent-child dynamics and parent-specific outcomes. We especially support further research into interventions which address both child and parent behavior including parental stress. Finally, we would like to close with a brief discussion of the limitations of this review and the studies examined. As discussed repeatedly, ASD is a complex and heterogeneous disorder with large individual differences in symptoms in children with ASD and in their family, educational, and therapeutic environments. It is not possible to accurately describe the general experiences of all families with a child with ASD. It is similarly not possible to select a single best intervention for all families. Developmental trajectories can vary widely and these trajectories are affected by a wide set of factors

including genetic, social, family, educational, and therapeutic. The studies reviewed here often had small sample sizes and the included samples were not representative of the ASD population as a whole. Further, even within these relatively homogenous samples there were large individual differences in outcomes. As a result, it will be critical going forward to try to understand and accommodate individual differences. We believe that some of the studies we reported on here actually provide promising models for how to do so. For example, in the Social Stories intervention, stories are designed on an individual child basis – to target behaviors which are difficult for that specific child in their specific family context. While this makes large-scale analysis more difficult, it takes into account the differences across people in an attempt to design a more effective intervention for each participant. We are optimistic that these types of studies, which take into account individual differences and account for the family effect, will lead to a greater understanding of ASD and greater improvements in parent and child outcomes.

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