

# **Coping with the Autism Diagnosis: A Parent's Guide to Managing Stress**



## **First Steps to Understanding and Facing the Challenges**

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## **The purpose and benefit of this booklet**

Every day, many children are diagnosed with autism spectrum disorders. Often, parents have gone through a long process of screening, evaluation, and consultation before the diagnosis of a pervasive developmental disorder (PDD) is heard. In most cases, the children are quite young and though it is they who are diagnosed with the disorder, the long-term implications will affect the parents and caregivers significantly. Many parents may think:

**\*What do I do first?**

**\*Where do I start?**

**\*How will I cope with these increased responsibilities in my life?**

**\*How will I continue to parent and maintain the many other aspects of my personal life?**

Often, parents are unable to address these issues immediately after hearing their child's diagnosis, and may feel overwhelmed by the news they have received to think ahead to the next steps. The goal of this guide is to help parents manage their own stress and begin to manage their own emotions in the wake of hearing their child's diagnosis of an autism spectrum disorder. This is done by providing with them with necessary information and practical solutions as they come to terms with the changes in their own lives and the lives of their families.



## **The autism spectrum – what does that really mean???**

Beyond the criteria spelled out in black and white and found in the Diagnostic and Statistical Manual, which clinicians use to diagnose autism and other disorders, there lurk many shades of gray. Although all the kids diagnosed have deficiencies in social functioning, communication, and play, the enormous range of symptoms, behaviors, and severities leave parents wondering what expectations would be realistic for their child's future.

**\*Will my child be able to learn like other children in their school?**

**\*Will there be any friendships or companions in my child's life?**

**\*What level of independence will my child achieve?**

**\*How will my child get through his or her life, and how will I manage to be the best parent in this situation?**

With a drastic rise in the prevalence of autism, more and more children, families, schools, and professionals are growing aware of this disorder and the need to find effective treatment. Along with the quest for treatment comes the need to appropriately understand and provide support for the parents of the children, who have such a large role in caring for and ensuring their wellbeing.

When thinking about autism, there is a question of what the actual diagnosis means for your child and the future. Despite the huge amount of research, the etiology of autism is complex and mostly unknown. Autism looks different in every child and the behaviors can seem so different, even with the same diagnosis. Autism and Asperger's Disorder are both in the general category of Pervasive Developmental Disorder, used to describe a pattern of behavioral difficulties related in the areas of social relating, communication, and attention/interest. Unlike most individuals diagnosed with Autism, children with the Asperger's Disorder diagnosis do not have had a clinically significant language and function at average to above average intellectual levels. Sometimes the diagnosis of Asperger's Disorder is given if the child exhibits a variety of symptoms typically linked with Autism, but in a different pattern than is typically seen. Although Asperger's was identified over 60 years ago, this is still a relatively new label in the Diagnostic and Statistical Manual, dating back only 15 years, so that it may not be as well researched and well defined as the classic autism diagnoses. Another common diagnosis is Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). This diagnosis is given when many of the criteria for Autism are present, but not quite enough to give the autism diagnosis. Both Autism and PDD-NOS can occur in conjunction with a wide spectrum of intellectual ability; your child's IQ may range from extremely low to the Average range or even higher. Whether Autism, Asperger's, or PDD-NOS, social and language development for children with this diagnosis will be significantly different and often delayed when compared to neuro-typical, normally developing children.



## **What about me, the parent?**

Transitioning to parenthood is a major life event, even without considering the changes brought on by raising a child with autism. All parents experience stressors that vary from physical adjustments to emotional turmoil about skills and competency to care for another young life, and the financial burden of raising children. Parenthood often leads to reassessing the purpose and meaning of life. As one researcher stated, "Becoming a

parent fundamentally changes one's life, making it more complex – not only through increasing demands, conflicts, and frustrations, but also by deepening joys, activating social ties, and enriching parents' self-concepts." When a child is born the parents' lives change permanently.

Each parent's level of stress will vary, depending on life circumstance. So far, psychological research has identified a few factors which almost certainly influence the amount of stress experienced by the families of children with autism, including the number of children in the family, the socioeconomic status of the family, and the children's birth order. In terms of the autistic disorder itself, parents are typically most distraught by their children's perceptual and speech abnormalities, such as echolalia, will they know what echolalia is? bizarre speech patterns, and uneven development in different domains, such as motor skills and language.

Rather than being confident of the child's expected development parents often wonder whether their children truly have a disorder or are simply developing unevenly. Children with autism tend to develop some skills rapidly and lag in others, and they may appear outwardly normal but have severe social and communication deficits. Often, parents of such children may feel that they are being judged on their parenting skills; others may assume that behaviors such as temper tantrums or repetitive routines are a result of poor parental control instead of an intrinsic part of their child's repertoire. Going out into social situations may become uncomfortable – a simple trip to the grocery store or to the home of a family friend may become a daunting task, and it might take you some time to adjust to other people's reactions to your child's behaviors and your difficulty managing it.

The effects of having an autistic child extend beyond the parents to siblings and the entire family. The differences in the skills, abilities, and behaviors that autistic children exhibit, as well as the complexity, unpredictability, and inexplicability of autism may take a psychological toll on all family members, including siblings. As parents, you may become more physically and psychologically tense, experiencing nervousness and pressure from the constant need to supervise your children. Parents participating research studies often felt guilt, uncertainty, anxiety, and frustration.



Be aware that the feelings of guilt, anxiety, and uncertainty are common among parents who first hear this diagnosis. Some of the expectations, hopes, and plans you had fathomed may not happen, and there is a sense of grief and loss. In time, as you learn about your child's strengths and weaknesses new goals will develop and expectations will be adjusted. In the meanwhile, discussing your emotions with members of your family and community could bring you a source of comfort and solace.

Autism is certainly not the only developmental disability that challenges parents, but the impact and types of stress may be different for parents raising children with autism. When compared to parents of children with physical limitations or Down's Syndrome, these aspects of autism often lead to disruption of family functioning, leaving parents feeling more upset and disappointed about the child's diagnosis. Parents of children with

autism experience greater stress than parents of children with learning disabilities, children with cystic fibrosis, and children with mental retardation. In comparison to mothers of children with Down's syndrome and mothers of normally developing children, mothers of children with autism indicated that more aspects of their family life were disrupted and changed. Mothers of children with autism also reported more concern about their children's dependence on the parents and about the impact of having an autistic child on the family as a whole.

But the news is not all bad! Research into parenting, stress, and autism has grown exponentially in the past decade. Now parents have more options for treatment than ever before, and get to learn about autism from many different sources as well as consulting with professionals. For some, the huge amount of data is a blessing, and for others it is a tricky maze to navigate. The following sections will provide parents with some direction to begin to find their way through the sea of information, and find the way that best means to suit the needs of their own family.

## **So much is happening – how will I manage it all?**

Every parent has to find a way to manage stress, no matter their socioeconomic status, family structure, and child's personality. The way in which parents choose to cope with stress depends on many variables, and there are certain coping styles that have been shown to help reduce more parenting-related stress than others.

There are many types of coping, which psychological research has associated with various levels of effectiveness. Your choice of coping strategies depends not only on your individual characteristics or personality, but also on your perception of the situation at hand. One strategy is active avoidance, in which parents avoid stressful situations, blame themselves, and express negative feelings. Other parents are able to choose problem-focused, positive coping, allowing them to strategize, seek advice and support, and come to terms with their current situation. Learning new techniques to manage your children's behavior from school or other professionals, leads to a higher likelihood of choosing problem-focused coping and dealing with problems in a proactive method. Because active avoidance coping, such as self-blame, is associated with more negative emotions and does not relieve stress, finding ways to empower yourself and learn more about the disorder may be one of the most effective solutions to managing stress.

According to psychological research, most parents try to cope by anticipating the difficulties likely to arise, and plan a response to use if such a situation occurred. Other common strategies many parents tend to use are keeping their children busy and actively participating in the services their children received. Though planning is generally helpful, parents often reported that they could not make long-term plans and think too far into the future. Parents may benefit from learning how to take one day at a time, focusing on the here and now and the events going on each day.

Mothers and fathers participating in research have also exhibited different ways of coping. Fathers often suppress their feelings, pull away from those around them, and try to cope independently. On the other hand, mothers openly expressed a broader range of emotions such as grief, sadness, and anger. Studies show that mothers are more likely than fathers to utilize social supports, including speaking with friends and family and seeking out parents in similar situations. The support of friends and turning to spirituality and faith were perceived to be nearly as important as support from family for both parents, though more often used by the mothers.



## From Coping to Life Management

After coming to terms with their child's diagnosis of autism, "life management" can be used to describe the way in which parents meet the demands of raising their child with autism. For a parent who is first hearing the diagnosis, it may seem like this is a hurdle that will be almost impossible to overcome. However, research on parents who have been primary caregivers to children with autism show that with time, their perceptions and handling the situation adjust and become an adaptive part of their routine.

After adapting to a crisis situation, parents develop new ways of managing their lives. These strategies describe methods which help daily events run smoothly, and are not necessarily directly related to a real or perceived stressor. In general, three strategies for managing parenting stress were described as effective.

- 1) Using a positive personal reframing of thoughts about the circumstances, such as accepting the child, finding a way to succeed, and discovering a sense of purpose in the event.**
- 2) Finding ways to maintain a balance with personal roles and responsibilities, such as nurturing relationships with spouse, family members, and friends, as well as taken on the roles of teachers and advocates in addition to parents to teach others about their child and the disability.**
- 3) Meeting the needs of the child and the family by locating and utilizing resources, which includes gathering information, collaborating with professionals, and connecting with other parents.**



As parents adjust to the challenges of raising children with autism, their personal attributes change. Namely, parents reported that they developed flexibility, patience, persistence, positive outlook, sense of humor, and willingness to accept help. Most stated that though they possessed these attributes to some degree prior to parenthood, parenting a child with a disability required developing these attributes to a greater degree. These

changes often led to new roles in parents' lives, such as parent group leaders, conference speakers, advocates, speakers, writers, and members of various councils. As such, many parents stated that they became more compassionate and less self-focused, and developed greater personal endurance.

Please be aware that the changes described above do not happen overnight – rather with years of adjustment and time. With the large number of stressors and many coping possibilities available, parents are not always efficient at choosing the right one, especially in the early stages. Your child and their behaviors will be unlike any other, but consulting with parents who are going through similar situations will help you gain perspective, provide an emotional outlet, and even compare strategies and ideas on how to cope with various stressors. Turning to others in similar situations is often helpful, but at times more specific guidance is needed to achieve the best outcome. Honing coping skills and learning to identify the best course of action may lead many parents to best results, and parents often turn to a trial-and-error method or professional consultation to find the best path.

## **How can I stay centered and focused?**

For some, an effective way to cope is to disconnect from their reality, in a way. One method of stress reduction that has been supported by research for various people and problems is meditation. Officially, meditation refers to “techniques that focus the mind and promote a state of calmness so that the mind and body can be brought into greater harmony to facilitate health and healing.” The ideas of meditation and mindfulness are quite trendy, but they have been scientifically supported as methods of stress management. There are many different approaches, but all have the goal of finding a source of inner calm and peace. One way to try this is to locate an area that will allow the parent to shut out the world. Though this is difficult for most adults starting out, concentrating on breathing slowly and deeply while keeping the mind clear usually gets easier with time. To help detach, it may be helpful to play some nature sounds or imagine floating on water, in a quiet field, or drifting with the clouds.



Meditation is effective for a number of reasons. It allows you to be less attached to feelings and thoughts about a certain subject. Meditation teaches how to let go of certain unpleasant emotions, which helps parents and other adults maintain perspective during stressful, emotional situations. Also, meditation is a way to practice maintaining focus. Being able to focus and detach allows parents to transfer these skills to other situations, and become less distracted and distraught by events which may not be important.

Often, psychologists and other professionals utilize progressive muscle relaxation and guided imagery to help patients cope with their stress, fears, and anxieties. Guided imagery relaxation is a mind-body intervention meant to relieve stress and promote a sense of tranquility and peace. By involving all of the senses, the mind relaxes the body through a process of inner communication. During guided imagery, people can only relax and are also given an opportunity to process stressful situations and practice

effective responses. This allows you to gain experience with future situations prior to a real event, and will allow the person to behave in a way that will be most adaptive to the situation.

When parents are visualizing an uncomfortable situation, it is important for them to maintain control to the best of their ability. For example, if you are imagining your child becoming very angry and throwing a tantrum in a public situation, the situation can be played out in a number of ways. You have the ability to control the images in your mind, tailoring the situation they are imagining to something unpleasant but manageable. The key points to keep in mind are that the imagery belongs completely to the person in the meditation – and it can be adjusted accordingly. Unwanted images or responses can be blocked out, and the situation can be tweaked and mentally rehearsed repeatedly – as often as needed until you feel prepared to cope with the situation more effectively.



## **Who else can I ask for help?**

Multiple researchers have stressed the importance of the informal relationships in families of children with disabilities. Support of the immediate and extended family is associated with slower stress levels in parents of children with a disability and spousal support is considered to be an important factor in adaptation and stress reduction for parents.

Parents and clinicians need to also be aware of other factors that may interfere with the treatment process. Although you may not be comfortable discussing their own personal life with their child's clinician, your openness about your own feelings and struggles can help move your child's treatment forward. Research has identified poverty, social isolation, depression, stress, and marital discord as factors that have had negative effects of the benefit from treatment. The identification of these potential barriers can assist parents and clinicians in achieving more positive outcomes, and it has contributed to clinicians understanding the need to include comprehensive assessment of your child and your entire family's needs in planning and tailoring interventions.



In addition to seeking out professionals, parents can also turn to each other to cope with the challenges of raising an autistic child. Parent support groups are a means of providing social support within the framework of the educational or community setting that the parents are already familiar. Support groups help parents by giving them a place to discuss their difficulties, to share coping strategies and accomplishments, and to meet other parents in a similar situation. Parents who have attended support groups have found that their participation increases their perception of the child as making a positive contribution to the family, and allowed them to change their perspective on some of the hardships associated with parenting.

Some parents report that participating in parenting support groups has helped them gain a sense of control. They attribute this to learning from people who had gone through similar experiences, increased access to information, as well as finding more hope and thinking in more positive terms. Also, parents attending groups found an increased sense of belonging with people who shared their experiences and could be empathic and understanding of their current circumstances. In some instances, parents not only had a greater acceptance of their child's disability, but had even indicated that their parenting skills had improved. Overall, parenting groups have contributed to psychological sense of community, providing emotional support and information, and giving the opportunity to help others.

## **Navigating the system – so many people, so many opinions**

There are many people with knowledge about autism and recommendations for the best treatment. Do you turn to your pediatrician? Psychologist? Speech pathologist? Special education teacher? For many parents the number of individuals involved in helping their child can be a blessing but also a source of confusion. Understanding each person's role and building a working relationship with them is key to helping not only your child, but yourself as well.

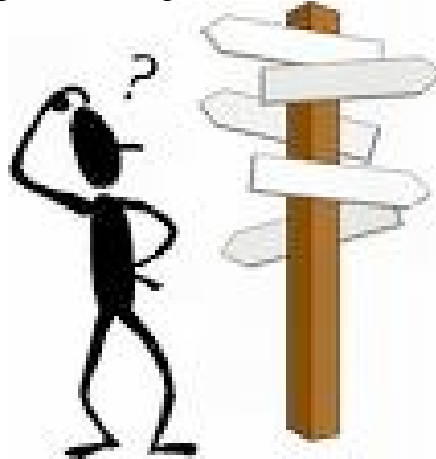
Before sitting down to meet with any professional, keep in mind how different your child is from all other children. The autism diagnosis includes a very broad range of behaviors and levels of functioning, and no two children are quite alike. With that in mind, make the professionals in your family's life aware of your child's uniqueness, and share the small details of what makes your child's behavior difficult to manage or frustrating. Do not be discouraged if an intervention that helped another child with autism is not effective for your own child, keep in mind that most interventions can and should be tweaked to account for your child's individuality.

Psychologists have implemented some interventions for children by focusing specifically and solely on the parents. Behavioral parent training interventions had several positive effects, such as improving the children's problem behaviors, increasing parenting skills, and promoting a secure parent-child attachment. By feeling more effective and in control, parents have been able to strengthen the bond with their child and decrease the

appearance of unwanted behaviors. Also, cognitive behavioral training was also used to teach parents coping skills directly related to psychological distress. Cognitive behavioral treatment teaches about the connections between thoughts and emotions, and how changing thinking patterns can lead to changes in mood and feelings. The aim of the cognitive behavioral studies was to support parents in learning new skills, including focus on cognitive distortions, automatic thoughts, problem solving, and decision making techniques. Learning how you may see the world through a skewed lens based on your own experiences may help you find more effective ways of perceiving situations, and learn how to find more adaptive ways to react to certain events and situations.

Parents of children with autism may often feel like they are unable to help their children or have a significant say in the types of treatment which may best suit them. Often professionals treating your child may emphasize the child's behavior but typically leave little room to focus on your own psychological distress. However, it is crucial for you and your child's therapist to acknowledge both of your emotional states, as your commitment and cooperation with treatment are crucial in order for interventions to be successful. Without confidence, parents have a more difficult time taking an active role and perceiving themselves as effective. Considering the uneven progress which is typical in autism, your determination may help the child and clinician find the support needed to continue to put forth effort in the face of adversity and some minor failures. Clinicians also rely on you as parents, as you provide a key source of information about daily activities and history, which can be crucial in determining which interventions would be most successful.

Parents may find the most benefit from sessions with professionals when they take a proactive role in the collaboration. Prioritizing and writing out questions prior to an appointment or session is helpful, and asking for specific information about topics is likely to lead to more information than asking professionals general questions. Also, parents become quite knowledgeable as part of caring for their child, and often can contribute to their professional's knowledge by sharing their information about the disorder and newest developments with professionals.



## **Intervention: What can I do now?**

Although professionals acquire extensive training and specialization, research on parent education programs has shown this to be a cost-effective, efficient form of intervention.

Educating parents about general behavioral principles has been identified as an effective approach, which can be applied to various situations and target specific issues.

By including parents in planning and implementing interventions, clinicians have found that their ideas and recommendations are more likely to be successful. Performing the interventions, such as behavioral training, in naturalistic settings such as the home or other places the family frequently goes has been shown to help the child learn the skills and use them in a variety of settings. When developing a program to support the families of children with disabilities, professionals must understand the "ecology" of the family. With your help, clinicians can examine and analyze your family's activities and daily routines, interventions can be tailored to your family's needs and specific practical details. Parents working with various clinical services may increase the effectiveness of treatment by sharing specifics about their own family, and helping clinicians tweak their programs to suit the entire family's needs to the greatest extent possible.

In choosing the professionals to work with your family, it is helpful to examine their perspective and approach toward working with families. Working with clinicians from an ecocultural perspective is likely to bring about the best communication about the child's and family's needs. You will notice that clinicians working from this perspective begin with identifying your family's strengths and positive attributes, rather than focusing solely on areas of weakness or pathology. Help your clinician by examining what you are already doing well and the progress you have made, and help them to build on what you are already doing in an effective manner. Also, join the clinician in examining your child's activities and understanding what it means to your family. Consider your family's routines when planning interventions and changing certain behaviors. There is a better chance for interventions to be carried out if they fit into your existing routines naturally, and are attuned to your values and goals. Remember to include cultural elements of your daily life in this planning, as well as traditions that are unique to your family or specific community.

Another approach that emphasizes the collaboration between parents and clinicians is PATH, developed by Falvey in 2002. The PATH model is based on three basic principles. First, planning should focus on everyday events and activities in which the child and family may already participate. Second, your own role in the family and relationships you have within the community may play a more important role than the services you put in place, and your clinician should think about your social environment in every phase of planning and intervention. Third, the entire family and community who know and care for your child should have a role in planning the intervention's activities and goals.

In working with clinicians of all sorts, it is important for parents to stay aware of their own level of comfort and ensure that the professionals are addressing their own unique needs. It is helpful for families to examine each suggested intervention in terms of likelihood of follow through, and to feel comfortable enough to make suggestions which may tailor the evaluation to suit their needs while still remaining within the realm of the clinician's recommendations and expertise.



## **So what can I do on my own at home?**

Parents often feel lost in controlling their children's behaviors in the home and outside. The amount of literature with recommendations, strategies, and approaches can be overwhelming, and the different sources may not always offer consistent information. This next session will summarize a few key points that can help to get parents begin to understand the most relevant and helpful techniques which have also been supported by research studies.

### **Understanding ABA**

As there is not yet a cure of autism, one of the best courses of treatment at this time is Applied Behavior Analysis (ABA). "The overwhelming evidence strongly suggests that the treatment of choice for maximal expansion of the autistic child's behavioral repertoire is a systematic behavioral education program, involving as many child contact hours as possible, and using therapists (including parents) who have been trained in the behavioral techniques." This refers specifically to ABA, and the basic concepts of this theory are outlined below.

Behavior analysis is a scientific approach to understanding behavior, the goal of which is to change socially important behaviors in meaningful ways. For each child, the parent helps to identify which skills need to be increased, and problem behaviors need to be decreased, and they are defined in observable terms and measured carefully by direct observation. An initial assessment is done to determine skills that the child has acquired and which skills need to be developed, and this initial assessment guides the treatment plan and goals. The skills and goals are then broken into smaller components and arranged from simple to more complex. The overall goal is to help each child achieve their maximum potential in a variety of domains.

In a quality ABA program, the procedures and implementation are explained clearly to the parents and all those involved in the interventions. There is a set of instructions for teaching each skill, and everyone who works with the child learns how to implement the behavior programs consistently. It is particularly important for parents in a variety of settings so that the child learns generalize and use these skills outside of the formal training sessions. Unwanted behaviors, such as self injurious, aggressive and disruptive behavior, are explicitly not reinforced and the children are taught appropriate alternative behaviors. The professional in charge of implemented the ABA program monitors progress frequently, and intervention methods are adjusted if the plans in place are not working.



## **Pivotal Response Training**

In addition to teaching parents skills to deal with specific problems, it has been shown that parents are able to teach children how to generalize skills to a variety of situations around the home. Teaching children to respond to a multiple cues rather than specifically targeting individual behaviors is more effective and successful. The principles of Pivotal Response Training (PRT), an ABA intervention, focus on two pivotal behaviors that affect a broad range of other behaviors: motivation and responsiveness to multiple cues. There are four major components of PRT which make it effective: child choice, turn-taking, reinforcing attempts, and interspersing maintenance tasks.

Motivation is assessed by observable characteristics of a child's responding. A child is considered motivated when he or she becomes more responsive to elements of their environment. This may include an increase in the number of responses a child makes, a decrease in the wait time involved, and emotional responses in the surroundings such as interest, enthusiasm, or happiness. "Child choice" designs interventions around topics for which the child has shown a preference. For example, a child can express his choice by selecting preferred materials from a set, or by choosing an object that child already prefers.

The child choice is taken into consideration not only for teaching, but also for routine, daily activities, such as clothes selection or mealtime choices. According to the PRT model, a child learns best when her or she is rewarded with something that flows naturally from the situation, and the reinforcer is directly connected to their task in a logical way. The fourth component, child initiation, teaches children to initiate interactions by verbal communication and asking questions. Teaching autistic children to ask a simple question allows them to generalize question-asking to other appropriate circumstances.



## **Social Stories**

Social stories are another example of an intervention that parents often use that is also based on ABA principles. Social stories have become a popular method to remediate the social, behavioral, and communicative impairments of children with autism. A social

story is a proactive behavior intervention that provides children with autism instructions on positive, appropriate social behaviors. In many cases, social stories are paired with pictures of photographs, providing the child with a visual representation of the situation as well as a description on what is likely to occur. Social stories teach children about a situation before it is encountered, without the complexity of interpersonal interaction. This may include introducing a new school environment or a family event, or more generally teaching the concepts of manners and societal expectations. Social stories explain more details of a situation to the child, help him or her foresee what will happen, and assist in adjusting his or her behavior accordingly. In this way, social stories have been effective at increasing children's flexibility during social activities and helping them initiate prosocial, interactive behaviors, instead of merely decreasing unwanted behaviors.

The first step in creating a social story is identifying target behaviors. Target behaviors consist of socially inappropriate or awkward responses that are not adaptive to the situations. After the target behavior has been identified, the next step is to conduct a functional behavior assessment. This is a process devised to identify the target problematic behavior and to determine its function or purpose. The functional assessment is based on data collected from behavioral observations, interviews, and self-assessments. During this step, the clinician or parent examines the situation, paying close attention to the antecedents and consequences of the problematic behaviors. By theorizing why the behavior is occurring and changing certain environmental factors and responses, the clinician is able to comprehend why the child is acting in a certain way. The third step in planning for a social story is considering the entire plan in place for the child with autism, which typically includes several social-behavioral interventions. Social stories are typically implemented as a part of a larger behavioral plan, and it is important to consider how the social story will be used in conjunction with the other planned strategies and reinforcers already in place.

After the clinician or parent has identified what behavior is being targeted, its function, and how a social story will fit in with other interventions, the fourth step is writing the social story. The social story is written based on the information gathered about the child, and the story gives specific instructions on how to behave in an unfamiliar or problematic event or situation. In writing the text of the social story, there are three types of sentences that should be used. Descriptive sentences give information about what is happening and what people are doing during the target event or situation. Directive sentences, on the other hand, provide students with instructions on how to behave, focusing on a desired social response. The third type of sentences are perspective sentences, which provide the child with autism with information about how other think and feel about the given situation or the child's behavior, giving a description of others' perspectives.

There are some guidelines for putting together the most effective social stories. Researchers have found that the most effective social stories use a minimum of text, include only one concept per page, and are appropriate to the child's reading level. On each page, there should be no more than one directive sentence and approximately one to three descriptive or perspective sentences. The language should be flexible, using words such as "usually" or "try" rather than "always" or "must," to be more consistent with real life. The child or clinician can also add illustrations to the story, or photographs can be taken of the child in the social situation. These pictures can add interest and visual support for the presented ideas. The images, like the text, should be kept as simple as possible.

After writing the social story, it should be read to the child. Initially, it is important to ask questions to ensure understanding. The parent or clinician reading the story should ensure that the child understands the content, and can answer basic questions about what is happening in the depicted situation. As long as the social story is being used, it should be readily available to the child, and reviewed as often as necessary. Some children may need to read the story regularly over the course of weeks or months, whereas others may only require occasional review.



## **So now, what else can I try?**

Parenting any child comes with a set of stressors and a life change for the parents. When a child is diagnosed with autism, this stress and sense of responsibility increase even further. With autism awareness increasingly in the media and in popular culture, many are claiming “miracle treatments” and “cures.” As a parent, how can you differentiate between all of the different claims?

When looking online, it helps to be aware of the sources of information cited. University websites, ending with “.edu,” typically cite information that comes from reliable, scientific literature. There are also many non-profit and government-funded organizations raising awareness and conducting research into autism spectrum disorders, and websites ending in “.org” or “.gov” are also more likely to be reliable.

Often, “experts” will talk on the radio and television about outstanding improvements and “cures” for certain individuals who were diagnosed with autism. When listening to these speakers, ask yourself a few questions. How severe were these child’s behaviors? Are they similar to my own child’s behaviors? Could there have been anything else that may have accounted for what had happened? Has this “cure” worked for more than one child or just in this instance? What might the person stand to gain from publicizing this information? Keeping these questions in mind while listening may help you sort through what may be most likely to help your own child, and which treatment methods may not even be worth investigating.

With the prevalence of autism rising in recent years, more awareness and research have gone into appropriately treating this disorder, and helping parents play a more active role in their children’s treatment. Though some strategies are presented here, they are only a sample of the information that is available to parents. The following books and websites can provide parents with additional resources, ideas, and information on how to best manage their own stress, cope with their child’s diagnosis, and plan for the best possible future.

## Additional Resources

### Websites:

<http://www.autismweb.com/>  
<http://www.autismspeaks.org/>  
<http://www.autism-resources.com/>  
<http://www.autism-society.org/>  
<http://www.cdc.gov/ncbddd/autism/index.htm>  
<http://www.autism.com/index.asp>  
<http://www.autismresearchnetwork.org/AN/>

### Books:

Could It Be Autism?: A Parent's Guide to the First Signs and Next Steps by Nancy Wiseman (Broadway Books, 2006)  
Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child's Life by Lynn Koegel Ph.D. (Penguin Books, 2005)  
Facing Autism: Giving Parents Reason for Hope and Guidance for Help by Lynn M. Hamilton (WaterBrook Press, 2000)  
1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders by Ellen Notbohm and Veronica Zysk (Future Horizons, 2004)  
Thinking in Pictures: My Life with Autism by Temple Grandin (Vintage Books, 2006)  
Behavioral Intervention for Young Children With Autism: A Manual for Parents and Professionals, edited by Catherine Maurice, Gina Green and Stephen C. Luce (Pro-Ed, 1996)  
Making Peace with Autism by Susan Senator (Trumpeter Books, 2006)  
Children with Autism: A Parent Guide by Michael Powers (Woodbine House, 2000)

### Parent Guides:

The Organization for Autism Research and the Ohio Center for Autism and Low Incidence have published parent guides which can be downloaded from the following websites:

<http://www.researchautism.org/uploads/parents%20guide.pdf>  
[http://www.ocali.org/family/fs\\_res\\_guide.php](http://www.ocali.org/family/fs_res_guide.php)

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