COPING STRATEGIES FOR FAMILIES OF CHILDREN WITH AUTISM: A HANDBOOK

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ABSTRACT

COPING STRATEGIES FOR FAMILIES OF CHILDREN WITH AUTISM: A HANDBOOK

By

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Families often do not know what to expect when learning of the fact that one of their immediate family members has been diagnosed with Autism. Autism affects the immediate family dynamics the most, and learning how to appropriately cope with a child with Autism is especially important for not only the family members, but for the development of the child as well. This project will provide a handbook with helpful information for all members of the immediate family, including effective coping skills and resources to aid the family and the child.
CHAPTER I

Introduction

According to Centers for Disease Control and Prevention (2013), it is estimated that 1 in 88 children has been identified with an autism spectrum disorder. This ratio has been getting smaller throughout the years, with more and more children being diagnosed every year. Its increase in diagnosis has raised the media’s attention because of its incurable status and various possible causes. Families around the world become bewildered when first notified of their child’s developmental disorder, and many are left without much else but a diagnosis.

Background of the Problem

The diagnosis of Autism happens to children all over the world, in every socioeconomic status, and in every ethnicity and race. Some families have an educated background, with more knowledge on the resources that are available to them. Other families, however, do not have that luxury, and are often not provided with resources, and are therefore left to investigate on their own. Immigrant parents who do not speak the native tongue of the country they live in may experience added difficulty in searching for help because of language barriers. In other words, not every family receives information on the diagnosis and on the resources currently available. For those who are aware of resources, some may find it difficult to take advantage of them because of time constraints with jobs and other priorities, since some resources take considerable time and require commitments.

Statement of the Problem

Many parents and siblings experience depression and great amounts of stress due to the difficulties that having a member with Autism presents. These families can often find solace in many resources, such as individual, group, and family psychotherapy. The consequences of
coping with stress ineffectively not only negatively affects the others members of the family, but also affects the child with Autism in the same way. Siblings who cope ineffectively can experience emotional and behavioral problems. Moreover, many siblings are misinformed or not informed at all about what the diagnosis means, and are often confused about what their brother or sister has, and have lower quality relationships with their siblings simply because of not being informed. Questions that result from this confusion include: Why? Is this my fault? Will my brother/sister get better?

**Purpose of the Project**

This project will provide a helpful resource for families to have in order to decrease confusion and increase more confidence about their lives after being informed of the diagnosis. Many families are in search of a more comprehensive source of information in order to lessen the stress of researching or asking about the several areas they need to look into for help. This project will provide this, and will also provide parents and siblings with information on what they can expect in their lives going forward—specifically, the psychological effects of having a family member with Autism. It is important for all members of the family to recognize that their thoughts and feelings are common and expected, especially if they have not had a member in the family with Autism before.

Most importantly, and what will be most useful for parents and siblings, this project provides several effective coping strategies that all members of the family can utilize. It is understood that many families, as mentioned above, cannot access outside resources for additional help for various reasons, and because of this, it is important that families have a straightforward and understandable guide that they can have and read at home to help them transition into their new life, which this project provides in the form of a handbook.
Definitions

**ASD:** the acronym for Autism Spectrum Disorder, more commonly known as Autism; a pervasive developmental disorder characterized by significant impairment in sociability, behavior, and communication.

**Coping:** to deal with and attempt to overcome problems and difficulties (Stress, n.d.).

**Coping strategies:** how a person deals with problems and difficulties.

**Depression:** persistent feelings of sadness and loss of interest in previously enjoyed activities (American Psychiatric Association, 2013c).

**DSM-5:** the fifth and most current edition of the Diagnostic and Statistical Manual of Mental Disorders; it is the standard classification of mental disorders used by mental health professionals in the United States and contains a listing of diagnostic criteria for every psychiatric disorder recognized by the U.S. healthcare system (American Psychiatric Association, 2013b).

**Emotional support:** support given for various emotional responses, including depression, anxiety, marital or familial conflict, and isolation, which may result from significant stressors (Hansen & Rogers, 2012).

**Social support:** support given from parent or peer support groups, family, agencies, professionals, schools, friends, neighbors, and social groups (Hansen & Rogers, 2012; Rivers & Stoneman, 2003).

**Socioeconomic status:** or SES, is the social standing or class of an individual or group, often measured as a combination of education, income, and occupation (American Psychological Association, 2013).
**Stress:** bodily or mental tension resulting from factors that tend to alter an existent equilibrium (Stress, n.d.).

**Typically developing sibling:** a sibling without a disability; for the purposes of this project, this refers to a sibling without Autism and will be interchangeable with “sibling.”

**Organization of the Project**

Chapter two provides a review of the literature on the history of Autism, relevant theory, current diagnostic criteria, negative and positive effects of having a member with Autism on parents and siblings, and effective coping strategies for both parents and siblings. Chapter three discusses the development of the project, its intended audience, environment and equipment, and an outline of the project. Chapter four presents a summary, discussion, and recommendations for future research. The appendix contains the handbook on coping strategies for families of children with Autism.
CHAPTER II

Literature Review

Historical Perspective

The first descriptions of autism-like behavior started during the ancient times of the Eastern country of Russia. Descriptions about the behavior included being non-verbal, having high tolerances to pain, and acting indifferent in social situations (Feinstein, 2011). There are many cases of people during the 18th century that have been analyzed and concluded to show autistic-like behaviors as well—such as King Christian VII from Denmark exhibiting Asperger’s-like behaviors. In the 1800s, Dr. John Langdon Down, who first described the genetic disorder now known as Down syndrome, wrote about cases of people who exhibited advanced skills in mathematics, music, and the arts. These people are now known as “autistic savants.”

The two pioneers in the study of autism were Austrians Dr. Hans Asperger, a medical doctor, and Dr. Leo Kanner, a psychiatrist. Asperger is known to be the first person to use the term “autistic” as early as 1934 (Feinstein, 2011). He contributed to the field of psychology in many ways, including a landmark paper in 1944 about “autistic psychopathy.” Presently, the diagnosis of Asperger’s disorder is no longer used in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)—all pervasive developmental disorders, that once were diagnosed separately, have been replaced by the umbrella term “Autistic Spectrum Disorder” (Autism Research Institute, n.d.). Kanner, who spoke and wrote about similar discoveries, also wrote a landmark paper, which he called “Autistic Disturbances of Affective Contact” (Feinstein, 2011, p. 10). Both pioneers created a starting point for the study of Autism and related disorders that has grown in depth since.
Theoretical Literature

Autism has been a major testing ground for many theories, including those of language, affective development, and social interaction (Volkmar, Paul, Klin, & Cohen, 2005). The major difficulties include impairment in visual perceptual abilities and in social judgment. Understanding implicit intentions in social situations, utilizing abstract reasoning, applying concepts to new situations, and understanding what another knows, wants, and expects are difficulties in those with Autism. Volkmar and others also state that many parents report feeling concerned about their child’s social interactions early on that later progress to questions about their child’s language and social skills.

Individuals with Autism exhibit difficulties in imaginative play, the transitioning of one activity to another (change), and in the understanding that others may not share their interests (Volkmar, Paul, Klin, & Cohen, 2005). There is a tendency to be constricted in interests and to be isolated from others. While difficulties do exist, cognitive advances occur as well. Talents in music, mathematics, and the arts, as mentioned earlier, exist in some individuals. According to Volkmar and others, it is claimed that the most unique human skill is using language. In the Autistic population, 30-40% of individuals with just Autism are mute, and those that are verbal have impairments in the rhythm or intonation of speech, called prosody, and in narrative and social skills.

Definition of Autism

Autism is a developmental disorder usually diagnosed before the age of three, and is in the category labeled Pervasive Developmental Disorders. According to Migyanka (Laverick & Jalongo, 2011), this disorder causes significant impairment in the social, behavioral, and communication areas of the child. Brain development is affected in the parts of social
interaction, communication abilities, and cognitive function. Non-verbal and verbal communication is affected, as well as impairment in play activities. Autism’s cause is still unknown. It is called a “spectrum” disorder because individuals with this diagnosis are different in their difficulties. In other words, there is a range in terms of severity of symptoms. The terms “high functioning” and “low functioning” are often used to provide a better picture of the child’s level of impairment. According to the American Psychiatric Association (2013a), the DSM-5 has now transferred Autism into the umbrella term “Autism Spectrum Disorder,” including the aforementioned Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. The new diagnostic criteria also include the level of severity.

According to the DSM-5, the updated criteria on Autism Spectrum Disorder include the following criteria (Autism Speaks, 2013):

A person must show impairment in “social-emotional reciprocity.” Examples of these deficits include “abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.” Impairment is also found in “nonverbal communication.” This can include “abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.” There is also impairment “in developing, maintaining, and understanding relationships,” such as “difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.”

A person diagnosed with ASD shows at least two of the following symptoms: (1) A person can exhibit “repetitive motor movements, use of objects, or speech,” (2) they can insist
“on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior,” (3) “highly restricted, fixated interests that are abnormal in intensity or focus,” such as a strong attachment to an unusual toy(s), and (4) “hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment,” such as a high tolerance to pain or temperature.

Symptoms must be present early in the child’s development, and cause significant difficulty in the areas of sociability and occupation, and other areas. Lastly, the symptoms are not better accounted for by an “intellectual disability” or “global developmental delay.” However, intellectual disability and ASD can co-occur, depending on the developmental level of the child.

Effects on Parents

Negative Effects

The effects on parents when a child has Autism vary culturally. According to Hansen and Rogers (2012), cultural differences add to the “variability of family responses” to ASD. For the purposes of this project, the focus will be on the American family; families from other cultures may experience similar or different effects. Families generally react with feelings of denial, devastation, and distancing (Hansen & Rogers, 2012). Researchers have found that although these feelings may occur, they are less important than the adjustment the family has over time, which includes adjusting to the disability and to the alteration of their way of life. Sastry and Aguirre (2012) state similar findings, explaining that parents focus on “coming to terms” with their new lifestyle. Researchers included that the process that some parents go through resembles the stages of grief, and that all parents go through loss, as they lose their
former way of life. The way a mother does this is crucial to the quality of “emotional and cognitive support” she gives to her child with Autism.

At the time when parents receive the diagnosis, many parents have reported feeling as though they were delivered the diagnosis without both a minimal amount of hope and sufficient information (Solomon & Chung, 2012). According Solomon and Chung, 40% of 146 caregivers reported in a 2007 survey that they were provided with information about the diagnosis of Autism and resources to help the family. In the same survey, participants were asked where they searched for information about the diagnosis. The results showed that 15-20% of the participants ended up “turning to other healthcare, educational, or intervention specialists” while the other 71-73% of participants turned to the internet and other media in search for answers (Solomon & Chung, 2012, p. 255).

One of the negative effects shown to result from the diagnosis of Autism is depression. According to Hansen and Rogers (2012), a 2009 study done by Carter and others showed that 28-42% of highly educated mothers of toddlers with ASD had high depressive symptoms that lasted over two years. Another negative effect is parental stress. Hansen and Rogers state that studies have shown that parental stress is higher with children with Autism than with other developmental disorders. In part, this is due to parents having to stay home to support the child instead of working, and also having to pay for costly supplemental services. Dyke, Mulroy, and Leonard (2009) explained on this issue, stating that financial limitations restricted opportunities for family holidays, education, and “material goods” (Dyke, Mulroy, & Leonard, 2009, p. 23). Furthermore, they explained that both sudden and prearranged opportunities, as well as what they refer to as “normal” familial outings, were also restricted (Dyke, Mulroy, & Leonard, 2009, p. 23). Hansen and Rogers stated Parents’ stress increases with the additional demands a child
with ASD presents—nearby supervision and continuously helping the child. Specifically, they also stated that mothers reported having higher stress levels than fathers.

Higgins, Bailey and Pearce (2005) stated that the stress is also due to the child’s distinctive symptoms, which may include antisocial, disrupting, self-injurious, obsessive, and compulsive behavior, depending on the severity level of Autism. These symptoms have the ability to inhibit a typical familial life. A study done by Sharpley, Bitsika, and Efremidis (1997, Results section, para. 3) showed that 81.9% of participant parents reported that they sometimes felt “stretched beyond their limits,” including feeling unable to cope, anxious, depressed, alone, and self-blaming. Hansen and Rogers (2012) state that this type of stress also affects marital satisfaction, as suggested by a study that found that divorce rates were 24% higher in these families than in families with typically developing members, which was at 14%. Additionally, Hansen and Rogers add that this stress not only affects the parenting and the relationship between parents, but also the rest of the members of the family, such as siblings and extended family, and also affects the progress of interventions made for the child with ASD. All in all, the resulting stress, depression, anxiety, and fatigue affect parents’ “sense of self-efficacy” and their “parenting skills.”

*Positive Effects*

Positive effects of having a family member with ASD include having an appreciation for life’s simple pleasures, acceptance of others with disabilities, different empathy levels, and positive experiences with their child with ASD, according to King, Zwaigenbaum, Bates, Baxter, and Rosenbaum (2012). Some families report that they feel closer and stronger as a result. King and others showed three benefits—parental, familial, and societal benefits—reported by sixteen families of children with Autism through interviews. The following briefly explains the results
of the interviews conducted. For parental benefits, the majority of families reported having an appreciation of their child as a benefit, which involved struggling in appreciating the child, and then learning and having that appreciation grow over time, and included loving the child for “who he is” and not desiring a difference in the child. A second parental benefit, celebrating the child’s capabilities, involved families rejoicing over the child’s capabilities instead of focusing their attention on the child’s disadvantages.

Secondly, familial benefits were also reported, which included three appreciations—of the family, of new opportunities, and of lessons for the family (King et al., 2012). These families placed family at a higher value and experienced a higher amount of closeness with each other. In appreciating new opportunities, families experienced opportunities that they would not have experienced otherwise. The lifestyle change brought on new and different opportunities for these families. In appreciating lessons for the family, families felt less self-interested, more considerate, and more cognizant of others advantages.

Lastly, for societal benefits, families benefited in that they acquired an opportunity to learn about human differences, to recognize capabilities, and benefited in that they could help other similar families cope (King et al., 2012). All in all, these findings show the parental positivity that can come from having a member with a disability.

**Effects on Siblings**

*Negative Effects*

Similar to parents, siblings may experience stress, fatigue, and depression. The majority of siblings, according to Pilowsky and others, experience normal adjusting (Hansen & Rogers, 2012). However, there are a few studies that have found that siblings of children with Autism have more behavioral issues, higher anxiety and depression, and lower “pro-social behavior”
when compared to siblings of those who are typically developing (Cebula, 2012). Some siblings point out that there are moments where it is challenging. According to a 2003 study by Harris and Glasberg, a sample of siblings between the ages of 5 and 17 provides varying ideas and information about their sibling’s diagnosis (Solomon & Chung, 2012). The results showed that 20% of siblings were unaccustomed to the term “Autism,” 25% of the sample concluded that Autism was contagious, and in the whole sample, the results showed that siblings had a limited view of what the term Autism meant, and were fixated on solely one of the several symptoms of Autism.

Siblings of children with Autism have various experiences, both unique and challenging. According to a study by Petalas, Hastings, Nash, Dowey, and Reilly (2009), many siblings reported prejudgment and confusion from others, as well as having to answer others’ curious questions. The negative attitudes from the community, Petalas and others state, led these siblings to experience a range of feelings, including anger, anxiety, and embarrassment. In addition, they found that adjustment levels can be increased by certain techniques performed by their parents. Effectively communicating and being open about conversing about the disability, researchers found, as well as searching for their parents’ help when feeling upset, assists in improved adjustment. In contrast, the absence of parental support and siblings not being able to share experiences did not help for siblings’ healthy adjustment to the change in the family dynamic.

There are contradictory findings in the literature involving negative effects of having a sibling with Autism. It was found that typically developing siblings, according to their parents, had elevated “levels of externalizing problems” and, according to their teachers, had elevated “levels of internalizing problems” (Dempsey et al., 2012, p. 1394). Siblings were also found to
have high levels of problems with adjusting and with emotions. Similarly, Petalas and others found that siblings were at a higher risk for developing emotional and behavioral issues (Solomon & Chung, 2012). A 2006 study by Giallo and Gavidia-Payne found that socioeconomic status and familial stress were correlated with high adjustment issues amongst siblings (Dempsey et al., 2012). Gender-specific findings were also included—male typically developing siblings were evaluated to have higher behavioral difficulties and lower “prosocial behaviors,” a 2003 study by Hastings found (Dempsey et al., 2012, p. 1394). In addition, according to Breslau, having a sibling with a disability may drive higher amounts of aggression in males, and higher amounts of depression or anxiety in females (Sage and Jegatheesan, 2010). For sibling adulthood, there is some research that indicates that these siblings experience social and emotional issues at that stage of life (Orsmond & Seltzer, 2007b).

Positive Effects

On the contrary, findings suggesting that no negative effect on siblings’ behavioral status was found. It was found that having a sibling with Autism may improve some of their “psychosocial” and “emotional” development (Dempsey et al., 2012). Additionally, a 2002 study by Kaminsky and Dewey found that siblings were well-adjusted across “all behavioral domains” (Dempsey et al., 2012, p. 1395). Siblings reported that they experienced more elevated “self-concept” when compared to the normative sample, a 2007 study by Macks and Reeve found (Dempsey et al., 2012, p. 1395). A 2002 study by Taunt and Hastings found that siblings had the possibility of even flourishing from this type of circumstance (Sage and Jegatheesan, 2010).

According to Cebula (2012), some siblings report that having a sibling with Autism is a positive experience. In addition, Orsmond and Seltzer (2007b, p. 316) state that child and
adolescent siblings have positive reports about their relationships with their sibling with Autism, which includes viewing their siblings with higher respect, viewing them as “activity partners,” and having lower conflict and rivalry with them. Rivers and Stoneman (2003) stated that siblings of a child with Autism reported less conflict and more warmth than siblings of typically developing children. In addition, they stated that generally, typically developing siblings observed the relationship with their sibling with Autism more positively than their parents did. Similar to the positive effects on parents, siblings reported various personality positive effects, including a higher level of tolerance and awareness of differences in others, being caring and considerate, higher level of maturity than peers, and an elevated level of appreciation of their personal health and capabilities (Dyke, Mulroy, & Leonard, 2009).

In adulthood, sibling relationships are generally positive because there is a higher likelihood that these relationships involve less “direct caregiving” and more “emotional support” (Orsmond & Seltzer, 2007b, p. 314). A career-related effect noted that Dyke and others explained an observation of adult siblings of children with a disability who tended to choose careers involving medicine, education, and "allied health fields" (Dyke, Mulroy, & Leonard, 2009, p. 24). In addition, Marks, Matson, and Barraza found that siblings in the special education field, specifically, reported that they credited their career choice to their experience with their siblings with a disability (Heller & Arnold, 2010). Due to the involvement and responsibility they had during their upbringing, they were led to having an interest in the field and aspirations to improve the help for others with disabilities.

Although contradicting results are present in the literature, a study done by Dempsey, Llorens, Brewton, Mulchandani, and Goin-Kochel (2012) sought to explain this discrepancy in the literature. Their findings show that typically developing siblings may display resiliency in
response to the presence of their sibling with Autism. In other words, the exposure of their sibling with Autism did not increase the typically developing sibling’s level of emotional and behavioral difficulties overall. Emotional and/or behavioral problems may be correlated to siblings’ socioeconomic status and other familial factors.

**Effective Coping Strategies**

*What Helps Parents*

Researchers have found that maladaptive coping has a detrimental effect on the child with Autism (Higgins, Bailey, & Pearce, 2005). Mothers’ parental stress has a maladaptive effect on the educational progress of the child. Similarly, the child’s behavioral improvement may be correlated to his or her parents’ health and adjustment socially (Robbins, Dunlap, & Plienis, 1991). Furthermore, Robbins, Dunlap, and Plienis explain that this is likely because successes of behavioral interventions are contingent on the parent’s availability and capability to interact with the child. This research suggests that effective coping strategies are crucial for both the healthy psychological development of the family members and the child with Autism.

According to Pottie and Ingram (2008, p. 855), Lazarus and Folkman developed a model that theorizes coping as a circular practice that involves several characteristics, including “individual factors (e.g., personality)” and “situational factors (e.g., other stressors)” that play a factor in coping. They specifically state that the effectiveness of a coping strategy is based on a “match” between the coping method and the behavior of the child, or “stressor” (Pottie & Ingram, 2008, p. 855). Levels of positive mood were higher in parents when they exercised specific coping methods: utilized problem focused coping, acquired social support, and practiced positive reframing of the situation, emotional regulation, and compromise. On the contrary, levels of negative mood were higher when parents exercised the following coping methods:
escaping, blaming, withdrawing from the situation, and portraying helplessness. According to Hansen and Rogers (2012), families must be able to forgo blaming themselves and “other distressing chronic emotions” and thoughts.

Family social support in the community can positively affect parents’ level of happiness as well. According to Hansen and Rogers (2012), families usually turn to support outside the family in the beginning, such as professionals, and then turn to family later on, who tend to contribute to parents’ senses of well-being and satisfaction of their lives. The personal interpretation parents have of their new way of life has shown to have major effects on their personal coping. For instance, Hansen and Rogers state that families who interpret their new lifestyle as beneficial are more likely to feel happy and adjusted. Parents can help themselves by learning how to manage their daily lives while having a child with Autism (Solomon & Chung, 2012). Moreover, they also state that by learning how Autistic children best work—through structure and routine—parents can reduce their daily stress.

According to Solomon and Chung (2012), since having a child with Autism creates added activities for the family, such as the child’s participation in speech therapy and/or the family’s involvement in psychotherapy with the child or just the child, prioritizing and organizing these activities is a must. This can be done by looking at a calendar and prioritizing and setting practical “expectations” for the entire family (Solomon & Chung, 2012, p. 258). Next, because divisions of labor may occur in the household that are either gender-biased or undesired, it is important for parents to talk about their experiences to each other in order to reduce the likelihood of blaming, disconnectedness, and withdrawal. Furthermore, parents can benefit from going out on “date nights” to remind them that their roles as partners still exist, since the roles as caregivers can often take over daily life. Lastly, it is important for parents to remember self-
care, which provides a retreat and a pause to daily preoccupations. Self-care can be done in many ways, such as listening to music, exercising, meditation, and leaving the home to participate in an activity alone or with friends.

What Helps Siblings

Parents can help not only themselves during this process, but their typically developing children as well, as they need much aid during this process of possible confusion and life change. Solomon and Chung (2012) suggest that parents need to talk to these children about Autism, because of the high likeliness that they are misinformed about what it means. Moreover, Sage and Jegathesesan (2010) state that the knowledge of the disability is important in developing both positive and nurturing sibling relationships. It was found that not forcing accountability on the typically developing sibling to care for the child with Autism and not assigning “higher role expectations” helped to develop a warm sibling relationship.

A study by Ross and Cuskelly (2006) found that among multiple coping strategies utilized by siblings in dealing with an aggressive event, including strategies such as social withdrawal, problem-solving, distraction, resignation, cognitive restructuring, blaming others, self-critique, and social support, the most effective strategies were distraction, problem solving, social support, and cognitive restructuring. For “symptom-specific” events, siblings utilized several coping strategies, the most common being wishful thinking, distraction, and emotional regulation. Of all the strategies used for this type of event, Ross and Cuskelly found that siblings ranked the following as the highest in their effectiveness: emotional regulation, distraction, problem solving, cognitive restructuring, and social support.

Rivers and Stoneman (2003) found that when the marital stress was higher, the relationship between the child with Autism and his or her siblings is negatively impacted. This
suggests that parents can aid their typically developing children by effectively coping with their relationship stress. Moreover, Rivers and Stoneman stated that this type of stress between parents results in a relationship between siblings that is low in satisfaction, per sibling report, because it emotionally impacts the children. Researchers added that another way that parents could aid their typically developing children in coping was to have social support as a means of lowering their marital stress. Moreover, they add that formal social support includes agencies, professionals, and schools, and informal social support includes family, friends, neighbors, and social groups. In turn, siblings’ relationships benefited from parents employing these types of resources. According to Beyer (2009), other effective coping strategies include not being preoccupied about the future of the sibling with Autism and minimally perceiving “parental favoritism.” Both of these coping strategies contribute positively to the quality of the sibling relationship.

Beyer (2009) goes on to state that there are four areas of focus that can help these sibling relationships: teaching play skills, developing coping skills, private time, and avoiding needless physical and emotional pressure. Teaching play skills promotes more positive interactions between siblings. This area involves teaching the siblings how to play together, such as rolling a ball to one another or catching a ball together as a starting point. Gradually, the complexity of the play would increase as the siblings get older and obtain more complex skills, such as shooting baskets in a game of basketball or jogging together. This can position an older typically developing sibling in the role of the “teacher” of play after learning specific teaching skills, which they may enjoy. Moreover, Bristol and Schopler stated that typically developing siblings reported feeling proud of this ability to teach their younger sibling with Autism (Rivers & Stoneman, 2003).
The second area, developing coping skills, involves encouraging the typically developing sibling to speak of his or her experience about the sibling with Autism (Beyer, 2009). This could involve conversing about their challenges, their feelings, and preoccupations in relation to their sibling with Autism. In turn, these siblings can receive reassurance that their experience is normal. As previously discussed, siblings are often misinformed about the diagnosis of Autism and what it means. Beyer adds that according to Glasperg, parents need to do so, and in specific way. Discussing the meaning behind the disability is most effective when explained in terms the typically developing child will understand, per their cognitive maturity. Moreover, Glasperg noted that giving a detailed explanation will not benefit very young children; however, they must still be reassured about their preoccupations. Explaining to siblings about the disability will not only clear misconceptions that they may already have, but will also help the sibling not experience feelings of loneliness or guilt about causing the disability. Another helpful strategy in this area of focus is the participation of siblings in social groups related to Autism. This involvement helps siblings to feel less alone and supported, to relate, and to share their experiences with others, since many siblings do not feel comfortable sharing experiences with those who do not have similar familial situations.

The third area of focus, private time, involves parents designating special time to spend with their typically developing children in order for these children to feel valued and to lessen possible feelings of resentment about the sibling with Autism (Beyer, 2009). Often, because of the demands that a child with Autism poses, the family will focus on this child, and typically developing siblings may feel out of the spotlight and develop feelings of resentment, “perceived parental favoritism,” depressive symptoms, low sensitivity, and low intimacy with their sibling with Autism (Beyer, 2009, p. 449). Therefore, it is important for parents to set a unique time to
focus on these children in order to decrease the likelihood of these negative feelings. Because of possible time constraints, parents can practice this strategy by: spending time with this child or children during their errand outing, seeking out other family members to help out, and utilizing a respite worker for the child with Autism.

Lastly, the fourth area of focus is avoiding needless physical and emotional pressure (Beyer, 2009). Beyer stated that according to researchers Smith and others, siblings frequently become a second parent to their sibling with Autism, and it is therefore suggested that parents not add further responsibility to the child, which in turn could lead to a negative sibling relationship. As briefly mentioned, siblings may feel concerned about the future of their brother or sister. Therefore, if this is the case, parents can help these children ease their worries by exploring future residence possibilities for the child with ASD before they are unable to do so because of the limitations that will exist when they reach an older age or other reasons that would hinder them later on. Actively engaging this typically developing child in the process was also found to be helpful in easing their preoccupations.

As siblings age, effective coping strategies are crucial to have because of their parents aging, according to Orsmond and Seltzer (2007a). In other words, this suggests that the bond between typically developing children and their sibling with Autism remains important as they all age into adulthood, since this relationship will most likely remain after their parents pass away, become ill, or are otherwise unable to care for the child with Autism. The sibling relationship is usually the longest human relationship (Beyer, 2009). Orsmond and Seltzer (2007a) also noted that effective coping strategies are problem-focused. They explain that this type of coping strategy straightly focuses on the issue at hand, and is a mostly adaptive strategy. Problem-focused coping strategies include planning, positively reinterpreting, and holding back
from engaging in competitive activities. On the contrary, Ormond and Seltzer state that the other type of coping, called emotion-focused coping strategies, are ineffective because they involve avoidance and making the event emotional—fixating on emotions, venting, and disengaging both behaviorally and mentally.
CHAPTER III

Project Audience and Implementation Factors

Development of Project

This handbook was developed to provide families of a child with Autism a resource with helpful information provided clearly and concisely. The idea for a handbook came from my own upbringing and the necessity for information on my brother’s Autism as a child. I believe that my family and I would have benefited greatly from the information that is provided in this handbook. From creating the literature review, I have gained a great amount of information for myself and have gained a deeper understanding of my personal childhood and life experiences in coping with having a brother with Autism. I am hopeful that the information provided in the handbook will have a similar effect to others with family members with Autism. It is also my hope that more families in the future will be provided with clear information and resources to help them along the way, in order to prevent both the negative effects of coping ineffectively and lacking knowledge of resources can bring to all members of the family.

The handbook provides pertinent information that is important to know in the beginning of the family’s life with the addition of a child with Autism. Moreover, the handbook provides the important information needed in the early stages of the family’s development with this unique child. The handbook was created to first teach families on what Autism is, what can be expected to occur to them and their typically developing children psychologically, and finally, the handbook will provide effective coping strategies that will aid the family in progressing with their lives in a healthy and adaptive way. The handbook ends with resources for financial and psychological help, which are recommended to be used in conjunction with reading the handbook for maximum benefit.
Intended Audience

This handbook is intended for the parents and siblings of a child with Autism. The handbook can be provided to families once they are provided with a diagnosis of Autism for their child. The handbook can be used as a take-home tool for families to read about what may occur from that point on, and where to seek help. If families learn that taking advantage of the resources is inopportune at the time, they can use the information in the handbook for the time-being. This handbook can also be useful for friends and extended family in order to better understand the life changes these families have or will go through.

Although the focus is families, since this population is affected more than the individuals in the child’s school or neighborhood, it can also be utilized and found helpful by these people—including teachers, co-workers of the child’s parents, and neighbors. The handbook can be a source for these individuals to use in comprehending their students’, co-workers’, and neighbors’ lives who deal with this specific challenge of having a child with Autism. It is important to note that although the information provided covers important topics that can aid families, it does not replace a mental health professional or other community services.

Environment and Equipment

This handbook can be provided to families in mental health agencies or facilities, psychotherapy and physician offices, K-12 and postsecondary schools, and other appropriate environments where individuals can obtain the handbook to better understand the diagnosis and life changes. The handbook does not require additional equipment.

Project Outline

The handbook will include the following:

1. Definition and diagnostic criteria for ASD from the DSM-5
2. What parents and siblings may experience
3. Coping strategies for parents and siblings

4. Financial and psychological resources for parents and siblings

5. References

See Appendix A for handbook
Chapter IV

Conclusion

Summary

This project was developed for families with a child with Autism. The diagnosis of Autism continues to rise, making information on the diagnosis and resources to help crucial for families to have. Many families do not get to obtain this type of information, and are often left to search on their own, and sometimes with limited ways to search. For some who do have access to obtain information, the search may be difficult because of not knowing where to search for credible and updated information.

The handbook includes important areas for families to be knowledgeable about in the updated literature on Autism. The purpose in creating a handbook was to provide these unique families with a straightforward and understandable guide that they can utilize at home in coping with their child’s behavior. The handbook can be provided to families by mental health professionals, in K-12 schools and postsecondary schools, and other related environments.

Discussion

Identifying strategies to cope with the stress and challenges that a child with Autism brings is unquestionably crucial for healthy development of all members of the family. The literature review brought to light the effects, both negative and positive, of having an immediate family member with Autism as well as the importance of coping effectively. The handbook provides internet resources and resources that accommodate families without internet access by listing locations and phone numbers.

The literature review also made it evident that there is minimal research on the positive effects of having an immediate family member with Autism. As a result, minimal literature is
provided on that subcategory in the literature review of this project, and minimal positive effects are provided in the handbook. These positive effects of having an immediate family member with Autism are important to research on because they would help in the formation of more and different coping strategies for families in the years to come. Having a variety of coping strategies supported by research gives families more to choose from and practice in their daily lives. Also, it was evident during my research that there are contradictory findings in the literature of siblings of children with Autism for both negative and positive effects. It is noteworthy to find out the reasons to these discrepancies.

**Recommendations for Future Research**

Although this handbook contains important information that can help families cope more effectively, future work can delve into creating handbooks for families that include effects on parents and siblings across the lifespan. Families consist of varying ages, and therefore it is important to consider the psychological effects that a child with Autism may bring to older parents and older siblings, for example. Moreover, the coping strategies that parents and siblings utilize also vary across the lifespan. In other words, older parents and older siblings may cope with the challenges and stress differently.

Future research can focus not only on age differences in coping, but also in creating handbooks for specific families according to culture, since this handbook is formulated for the American family, as previously noted. The effects of Autism on the family vary by culture, and therefore it is important to create handbooks or guides with this in mind because some of the information provided may not apply because of cultural differences.

Socioeconomic status (SES) is also an important consideration in creating handbooks for families of children with Autism. The resources in these handbooks would be contoured to
reflect no-cost or low-cost resources in order to make it easier for low SES families to acquire help. Also, it would be important to research the correlation between socioeconomic status and psychological effects to parents and siblings, and create a handbook with that literature.
References


Orsmond, G. I., & Seltzer, M. M. (2007a). Siblings of individuals with autism or Down


Coping Strategies for Families of Children with Autism:

A Handbook

By

Xenia Christine Castillo
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Definition

For Parents

Autism is a pervasive developmental disorder usually diagnosed before the age of three. This disorder causes significant impairment in social, behavioral, and communication areas. Brain development is affected in the parts of social interaction, communication abilities, and cognitive function. Non-verbal and verbal communication is affected, as well as impairment in play activities. Autism’s cause is still unknown. It is called a “spectrum” disorder because individuals with this diagnosis are different in their difficulties. In other words, there is a range in terms of severity of symptoms. The terms “high functioning” and “low functioning” are often used to provide a better picture of the child’s level of impairment. The term “Autism Spectrum Disorder” is now used in place of Autism and other pervasive developmental disorders.

For Siblings

The following is a child-friendly definition of Autism stated by the organization KidsHealth. Parents can read this to their children or the children can read it themselves. It is important for parents to define Autism for their children in a way they will understand (see talk about Autism under For Siblings). Parents can use other words as they go if children have difficulty understanding.

People usually call it autism, but the official name is autism spectrum disorders. This is because doctors include autism in a group of problems that kids can have, including Asperger syndrome.
and others. These problems happen when the brain develops differently and has trouble with an important job: making sense of the world. When someone's brain has trouble interpreting these things, it can make it hard to talk, listen, understand, play, and learn.

A kid's symptoms could be very mild, severe, or somewhere in the middle. For example, some kids might be upset by too many noises or sounds that are too loud. Kids who have milder symptoms don't mind loud noises so much. Someone with mild symptoms might need only a little bit of help. But a kid with severe symptoms might need a lot of help with learning and doing everyday stuff.

Kids with autism often can't make connections that other kids make easily. For example, when people smile, you know they feel happy or friendly; when people look mad, you can tell by their face or their voice. But many kids who have autism spectrum disorders have trouble understanding what emotions look like and what another person is thinking. They might act in a way that seems unusual, and it can be hard to understand why they're doing it.

**DSM-5 Diagnostic Criteria**

The following is the criteria for the diagnosis of Autism Spectrum Disorder, from the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), according to the organization Autism Speaks. The DSM-5 is the standard classification of mental disorders used by mental health professionals in the United States. All criteria from A to D must be met:
A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions (this means that the child may not take an active role in social games, prefer solitary activities, use another’s hand as a tool as if it is a mechanical object, and may not notice another’s distress or have lack of interest in the topic of conversation).

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication (this means deficits in nonverbal behaviors such as eye gaze, facial expressions, body postures, and gestures).

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers (this means that the child experiences difficulty in acquiring and keeping friends, as well as difficulty in engaging in pretend play with others; the child may also not be interested in those in his or her same age group).
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

   (This means that the child displays repetitive movements, such as mannerisms of the hands- hand flapping, finger twisting or flicking, rubbing, or wringing hands, mannerisms of the body- rocking, swaying, or pacing, and odd posturing- posturing of the fingers, hands, or arms; echolalia refers to the repetition of words, phrases, intonation, or sounds of the speech of others, and idiosyncratic phrases are those that have private meaning or meaning that only makes sense to those familiar with the situation where the phrase came from).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

   (This means that the child reacts with distress or tantrums to even small changes or disruptions in routines; rituals are specific behaviors that a person performs repeatedly in certain situations).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
(This means that the child is preoccupied with specific kinds of objects, such as lint or a person's hair, and parts of objects).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

(Hyporeactivity to sensory input means that the child is under reactive to sensory stimuli, such as a high tolerance for pain, may act aggressively, or act clumsily. Hyperreactivity to sensory input means that the child is over reactive to sensory stimuli, such as screaming when hearing the telephone and having a strong negative response to touch).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

Severity Levels

The following are the severity levels for Autism Spectrum Disorder, based on social communication impairments and restricted repetitive patterns of behavior. The severity level is included as part of the diagnosis.
<table>
<thead>
<tr>
<th>Severity level</th>
<th>Social communication</th>
<th>Restricted, repetitive behaviors</th>
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| **Level 3**        | Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others.  
*For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.* | Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interferes with functioning in all spheres. Great distress/difficulty changing focus or action. |
| "Requiring very substantial support” |                                                                                       |                                                                                                                                                                                                                                |
| **Level 2**        | Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others.  
*For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.* | Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action. |
| "Requiring substantial support” |                                                                                       |                                                                                                                                                                                                                                |
| **Level 1**        | Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. | Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence. |
| "Requiring support” |                                                                                       |                                                                                                                                                                                                                                |
For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Experience

Parents and typically developing siblings of a child with Autism share both similar and different experiences. The effects a child with Autism poses on the family are both negative and positive. The following are experiences a parent and a sibling may go through during their life, more specifically during the years following the diagnosis and when the child’s symptoms present challenges to the family. Note: The term typically developing sibling will be defined as a sibling without a disability, specifically a sibling without Autism, and will be interchangeable with “sibling” throughout this handbook.

Parents: Negative Effects

The following are negative effects of having a child with Autism. The following is based on research on parents and coping. Parents may:

* **Feel denial, devastation, and distancing.** Parents may have difficulty accepting that their child has a developmental disorder. Parents may need to distance themselves from others as they adjust and accept their life changes.
Go through the stages of grief. All parents go through loss, as they lose their former way of life. The way a mother does this is crucial to the quality of emotional and cognitive support she gives to her child with Autism.

Be given the diagnosis without enough hope and information. Studies have shown that many parents are left without sufficient information on what Autism means, as well as resources to help.

Turn to other sources for help. Some parents have turned to other healthcare, educational sources, intervention specialists, the internet, and/or other media in search for answers.

Feel depressed. Many mothers of children with Autism have reported depressive symptoms. These symptoms include persistent feelings of sadness and loss of interest in previously enjoyed activities.

Perceive compromised skills. Parents have reported feeling as though their senses of self-efficacy and parenting skills have been compromised.

Participate less. Parents have reported feeling limited in family holiday and educational opportunities. Sudden and prearranged opportunities may also be limited.

Feel as though their outings are not “normal” anymore. Depending on the severity level of symptoms, many families find it difficult to go out because of the challenges of the child’s symptoms.

Have difficulty coping. Parents may feel anxious, depressed, alone, and self-blaming.

Feel parental stress. Some parents may have to stay home to support the child instead of working, and also have to pay for costly supplemental services, which creates an added stress.
Feel stress due to the additional demands. Parents report having to provide nearby supervision and continuously help the child, which can be stressful.

Feel stress due to the child’s symptoms. Depending on the severity level of Autism, children with ASD may be antisocial, disrupting, self-injurious, obsessive, and compulsive. These symptoms have the ability to inhibit a typical familial life.

Feel stress that affects their relationship with their partner or spouse. This stress can negatively impact parents’ typically developing children, extended family, and the progress of interventions made for the child with ASD.

Parents: Positive Effects

Positive effects of having a family member with ASD have also been reported by parents. The following are self-reports provided in research studies.

Positive personality traits. Parents have reported having an appreciation for life’s simple pleasures, acceptance of others with disabilities, different empathy levels, and positive experiences with their child.

Parental benefits. Families have reported having an appreciation of their child as a benefit. Parents learned to appreciate their child over time, although it was initially difficult. Parents also reported loving the child for who he or she is and not desiring a
difference in the child. Parents also learned to celebrate the child’s capabilities instead of focusing their attention on the child’s disadvantages.

**Familial benefits.** Families have reported placing family at a higher value and experienced a higher amount of closeness with each other. Families reported experiencing opportunities that they would not have experienced otherwise. Families felt less self-interested, more considerate, and more cognizant of others’ advantages.

**Societal benefits.** Families acquired an opportunity to learn about human differences, to recognize capabilities, and felt they could help other similar families cope.

**Siblings: Negative Effects**

Siblings experience many maladaptive effects as a result of having a sibling with Autism. The challenges presented may affect the sibling psychologically and how they relate to others. They may:

- **Experience stress, fatigue, and depression.** The challenges that a child with Autism presents can be stressful to a sibling, since they often aid in caregiving. It may also be tiring, and can manifest itself into depressive symptoms.

- **Experience higher behavioral and emotional issues.** Increased behavioral problems, anxiety, depression, and lower “pro-social behavior” may occur.

- **Be ill-informed about the diagnosis.** Some siblings were unaccustomed to the term “Autism,” some concluded that Autism was infectious, and many had a limited view of
what the term Autism meant and were fixated on solely one of the several symptoms of Autism.

★ Have difficulties with peers. Many siblings reported prejudgment and confusion from others, as well as having to answer others’ curious questions. Negative attitudes from the community has led siblings to experience a range of feelings, including anger, anxiety, and embarrassment.

★ Have trouble adjusting to the life change. Siblings were found to have difficulty adjusting and difficulty with emotions. Siblings were found to be at a higher risk for developing emotional and behavioral issues.

★ Experience negative feelings. Higher amounts of aggression in male siblings and higher amounts of depression or anxiety in female siblings have been found in these children. For sibling adults, some research indicates that these siblings experience social and emotional issues.

**Siblings: Positive Effects**

Research has also found that siblings can benefit from this type of circumstance. Although the family dynamic changes, siblings have reported various ways in which the change has benefited them. Siblings may:

- Have improved psychosocial and emotional development.

These developments involve solving problems in daily life and the ability to respond to challenges in a thoughtful, flexible, and creative way.
Have a higher self-concept. Related to self-esteem, self-concept is how individuals think of themselves.

Report positively about their sibling with Autism. Siblings have reported viewing their siblings with Autism with higher respect and as partners for activities. They have also reported having lower conflict and rivalry. Some have reported more warmth when compared to siblings of typically developing children.

Have high levels of positive characteristics. Siblings reported more acceptance and awareness of others’ differences, more care and consideration, more maturity than peers, and more appreciation of their personal health and capabilities.

Choose careers involving medicine, education, and related health fields. A study found that siblings in the special education field, specifically, reported that they credited their career choice to their experience with their siblings with a disability. The involvement and responsibility during their upbringing led to an interest in the field and aspirations to improve the help for others with disabilities.

Display resiliency. The exposure of their sibling with Autism increased siblings’ ability to recover from or adjust easily to change.

Coping Strategies

Due to the many psychological effects that a child with Autism may present to the family, coping strategies, or how a person deals with problems and difficulties, have been researched in order for parents and siblings to more effectively deal with this life change. Because parents
and siblings cope similarly and differently, coping strategies are listed accordingly. It is important to note that not all coping strategies work or are available for everyone, but if used consistently and correctly, parents and siblings can find solace in practicing some or all of the following strategies.

**For Parents**

Researchers have found that maladaptive coping has a detrimental effect on the child with Autism. It is important for parents to cope effectively for their own personal mental health and the mental health of the rest of the family. Mothers’ parental stress has a maladaptive effect on the educational progress of the child. Similarly, the child’s behavioral improvement may be correlated to the child’s parents’ health and adjustment socially. This is likely because successes of behavioral interventions are contingent on the parents’ availability and capability to interact with the child. This research suggests that effective coping strategies are crucial for both the healthy psychological development of the family members and the child with Autism. Levels of positive mood were higher in parents when they exercised specific coping methods:

- **Problem-focused coping.** This type of coping strategy straightly focuses on the issue at hand, and is a mostly adaptive strategy. Problem-focused coping strategies include planning, positively reinterpreting, and holding back from engaging in competitive activities.
- **Social support.** Families seek support outside the family in the beginning, such as professionals, and then turn to family later on, who tend to contribute to parents’ senses of...
well-being and life satisfaction. Families can use *formal social support*, which includes agencies, professionals, and schools, and *informal social support*, which includes family, friends, neighbors, and social groups.

- **Positive reframing of the situation.** The way parents interpret their new way of life has shown to have major effects on coping. This technique involves looking at an event in a positive way rather than negatively. It reduces tension and puts things in a healthier perspective. Families who interpret their new lifestyle as beneficial more than disadvantageous are more likely to feel happy and adjusted.

- **Emotional regulation.** Managing stress and emotions. This can be done by practicing breathing exercises and/or distracting with a pleasant activity. Effectively regulating one’s emotions is important in improving well-being and positively influences quality of relationships with others, work, personal health, as well as parenting skills.

- **Self-care.** It is important for everyone to take breaks. Parents can listen to music, exercise, meditate, and/or leave the home to participate in an activity alone or with friends. Parents can find peace in taking care of their mental health by practicing pleasurable and healthy activities that provide a retreat and a pause to daily preoccupations.

- **Compromise.** Parents can practice compromising by meeting in the middle. This is a way to manage disagreements instead of with aggression or emotional outbursts.

- **Forgoing blaming themselves.** It is important for parents to remember that no one is to blame. Instead, parents benefit in learning to accept the life change and taking responsibility for their actions going forward.

- **Learning how to manage daily life.** By learning how these children best work, through structure and routine, parents can reduce their daily stress. Since having a child with Autism
creates added activities for the family, such as speech therapy and/or psychotherapy, a calendar can be used to prioritize and organize activities that set practical expectations for the entire family.

- **Talk about experiences.** Because divisions of labor may occur in the household that are gender-biased or undesired, it is important for parents to talk about their experiences to each other to reduce the likelihood of blaming, disconnectedness, and withdrawal. Date nights work by reminding parents that their roles as partners still exist, since roles as caregivers can often take over daily life.

What does not help and causes higher levels of negative mood:

- **Escaping**
- **Blaming**
- **Withdrawing from the situation**
- **Portraying helplessness**
- **Emotion-focused coping strategies, which involve avoidance and making the event emotional**—fixating on emotions, venting, and disengaging both behaviorally and mentally.

**For Siblings**

Parents can help not only themselves during this process, but their typically developing children as well, as they need much aid during this process of life change and possible confusion. According to research, the sibling relationship is usually the longest human relationship. The
bond between typically developing children and their sibling with Autism remains important as they all age into adulthood, since this relationship will most likely remain after their parents pass away, become ill, or are otherwise unable to care for the child with Autism. The following are coping strategies that parents can help their typically developing children to practice, and others can be practiced by siblings on their own.

* **Talk about Autism.** Many siblings are misinformed or not informed at all about what Autism means. Knowledge of the disability is important in developing both positive and nurturing sibling relationships. Parents need to be open about Autism, and encourage children to come to them for help when feeling upset, which helps improve their adjustment. Discussing the meaning is most effective when explained in terms the typically developing child will understand, per their cognitive maturity. For example, giving a detailed explanation to a very young child will not be beneficial. Explaining not only clears misconceptions, but also helps the sibling to not experience feelings of loneliness or guilt about causing the disability.

* **Effectively coping with marital or relationship stress.** Research shows that when marital stress is higher, the relationship between the child with Autism and his or her siblings is negatively impacted. In turn, siblings have reported having relationships low in satisfaction. Parents can help by managing this stress by using social support (see *social support* under *For Parents*) and other resources. Stress in the family can also have a detrimental effect on the adjustment of typically developing siblings.

* **Not being preoccupied about the future of the sibling with Autism.** Parents can help ease siblings’ worries by exploring future residence possibilities for the child before parents are
unable to do so due to limitations that can exist when they reach an older age or other reasons that would hinder them later on. Actively engaging the sibling in the process was found to be helpful in easing this type of preoccupation.

*Teaching play skills.* Teaching siblings how to play together, such as rolling a ball or catching a ball together, promotes more positive interactions between siblings. The play’s complexity would increase as siblings get older and obtain more complex skills, such as shooting baskets or jogging together. This can position an older typically developing sibling in the role of the “teacher” of play after learning specific teaching skills, which they may enjoy and feel proud of.

*Speak of his or her experience.* Conversing about challenges, feelings, and preoccupations helps siblings. Siblings benefit from receiving reassurance that their experience is normal and about their preoccupations. Siblings can also find help in social groups related to Autism. This involvement helps siblings not only as a distraction, but also to feel less alone and supported, to relate, and to share their experiences with others, since many siblings do not feel comfortable sharing experiences with those who do not have similar familial situations.

*Private time.* This involves parents designating a special time to spend with their typically developing children in order for these children to feel valued and to lessen possible feelings of resentment about the sibling with Autism. Often, because of the demands that a child with Autism poses, the family will focus on this child, and typically developing siblings may perceive parental favoritism, develop depressive symptoms, and have low intimacy with their sibling with Autism. It is important for parents to set a unique time to focus on these children in order to decrease the likelihood of these negative feelings. Because of possible time
constraints, parents can practice this strategy by spending time with this child during their errand outings, seeking out other family members to help out, and utilizing a respite worker for the child with Autism.

* **Avoiding needless physical and emotional pressure.** Research shows that siblings frequently become a second parent to their sibling with Autism, and it is therefore suggested that parents not add further responsibility to the child, which in turn could lead to a negative sibling relationship. Parents can help develop warm sibling relationships by not forcing accountability on the typically developing sibling to care for the child with Autism, as well as not assigning higher role expectations.

* **Cognitive restructuring.** This coping strategy is related to positive reframing (see *positive reframing of the situation* under *For Parents*). This strategy involves changing automatic thoughts and beliefs that are negative. Multiple strategies in working out negative thoughts are available, including writing down these thoughts and changing them to more correct, rational ones. A mental health professional can help with this technique.

* **Emotional regulation.** Like parents, siblings also benefit from knowing how to effectively regulate their emotions (see *emotional regulation* under *For Parents*). Not knowing how to regulate emotions can increase emotional and behavioral problems in the home, in school, and in other environments.
Resources

The following are resources parents and siblings can use in finding help. They include highly recognized organizations and government agencies.

*Autism Speaks* is the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

**Website:** [http://www.autismspeaks.org/family-services/resource-guide](http://www.autismspeaks.org/family-services/resource-guide)

*This link takes viewers to a list of options for various state-specific resources. This link directs to the viewer to many services, including speech therapists, psychologists, respite care, parent training, specialized schools, intervention specialists, health care, community support services.*

**Locations (these are the three main offices, more local locations can be provided via telephone to any of these offices, or at the website above):**

Autism Speaks  
1 East 33rd Street  
4th Floor  
New York, NY 10016  
(212) 252-8584

Autism Speaks  
1060 State Road, 2nd Floor  
Princeton, NJ 08540  
(609) 228-7310
Autism Speaks
6330 San Vicente Blvd., Suite 401
Los Angeles, CA 90048
(323) 549-0500

Telephone Service:

Autism Response Team (ART)

Members of ART are specially trained to connect families with information, resources and opportunities.

English (888) 288-4762
Spanish (888) 772-9050

Autism NOW is the National Autism Resource and Information Center provides quality resources and information for individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities, their families, and other targeted key stakeholders.

Website: http://autismnow.org/

This link takes viewer to the home page where links are provided for the latest news and resources, as well as upcoming events.

Location:

National Autism Resource & Information Center
1825 K Street NW, Suite 1200
Washington, DC 20006

Telephone Service:

National Information and Referral Call Center

(202) 600-3480
Toll-free 1 (855) 828-8476
**Regional centers** are nonprofit private corporations that contract with the Department of Developmental Services to provide or coordinate services and support for individuals with developmental disabilities.

**Website:** http://www.dds.ca.gov/RC/RCList.cfm

*This link takes viewers to a list of regional centers in the state of California.*

**Locations (more locations can be provided via telephone to any of these offices, or at the website above):**

Frank D. Lanterman Regional Center  
3303 Wilshire Boulevard, Suite 700  
Los Angeles, CA 90010  
(213) 383-1300

North Los Angeles County Regional Center  
15400 Sherman Way, Suite 170  
Van Nuys, CA 91406-4211  
(818) 778-1900

San Diego Regional Center  
4355 Ruffin Road, Suite 200  
San Diego, CA 92123-1648  
(858) 576-2996

*The Social Security Administration* (SSA) administers programs that provide benefits based on disability, one of them being the supplemental security income (SSI) program that provides payments to individuals (including children under age 18) who are disabled and have limited income and resources.

**Website:** http://www.ssa.gov/disability/professionals/bluebook/general-info.htm

*This link provides information on the program and frequently asked questions. Links provided there can direct viewers to an online application for disability benefits.*
Locations (more locations can be provided via the toll-free telephone service or at the website above; the SSA does not publish local office phone numbers):

Social Security Administration
44451 20th Street W
Lancaster, CA 93534

Social Security Administration
9168 De Soto Avenue
Chatsworth, CA 91311

Social Security Administration
611 W 6th St #600
Los Angeles, CA 90017

Telephone Service:

Automated service:

Toll-free 1 (800) 772-1213
References


Orsmond, G. I., & Seltzer, M. M. (2007a). Siblings of individuals with autism or Down


