

AUTISM SPECTRUM DISORDER PARENT HANDBOOK FOR SAUDI ARABIA

by

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## **ABSTRACT**

Autism is a disorder that is gaining attention around the world in recent years. As the number of children with Autism increases, parents of these children are often at a loss as to where to turn for help and support. This project consists of a handbook for parents of children with Autism. The handbook is a collection of resources that parents can access to learn more about the disorder.

Currently in Saudi Arabia there is much less information available for parents about Autism than there is in the United States of America. In the United States there are many foundations, support groups, special schools, and therapies specializing in Autism. While it is still a confusing time for parents when their child is diagnosed as having an Autism Spectrum Disorder, in the United States parents have more of a sense of support through the awareness that exists. In Saudi Arabia, while awareness about Autism is growing, it is still in the beginning stages.

The handbook that was created through this project will be used as a resource for parents in Saudi Arabia that will help to bridge the informational gap that exists there about Autism. The handbook will explain what Autism is, what evidence based practices are effective in working with people with Autism, and it will provide websites for parents to utilize.

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## **CHAPTER 1**

### **INTRODUCTION**

Autism is a complex disorder that challenges many families. Being that it is a spectrum disorder, it can be hard for people to understand the differences that are present in individuals with Autism.

According to WebMD (2013):

Autism is a disorder that is diagnosed all over the world. The symptoms can range from minor learning disorders to severe cases of Asperger Syndrome. Autism is a brain development disorder that can affect a person's social interaction skills, verbal and non-verbal skills, and repetitive behaviors. Autism and its associated behaviors have been estimated to affect more than one in every five hundred people worldwide. At the rate that autism is being diagnosed it is known to be one of the most common developmental disabilities known to the general public. Even with autism being one of the most common developmental disabilities, many people still do not know how autism affects people and how they can effectively work with individuals with autism (1).

Children that are behind in their development and raise concerns about their learning abilities are sent to specialists to evaluate their development (“Autism Speaks,” 2013). The specialist focuses on developmental evaluation and early intervention. It takes an entire team to determine a child’s strengths and weaknesses in different areas before they diagnose a child with an Autism Spectrum Disorder (ASD). Autism has such a wide range of symptoms that they must determine where the child falls within the spectrum in order to start to help the child.

The word Autism was first used to describe the symptoms of schizophrenia, and it was not until 1960 that both terms were linked together (WebMD, 2013). Treatment for autism ranged from medications; such as LSD and electric shock, having the techniques focus on punishment and pain. From the 1980’s to the present however, there has been a focus on using behavioral therapy and language therapy. These two have been the cornerstone of treatment as well as additional forms being used as needed.

### **Statement of Need**

According to the law there are certain rights that each student has when it comes to their education. Many people do not realize what some of the rights are and need to work with the schools in order to make sure students are getting the help they are entitled to receive. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) outlines the current rights of students with an Autism Spectrum Disorder. This law states that children must be given a free education that is appropriate for them. In terms of children with an Autism Spectrum Disorder this means that they should get an individualized plan for their education in a public school. IDEA (2004) has six parts that are included in the law and must be met in accordance to the law. Those parts are; FAPE,

non-discriminatory assessment, Individual Education Plan, Least Restrictive Environment, parents and student involvement, and safeguards (IDEA, 2004).

The first part is that children are entitled to Free and Appropriate Education (FAPE). The most important aspect of FAPE in terms of children with Autism Spectrum Disorders is that it must meet the individual needs of the child. This means that the education must be specific to meet the needs for each child and must not cost anything to the family of the child. All public schools must offer the services necessary to aid the child's education and must pay for those services (Free Appropriate Public Education, 1999). The focus is that the education provided must help the student progress in their education goals. The education program must be beneficial to them and show their improvement. Special education resources must be made available to the child with an Autism Spectrum Disorder to facilitate their goals. Another aspect of appropriate education is that they cannot be regressing or getting worse than they were before. The education must actively improve the student's abilities (IDEA, 2004).

The second principle of IDEA is that the evaluation must consist of non-discriminatory assessments. This means that the assessments used must be free of biases such as cultural or gender. And that those who are completing the assessments are trained in these methods. Assessments should be given in native language whenever possible.

Third on the list of things included in IDEA is an Individualized Education Program (IEP). Educators are only given 30 days after a child is referred for special education services to conduct an evaluation of the student. If the student is found to be eligible for special education services, the key to an IEP is that it must be specific to the individual needs of each child in order to help them become successful in the general



curriculum. The first step is to hold an IEP meeting with the school, parents, student and any other qualified participants. Once the meeting is held, the team writes the IEP for the student. Once the parents give consent the IEP will go into effect. If the parents do not agree with the IEP they can try to negotiate a change or get a hearing. The IEP must be reevaluated each year to see if the child meets the goals or if the IEP needs to be adapted (IDEA, 2004).

Fourth on the list of principles required for IDEA is that children have to be in the Least Restrictive Environment (LRE). This means that disabled children should not be taken out of places that have nondisabled children. The only time children are taken out of classes with nondisabled children is when the child does not progress in a way that is considered satisfactory. As a standard, disabled children have some classes with nondisabled children and special education classes when that is what will be most beneficial to that student's success ("Department", nd).

Another part of IDEA (2004) is that parents and students are involved in decision making about the student. Parents tend to know their child the best and know more about how they do in certain situations. Since professionals do not know this firsthand knowledge they must work with the parents and consider the parent's concerns about their child's education. Schools also need to be aware of the student's interests and concerns about their own education. At age 14 or before students should be active in the IEP process and how their education system is being set up ("Massachusetts", nd).

Last on the things included in IDEA (2004) is to implement safeguards. The safeguards describe all of the rights of parents and schools. It explains what happens when a child turns 18 and how that affects their education. Also, it talks about what a

parent can do if they do not agree with the school's plan or evaluation of the child. On the reverse of that it explains that the school is not in violation if the parents refuse to give consent and cannot come to an agreement (McCulloch, 2005).

### **Rationale for This Project**

Having children around and learning with typically functioning children has been a fundamental part of the treatment for children with an Autism Spectrum Disorder. Specialized training is necessary, but having them integrated with typically functioning children at the same age is also important. They are able to see other children interact with each other and it forces them to socialize and practice being around other people.

The number of children in Saudi Arabia with an Autism Spectrum Disorder is 1 in 100 children (Saudi Gazette). This is not far off from the Center for Disease Control's estimate of 1 in 68 children being diagnosed with autism. The increase in the prevalence of children with Autism Spectrum Disorders has made it clear that more information needs to be available for parents with children that have autism. With Autism Spectrum Disorders being as prevalent as it is, there needs to be substantial research done to develop better treatments and prevention of autism. Autism is still new to the world in terms of how to treat and care for people with an Autism Spectrum Disorder. One reason autism statistics are low for Saudi Arabia is because of the lack of awareness about Autism.

It seems almost everyone has a family member in Saudi Arabia, a cousin or sibling who has a form of Autism. In Saudi Arabia people have a hard time meeting anyone that does not know someone with an Autism Spectrum Disorder. The struggles are so apparent that the family goes through when they start to notice that something was

different about that person. They did not know what was going on or why they could not engage the child when he was young. When they wanted to get help it was not easy. There was a lack of information and treatments in Saudi Arabia. Special schools exist but there are not many and the success of those programs is minimal. The more awareness and help there is for people to treat Autism the better children with autism will fare in the future. This is why it is important to be a national expert on Autism Spectrum Disorders, to help families when they learn that their child has an Autism Spectrum Disorder.

Saudi Arabia is at a point where they are trying to bring awareness to the people about Autism. One of the Princesses, Samira Al-Faisal Al-Saud, has a child with Autism. She is a leader in bringing awareness to Saudi Arabia. The more awareness they gain the more treatments and research will be developed. Development of a handbook is to help parents understand what they are looking for as well as things that will be useful. Included in the handbook will be a brief history, rights of students, and other information that will guide parents. The handbook will help to guide parents on how to work with their children. They will know what to expect as well as extra ways that they can develop their children's skills giving them better chances of success in life.

### **Purpose of the Project**

The purpose of the project is to develop a handbook of effective strategies and resources that will assist parents and teachers in educating children with autism.

### **Statement of Project Goals**

The project will be completed in four phases. The four phases and outcomes of each phase are identified below:

Phase 1: Describe the characteristics, challenging behavior and difficulties that autistic students have in instructional settings.

The result of this phase of the project will be a comprehensive, research-based list of characteristics, challenging behavior and difficulties that autistic students have in instructional settings.

Phase 2: Identify national and international parent-directed and school-directed autism programs that are available for parents and schools

The result of this phase of the project will be a list of national and international parent-directed and school-directed autism programs that are available to students with autism.

Phase 3: Identify effective strategies and activities that parents and teachers can use in helping improve autistic student success

The result of this phase of the project will be a list of effective strategies and activities that parents and teachers can use in helping improve autistic student success.

Phase 4: Making a Parent Handbook for parents that have a child with Autism Spectrum Disorder.

The result of this phase of the project is the attached handbook that aids parents in learning about the type of autism their child is experiencing. The handbook will give them an understanding of the most current research so they know what makes a program effective. It will also give them information about programs available at both national and local levels. Finally, the handbook will inform parents on different types of applications and games they can use to help continue their learning at home.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter will provide important literature regarding the disorder of autism and will serve as the background information for the handbook that will be developed.

Current research shows that much is still being learned about Autism Spectrum Disorders and how to treat them. Each child is different and will need to be assessed in order to achieve the best results possible. Autism Spectrum Disorders have several treatments and strategies that are effective when assisting in their treatment. Most research explains that Autism Spectrum Disorders are best treated early with early interventions that are specified for the student. Many children with an autism spectrum disorder can effectively transition or have adjustments made for them in their adult lives.

#### **Background on Types of Autism**

Autism is a very complex developmental disability and usually appears during the first three years of a child's life (Almanasef, 2011). It is diagnosed to more boys than girls and is being diagnosed at the same consistency all over the globe. "A recent study about ASDs in Arab Countries recruited a total of 37 boys and 23 girls from three Arab countries and found that the boys had poor emotional responsiveness and the girls had more cognitive problems" (Almanasef, 2011, para 8). There are many different

classifications of Autism Spectrum Disorders. They range from low functioning to very high functioning. There are three areas that people with autism are missing or have trouble. The three areas are social interaction, communication, and repetitive, stereotyped behavior (Almanasef, 2011). Being that Autism is a biological disorder, people from all cultures exhibit the same basic deficits. Only the pattern and timing of its presentation differs from one culture to another (Almanasef, 2011). There is still very little known about the causes of Autism and the most effective forms of treatment. There are several known types of Autism that fall within what is known as Autism Spectrum Disorders. The types of Autism include Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, Rett Syndrome, and Childhood Degenerative Disorder (Autism, Aspergers, Rett, 2007).

The first Autism Spectrum Disorder is Autistic Disorder and is what most people are most familiar with. This disorder refers to having problems with social interaction and communication. The biggest challenge with this disorder is with young children, it affects their ability to play and use their imagination (Autism Speaks, 2013). The children with autism often have a hard time building and keeping relationships. They tend to seem disinterested in the relationship, even relationships with their families. From an early age they have trouble interacting with other people. Many of them do not understand the normal social interactions that are expected of them. This affects their ability to play with other kids, interact in social settings, as well as things like taking turns. They do not read facial expressions or understand how other feel (Autism Speaks, 2013). Some of them manage certain skills in a few areas and then lack in language, social skills, abstract

reasoning, and appropriate play. When they struggle with language it can make them angry causing them to lash out or hurt themselves (Autism Speaks, 2013).

Autism has a strong genetic component that has been shown by various studies. It has been seen to be more common in identical twins and siblings. Other related biological factors that seem to be related to autism are things like elevated levels of serotonin and dopamine in the blood (Autism Speaks, 2013). There is no medical drug to cure autism or even treat it as a whole. The only thing that drugs offer is relief for certain symptoms that are associated with the disorder.

The main areas that drugs help with are seizures, destructive behavior, and stimulus over-reactivity (Autism Speaks, 2013). Children with autism are best taught using behavioral approaches. The applied behavior analysis and precision teaching are two examples of behavioral approaches that are affective for children with autism. The best programs have certain features that make them effective. They have activities that will help them interact with others by weakening bad behaviors and strengthening the desired behaviors. The way they strengthen the behaviors they want is by using: compliance training, response chaining, prompting, errorless learning, and differential reinforcement of desirable behavior (Autism Speaks, 2013). Another part of this is what they call learning appropriate behavior to get rid of inappropriate behavior. This is used to help with the development of language skills. Many are nonverbal so reinforcing them when they make sounds drives them to want to make sounds again. Children enjoy getting praise so when they are rewarded for a positive behavior they are more likely to keep doing the desired behavior. The teacher can then use this process to continue to build up the behaviors that they want while extinguishing the bad behaviors (Autism

Speaks, 2013). The next things that the best programs pay attention to: respondent learning, operant learning, applied behavioral analysis, forms and processes of child-caregiver and child-peer interaction, cognitive developmental psychology and ecological psychology, and the personalization process (Autism Speaks, 2013). Another thing that excellent educational programs do is work on the eight phases of learning. These include; acquisition, fluency, endurance, behavioral momentum, generalization, adaptation, retention, and maintenance. These are what build the skills they learn to be consistent and teaches children to use what they learn and master new skills (Autism Speaks, 2013). The final thing that the better programs do is they have strong relationships with the parents so the parents understand what is going on and can use the same techniques to be consistent at home as well (Autism Speaks, 2013).

The second type is called Asperger's Syndrome; people who are diagnosed with this type of disorder do not typically have problems with their language skills. They actually tend to score above average on most intelligence tests, but have the same social interaction problems as most children and adults with autism (Autism Speaks, 2013). This disorder is seen as a genetically based, and affects brain development. The requirements of being considered Asperger's Syndrome are qualitative impairments in interaction, restricted areas of interest, and stereotyped behaviors and interests (Autism Speaks, 2013). When it comes to social impairment there are four areas that may be evidence. In order to be considered to have Asperger Syndrome they must have at least two of them. Social impairments are; impairment with the use of nonverbal behaviors, failure to develop peer relationships appropriate to their developmental level, not wanting to share achievements or joys with other people, and lack of social or emotional



reciprocity (Autism Speaks, 2013). There are four areas that may be lacking in terms of restricted areas of interest but only one of the three must be present to be considered Asperger Syndrome. The areas are; preoccupation with one or more stereotyped and restricted patterns of interest by the intensity or focus, inflexible adherence to specific, nonfunctional routines or rituals, and stereotyped and repetitive motor mannerisms, or persistent preoccupation with parts of objects (Autism Speaks, 2013).

Asperger Syndrome is different from other Autism Spectrum Disorders because of the lack of delays in language skills, self-help skills, cognitive development, and curiosity about the environment. They do tend to have a peculiar language behavior that includes misperception of social cues or odd vocal prosody. They have unique characteristics in six different areas of functioning. Those areas include: social, behavioral, emotional, intellectual/cognitive, academic, sensory, and motor. More than anything else, Asperger Syndrome would be considered a social disorder. They have behaviors or emotional challenges that are related to social deficits (Autism Speaks, 2013). When it comes to cognitive abilities with Asperger Syndrome, little is really known. Many are normal in their intellectual and language development. Yet some range in the genius range with their intelligence. This group benefits from being in a general classroom with other kids that function at a developmentally normal level. They sometimes struggle with abstract ideas and math. One of the biggest obstacles with this group is that teachers often miss the signs that they are in need of special attention. They seem to know and understand more than they actually do so they can go undetected for a long time (Autism Speaks, 2013).

The way they identify that an individual has Asperger Syndrome is with one of the screening measures that are available to professionals. Some of the screening measures are: the Australian Scale for Asperger's Syndrome, the Autism Spectrum Disorders Screening Questionnaire, and the Asperger Syndrome Diagnostic Scale. The only one that has been tested and is considered most reliable is the Autism Spectrum Disorders Screening Questionnaire (Autism Speaks, 2013). In the school system there would be a team of professionals that would help evaluate the student and all the information would be used to help make a diagnosis. Treatment for Asperger Syndrome is based on the individual challenges that the student faces. Some the problems will be behavior and the use of reinforcements specific to the child's interests would be used. When it comes to social issues they can have a buddy or work on helping the student understand when they make social errors so they better understand (Autism Speaks, 2013).

Pervasive Developmental Disorder Not Otherwise Specified is a category for children and adults who have some autistic behaviors but do not necessarily fit into a certain category, and the symptoms may not be as severe in most cases (Autism Speaks, 2013).

Another type of disorder is called the Rett syndrome, and is mainly diagnosed in girls. Children with Rett syndrome start to develop normally but then begin to lose their communication and social skills between the ages of one and four. It is most commonly noticed because of the development of repetitive hand movements, instead of using meaningful communicative hand gestures (Autism Speaks, 2013). What makes this form of Autism so unique is that the children appear to be normal functioning and then quickly

begin to lose mental and physical abilities that had been previously mastered. The deterioration of their abilities does stabilize and there are treatments to help regain skills (Autism Speaks, 2013). One of the things that is unusual with Rett Syndrome is that it unlike other gender specific disorders this one is directed at only women instead of men. There is evidence that it is a genetic disorder but there is no known gene for it at this time (Autism Speaks, 2013).

The deceleration of head growth is one of the first signs that a child may have Rett Syndrome. This is paired with the loss of previously acquired skills in language and the use of hands. The girls diagnosed with Rett Syndrome show signs of mental retardation. One of the things that parents will notice is the way they clap all the time or wring their hands. Some of the girls are never able to walk, while some had already mastered walking and show major abnormalities in their walking once symptoms of Rett Syndrome began. The child may have a number of other issues paired with Rett Syndrome such as; seizures, spasticity, scoliosis, and overall growth retardation. They may have episodic hyperventilation, breath holding, or night laughing (Autism Speaks, 2013).

The last known type of autism is called Childhood Disintegrative Disorder; these children develop normally for at least two years and then lose some or most of their communication and social skills. Another name for this disorder is Heller's Dementia Infantilis. In the article by Alexander Wesfphal, they describe six cases of regression that were linked to Autism. All of the children begin their development and then suddenly lose their language and motor skills. According to article, some of the children did not even recognize their own parents. They do not know what causes the disorder or what

starts the sudden change. Some of the children were not able to take care of themselves anymore. Yet, others were able to learn a new language and other new tasks. It was all situational and depended on the individual child. It was observed that several of the children were calmed by music. One of the girls was even able to learn new songs as well as repeat old ones that she knew before the regression (Wesfphal, 2013). "A child, most often a boy who is developmentally, socially, and verbally on par for his age, suddenly stops acquiring new words and skills in the second year of life and then regresses, losing speech, cognitive abilities, and social dexterity (Zahrani, 2013, p.103). This type of autism is especially hard for families, and they tend to blame outside factors instead of biological reasons.

The assessment of children with Autism is done by a whole group of people. It is not possible for one person to make a diagnosis. Instead it is done by a team of professionals that use several different observations and tests to make a diagnosis (Ateeqi, 2010). A study was done of the effectiveness of several different observation sheets including a newer sheet called COS-5. This new observation sheet can be better because it does not take as long as other observation sheets. It also makes new information available to other professionals in a way that is not done with other observation sheets (Fujimoto, 2014). A newer type of treatment for Autism Spectrum Disorders that is currently being tested is auditory integration training. The research found that the people who tested auditory integration training saw improvement in their skills 3 and 6 months after the treatment. They became more socially aware, social cognition, and social communication (Ayadhi, 2013). It is agreed that autism has a genetic base, yet, there is little understanding of what genes are influencing autism. Some

research has been done to try and find out what is causing autism in children with no real results" ("Detection of Clinically", p. 249)

Early interventions are considered a key element in treating and training children with an Autism Spectrum Disorder. They focus on things such as; effective communication, interaction with normal functioning children, and parent involvement. When children begin this training early they have better rates of success. "There has been increasing interest in developing effective interventions for young children with autism since the evidence suggests that early intervention programs are indeed beneficial for children with autism... and can also improve outcomes in later years for many individuals." (Alabdali, "Systematic Review", 2014) The goal with educating children with an Autism Spectrum Disorder is to get them to a point where they can be as functioning in society as possible. The increased prevalence appears to be attributable to greater public awareness, broadening ASD diagnostic criteria, lower age at diagnosis, and diagnostic substitution (Zahrani, 2013).

Parent involvement, as well as the building parental relationships with autistic children helps to reinforce the skills and effectiveness of the treatments. When parents are involved and supportive of the treatment plan it is going to be more successful. It makes changing the treatment plan easier because both the professionals and parents are seeing that changes need to be made in order for the child to meet the goals that are set. Parents are also with their children most of the time so they need to be implementing the treatment as well to reinforce and maintain the skills that the child is mastering in their treatment. Parents often feel disconnected from children with autism and are not able to build a strong relationship without assistance. A common characteristic of children with

Autism is impaired social interaction. They typically avoid eye contact and appear as if they lack sympathy for others (Murshid, 2011).

Autism Spectrum Disorders are a concerning issue around the world. It has been shown that it is not just in one area but in all countries no matter how developed the country may be. Studies of current epidemics suggest that Autism might affect one in 150 American children (Ayadhi, 2013). There are five categories of Autism Spectrum Disorders. The first one is Autistic Disorder and is what most people think of when they think about autism. The next is also called high functioning and is called Asperger's Syndrome. Another is Pervasive Developmental Disorder Not Otherwise Specified. This one includes disorders that fall under autism but do not fit into one of the other categories. The next disorder only occurs in girls. Rett Syndrome is a regressive disorder that comes after normal development. The last one is Childhood Degenerative Disorder and is similar to Rett Syndrome. It comes after the first few years of normal development. Then a sudden loss of skills and abilities that eventually stabilize. As autism becomes more common, more research is needed to help families learn how to help their children and family adjust.

## CHAPTER 3

### METHODOLOGY

#### **Phase 1: Describe the characteristics, challenging behavior and difficulties that autistic students have in instructional settings.**

The result of this phase of the project will be a comprehensive, research-based list of characteristics, challenging behavior and difficulties that autistic students have in instructional settings. In order to complete this phase of the project, I will need to conduct research into these important issues. Parents and teachers need to understand the specific characteristics and behaviors that are displayed by autistic students.

Fortunately, the U.S.A. has many helpful resources of the characteristics and behaviors. For example, Autism Speaks as well as several other resources identifies the issues and characteristics of Autism. Autism Speaks is an informational organization that covers everything to do with Autism Spectrum Disorders and shares that information with the public. Some of the information will be from personal experience, training, and experts in the field. Working with children with an Autism Spectrum Disorder exposes some of the difficulties of working with this population of children. As part of the education and training to work with children with Autism Spectrum Disorders, the common symptoms and characteristics become integrated so that spotting these signs is

easier. The experts that are instructing and monitoring the interactions with students assist with the knowledge needed to identify problems that can arise when working with this population.

**Phase 2: Identify national and international parent-directed and school-directed autism programs that are available for parents and schools**

The result of this phase of the project will be a list of national and international parent-directed and school-directed autism programs that are available to students with autism. Many parents and teachers are unaware of the resources that are available to help them deal with these students. Therefore, it is important that I provide a comprehensive list of resources to help all parents and teachers.

In order to get the information needed about the programs available I will need to speak with experts in the field about the programs that they use. They can give insight into the different programs available for them at the institution as well as the programs they suggest to the parents of their students. Research into effective programs and interventions will also give me a better idea of what types of programs are available to parents and professionals.

**Phase 3: Identify effective strategies and activities that parents and teachers can use in helping improve autistic student success**

The result of this phase of the project will be a list of effective strategies and activities that parents and teachers can use in helping improve autistic student success. Once the diagnosis of autism has been made, identifying effective strategies that will help these students is critical. I will conduct a literature review and make a list of all of the available strategies and activities parents and teachers can use.



There are many resources to help compile the list of strategies and activities. For example, Autism Speaks has compiled a list of applications that help autistic children work on their skills independently at school or at home. There are several other resources that offer different games and applications that help children practice the skills they are trying to master. Research is being conducted on the effectiveness of the different applications to reinforce and teach children with Autism Spectrum Disorders. Many of the applications available have not had research conducted yet so studies should be able to give insight into which types of applications are most effective.

#### **Phase IV: Making a Parent Handbook for parents that have a child with Autism Spectrum Disorder for Saudi Arabia**

After collecting and organizing the data from the first three phases, I will put together a handbook to of information for parents to access. This handbook will be made available in Saudi Arabia for parents who have the need to find more information to assist their child. Through the experts I interact with and that instruct me, I will be connected with a community of people that would be qualified to review my handbook. I can get a pilot review of my handbook from parents of the children I already work with as well as ask the people I work with to ask parents to review my handbook.

## **CHAPTER 4**

### **HANDBOOK**

Phase one of the Handbook for Parents describes students with autism's characteristics in an instructional setting are found to be diverse and several depend on the nature of the autism situation. Each different type of autism in the spectrum has different characteristics that can be found. Some of those characteristics are impaired social interaction, communication, and repetitive stereotyped behaviors. A child that has an Autistic Disorder may not make eye contact or could be unable to communicate verbally. Yet, a child with Asperger Syndrome may be able to talk and be highly intelligent. The main characteristic that a child like this would share with other types in the spectrum would be the impaired social interaction. A child with Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) would show some characteristics but not others. A girl with Rett Syndrome would have started developing normally and then would have started to lose some of the skills she had learned. A characteristic that is often seen is clapping or wringing their hands. A person with Childhood Degenerative Disorder (CDD) would also seem to have normal development and then would lose most of the verbal skills they had before (Kondro, 2012).

In phase two, there are many programs that have good and thorough guidance and explanations on how to deal and treat a student with autism. The handbook talks about the main things that all good programs should include in their program. One of those things would be to have activities that help them communicate with others. The way they do this is by reinforcing good behaviors and getting rid of bad behaviors. Children love rewards so letting them do something they like when they do the desired behavior will make them want to do it again. These programs use strategies like prompting and errorless learning to keep the children doing the desired behaviors. And all of the programs focus on the eight phases of learning to help the children learn.

In phase three, many different games and applications that can help assist a child with autism at home are described. In the handbook several applications are listed that help with different areas of development. One works on communication skills while another one works on facial expression to help the child learn how to interact with other people. There is an application to help keep the child organized and yet another that helps them with their vocabulary.

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## **PARENT HANDBOOK**

### **Phase One**

This handbook was created to be used as a resource for parents in Saudi Arabia that will help to bridge the informational gap that exists about Autism. This handbook will explain what Autism is, what evidence based practices are effective in working with people with Autism, and it will provide websites for parents to utilize.

### **What is Autism?**

Autism is a brain development disorder that can affect a person's social interaction skills, verbal and non-verbal skills, and repetitive behaviors. Some examples of what this may look like is a child not responding to other children during play activities, lack of eye contact, or the need to spin objects over and over. It could also Autism and its associated behaviors have been estimated to affect more than one in one hundred people worldwide. At the rate that autism is being diagnosed, it is known to be one of the most common developmental disabilities known to the general public. Autism is a very complex developmental disability and usually appears during the first three years of a child's life (Almanasef, 2011). Around the globe, boys are nearly five times more likely than girls to have autism. There are three core areas of autism symptoms; these areas include social interaction, communication, and repetitive, stereotyped behavior (Almanasef, 2011).

### **Types of Autism**

There are several known types of autism that fall within what is known as Autism Spectrum Disorders. The types of autism include Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, Rett Syndrome,

and Childhood Degenerative Disorder. Each type of autism will be discussed in the following section.

### **Characteristics of Each Type**

#### **Autistic Disorder**

Many people with autism do not understand the normal social interactions that are expected of them.

- ❖ This affects their ability to:
  - Play with other kids. They have difficulty blending in with kids when playing in different settings, such as playgrounds and parks. They also often have trouble with sharing, taking turns, and playing with toys in a typical way. For example, while the other children play a game of tag, the child with autism might stand by the wall by him/her self spinning a basketball on the ground, rather than shooting baskets.
  - Interact in social settings. They tend to have problems in social settings because they often prefer to be alone, and have difficulty initiating conversation with peers. Also, individuals with autism can become easily anxious or frightened by new people or in situations that are unfamiliar to them.
- ❖ They have difficulty with:
  - Reading facial expressions. When a normal person talks to someone, both participants see the words each are uttering to help them understand each other easily. This is the reason why autistic children have difficulty in social settings and interactions with people.

- Understanding how others feel. For example, when people are happy or mad, they express these feelings by facial gestures or tone of speech, yet children with autism cannot understand these feelings, thus they cannot express them.
  - Managing certain daily living skills such as handling money, crossing streets, answering the phone, etc.
  - Using language. They often do not speak at an early age; therefore, they are behind typically developing children.
  - Utilizing social skills. For example, they might have difficulty greeting somebody or initiating conversation
  - Reasoning abstractly. Sometimes abstract concepts are difficult for them, so concrete concepts are easier. An example of this would be following a routine or schedule. For a child with autism, often the abstract concept of time is overwhelming therefore a visual schedule can be used to break down time into different events for the child. This will often help to reduce anxiety in the child.
  - Playing appropriately. For example, they might scream or hurt themselves when they disagree about something and playing with others definitely involves partial agreement and disagreement.
- ❖ Difficulties with communication might lead to:
- Anger - Lacking this basic skill that everybody is easily using, makes him or her frustrated and angry. This can cause meltdowns or even aggression



- Aggression – towards others or themselves. For example, they might express their anger and disagreement by using aggressive behaviors towards others or hurting themselves.
- Anxiety- changes in routines can cause stress for people with autism.

### **Asperger's Syndrome**

People who are diagnosed with this type of disorder do not typically have problems with their language skills. They actually tend to score above average on most intelligence tests, but have the same social interaction problems as most children and adults with autism. More than anything else, Asperger's Syndrome would be considered a social disorder.

#### ❖ Personal impairments in

- Interaction
- Restricted areas of interest
- Stereotyped behaviors and interests

#### ❖ Social impairments

- Misuse of nonverbal behaviors
- Failure to develop peer relationships appropriate to their developmental level therefore have difficulty making friends.
- Not wanting to share achievements or joys with other people. Everything they do may be limited to them and never seek consultation or help.
- Lack of social or emotional reciprocity, which justifies they desire to be alone in their work and joys.

- For example, a teenager with Asperger Syndrome may talk nonstop about a certain topic, which peers are not interested in, or lack eye contact and other typical bodily gestures used when typically interacting with others.
- ❖ Restricted areas of interest
  - Preoccupation with one or more stereotyped and restricted patterns of interest by the intensity or focus.
  - Inflexible adherence to specific, nonfunctional routines or rituals, and have outburst when the routine breaks.
  - Stereotyped and repetitive motor mannerisms.
  - Persistent preoccupation with parts of objects such as to keep touching and moving a particular object for a long period of time.
  - For example, a child may demand that a particular route is taken when driving to school, and if a change is made to that route, a meltdown or other problem may arise.
- ❖ Lack of, or delays in
  - Language skills.
  - Self-help skills (for example; eating, bathing, grooming, toileting).
  - Cognitive development.
  - Curiosity about the environment.
- ❖ Have a peculiar language behavior that includes:
  - Misperception of social cues, for instance, to express something is not their fault when in fact it is.

- Odd vocal prosody (abnormal rhythm, stress, and intonation of speech).  
For example, a person with Asperger Syndrome might speak as if they are always asking a question, due to the emphasized high pitched-endings of words or phrases. “Really!” might be mistaken for “Really?”.
- Difficulty recognizing idioms and sarcasm; tend to take things said literally (For example, someone may tell an individual with Asperger Syndrome that they “had a ball” at a party, which is interpreted as literally “having/holding a ball.” This can cause confusion for the individual with Asperger Syndrome and/or an odd response from the other person).
- ❖ Unique characteristics in six different areas of functioning:
  - Social- not engaging in play with other children
  - Behavioral- meltdown when faced with a schedule change
  - Emotional- seemingly unable to demonstrate feelings of affection
  - Intellectual/cognitive- strong area of preferred interest
  - Academic- not able to demonstrate competency of material taught in traditional way such as by taking an exam
  - Sensory/motor- avoidance of certain noises, smells, or textures

### **Pervasive Development Disorder**

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) is a category for children and adults who have some autistic behaviors but do not necessarily fit into a certain category, and the symptoms may not be as severe in most cases (Autism Speaks, 2013).

## **Rett Syndrome**

- ❖ Mainly diagnosed in girls
- ❖ Start to develop normally until the ages of one to four years
- ❖ Begin to lose their
  - Communication skills (for example, speaking, listening, and nonverbal methods of communication, such as waving one's hand or nodding one's head)
  - Social skills (for example, she may stop talking and develop extreme social anxiety and withdrawal or disinterest in other people)
  - Development of repetitive hand movements (for example, she may clap frequently, or rub/wring hands, which can sometimes lead to marks on the skin)
  - Instead of using meaningful communicative hand gestures (waving, shaking hands) they might appear to ignore other individuals
  - Deceleration of head growth
  - Loss of previously acquired skills in
    - Language
    - The use of hands
  - Show signs of cognitive impairment
- ❖ Some of the girls are never able to walk
  - Some had already mastered walking
  - Show major abnormalities in walking (for example, she may walk on her toes or walk with a wide gait)

- ❖ Other issues paired with Rett Syndrome
  - Seizures (seizures can range from periodic muscle spasms to full-blown epilepsy)
  - Spasticity (stiffness or tightness of muscles)
  - Scoliosis (sideway curvature of the spine)
  - Overall growth retardation
- ❖ May also have
  - Episodic hyperventilation (for example, she may breathe too deeply or too rapidly, which may even cause chest pain and/or a tingling sensation in the fingertips and around her mouth)
  - Breath holding
  - Night laughing (which is the tendency for children with autism to begin laughing a night for no apparent reason)

### **Childhood Degenerative Disorder**

- ❖ Develop normally for at least two years
- ❖ Then lose some or most of their
  - Communication skills (speech, nonverbal communication – for example; a child may lose their ability to speak most/all words as well as shake hands, wave, etc.)
  - Social skills- using manners such as “please” and “thank you” when requesting items, turn taking in games, or general concern for others
- ❖ Another name for this disorder is
  - Heller's Dementia Infantilis.

There is no medical drug to cure autism or even treat it as a whole. The only thing that drugs offer is relief for certain symptoms that are associated with the disorder. The main areas that drugs help with are seizures, destructive behavior, and stimulus over reactivity (Autism Speaks, 2013).

## **Phase Two:**

### **Programs**

Programs are the most important aspect of teaching individuals with Autism Spectrum Disorder (ASD). In order for the program to be effective it should include activities that help the individual interact with others. There are many things that can be done to improve programs, for example, paying attention to respondent learning, operant learning, working on fluency, adaptation, etc. The best programs have certain features that make them effective (Autism Speaks, 2013).

- ❖ have activities that will help them interact with others by
  - Weakening bad behaviors
  - Strengthening the desired behaviors
- ❖ The way to strengthen the behaviors desired is by using:
  - Compliance training- a child is asked to do simple tasks that the child could definitely do successfully. The child is highly praised for his/her success. Gradually the request is slightly more difficult with the idea being that the child be given many opportunities to be praised and thereby reinforcing the desired behavior.
  - Response chaining- method of discrete trial training where the teacher does not wait for the child to actually complete the whole desired

behavior. If the child partially completes the behavior or makes a move or effort towards the desired behavior, the child is rewarded.

- Prompting- assisting the child to success in order to reduce frustration so that reinforcement can be given.
  - Errorless learning- working on skills that are considered mastered to build compliance for the teaching of skills that have been in acquisition for a while
  - Differential reinforcement of desirable behavior- used to shape the desired behavior of the student and provides information regarding the quality of the demonstrated behavior (Autism, 2013).
- ❖ The best programs pay attention to:
- Respondent learning- learning occurs due to an association between two stimuli and the conditioning of involuntary responses.
  - Operant learning- reinforce the desired behaviors and withhold reinforcement for, or punish, undesired behaviors.
  - Applied behavioral analysis- practiced learning theory or understanding what leads to new skills
  - Forms and processes of child-caregiver and child-peer interaction
  - Cognitive developmental psychology- scientific approach which aims to explain how children and adults change over time
  - Ecological psychology- analysis of behavior settings aiming to predict behavior patterns that occur in certain settings
- ❖ Excellent educational programs work on the eight phases of learning

- Acquisition- beginning stages of learning a new behavior
  - Fluency-how well the child can perform the behavior under given circumstances
  - Endurance-amount of time the task can be attended to by the child
  - Behavioral momentum- the relationship between how persistent the behavior is and the rate at which this same behavior is reinforced
  - Generalization- tendency for a learned behavior to occur in the presence of stimuli that were not present during training
  - Adaptation- learned behavior being applied to other situations
  - Retention- able to complete the desired task even after time has elapsed
  - Maintenance- continuation of the conditions that generated a performance
- ❖ have strong relationships with the parents so the parents understand what is going on and can use the same techniques to be consistent at home (“The Phases of Learning”, 2014).

### **Support Groups**

There are many support groups throughout the world that help individuals with Autism Spectrum Disorders and their families. These groups can offer anything from speech therapy to services that support families who are struggling with difficulties caused by a child with autism. All these organizations are incredibly useful and provide families with much needed support.

### **Achieve Beyond**

Achieve Beyond offers therapy for speech, occupational, physical, special education, autism services, and behavior consults and services. They have locations in New York,



Texas, California, and Maryland. They accept people from all over the nation. Their website is [www.achievebeyondusa.com](http://www.achievebeyondusa.com)

### **Parents of A.N.G.E.L.S.**

This group is located in Bronx, New York. The organization hosts autism conferences, participates in awareness events and autism fundraisers. It has a resource center containing books, pamphlets, computer programs and other materials about autism, which is available to anyone in the New York area and/or autistic community locally or nationwide. Their goal is to help children with autism by teaching parents the tools they need to help their child. Their website is [www.bxangels.org](http://www.bxangels.org)

### **Rocky Mountain Autism Center**

This program offers services for families struggling with the difficulties of having a child with autism. Some things they offer are online consults and a unique approach to therapy. Their website is [www.rockmountainautismcenter.com](http://www.rockmountainautismcenter.com)

### **Generation Rescue**

Jenny McCarthy started generation Rescue. The group focuses on educating people on how to improve the lives of children with autism. They want parents to have support and knowledge about what they can do to adjust their lives to help their child. Their website is [www.generationrescue.org](http://www.generationrescue.org)

### **National Autism Association**

The National Autism Association is organized to help support and educate families that have a child with autism. They are set up to help locate support groups and give the latest research about autism. They are set up to help the community with things like keeping

your child safe. They have information on safety and wandering to help parents. Their website is [www.nationalautismassociation.org](http://www.nationalautismassociation.org)

### **Autism Society of America**

The Autism Society of America has branches all over the United States. They have informational sections for anyone affected by a child with autism. They have a guide for parents, the person with autism, professionals, as well as advocates. Their website is [www.autism-society.org](http://www.autism-society.org)

### **Meir Autism Treatment Center**

Meir Autism Treatment Center is located in Israel but helps people all over the world. They offer support services and training packages for families. They have individual coaching available along with group coaching and books for parents. Their website is [www.meirautism.org](http://www.meirautism.org)

### **Veronica Bird Charitable Foundation**

They promote better understanding and awareness of autism around the world. They fund projects and offer grants that will enable parents and professionals to obtain information about autism. It is located in Maryland and is a resource to find out more about autism. Their website is [www.aheadwithautism.com](http://www.aheadwithautism.com)

### **US Autism and Asperger Association (USAAA)**

USAAA provides education, research, support, and solutions through conferences, newsletters, and resources. They have a worldwide conference every year to give the most up to date information on autism. They also have several projects including sending children to college and educational trainings. Their website is [www.usautism.org](http://www.usautism.org)

### **Autism Treatment Center of America – Son-Rise Program**

The Autism Treatment Center of America focuses on the Son-Rise Program to help children with autism learn to talk and interact better. They believe that working on the social aspect of autism makes all the difference. This is a different approach to helping a child with autism. Their website is [www.autismtreatmentcenter.org](http://www.autismtreatmentcenter.org).

### **Center for Autism and Related Disorders (CARD)**

They are among the world's largest and most experienced organizations located throughout California and in other states. They also have an office in New Zealand. They focus on Applied Behavioral Analysis treatment. They have helped families all over the world. Their website is [www.centerforautism.com](http://www.centerforautism.com)

### **Phase Three:**

#### **Strategies for Parents and Teachers**

The best way to help a child with autism is to be prepared and there is no easier way than to create a strategy that suits the individual. Strategies work differently for every individual. Some strategies include using Applied Behavior Analysis (ABA) flashcards, Augmentative Assistive Communications Solution (AACORN) and many more. The strategy can be the difference on how much the individual learns and evolves.

- Applications for Learning
- ❖ Augmentative Assistive Communications Solution (AACORN)
  - Used to build communication skills

- For children with
  - Autism
  - Apraxia
  - Downs Syndrome
  - Multiple Sclerosis

❖ ABA Find It!

- Teaches child when they make an error
- Gets harder when they master each level
- Real-life backgrounds
- Can track progress
- Choose the categories of items that they learn
- Pictures of the items being taught

❖ ABA Flashcards

- Flashcards that promote learning and language building. Clear audio and text for auditory and visual learners.

❖ Alpha Writer

- Compose and read words
- Work with phonetics and phonograms
- Practice writing stories

❖ AutiPlan Pictoplanner

- Structure and overview in daily activities
- Plan detailed activities using clear pictures

- Plan recurring days automatically by using templates and week schedules.

❖ Autism Emotion

- Uses music and a photo slideshow
- Helps teach about different emotions:
  - Happy
  - Sad
  - Proud
  - Calm

❖ Therapies

- Applied Behavioral Therapy (ABA)- Therapy behavioral analysis is scientifically validated approach to understanding behavior
- Auditory Integration Therapy- Aims to address the sensory problems such as hearing distortion which is said to cause discomfort and confusion in people.
- Aquatic Therapy - an effective recreational treatment using water for the treatment of autism
- Music Therapy - uses music as the therapeutic stimulus to achieve non-musical treatment goals.
- Equine Therapy - the use of horses in behavior therapy for people with Autism.

**Conclusion**

In addition to the programs described in this brochure, there are also many

resources for Autism that are available through the use of computers and the iPad. Parents can use the Internet to search for applications that are effective and motivating for children with Autism.

While more is still being learned about Autism each day, there is support available to parents so that they do not have to feel helpless. With education and resources comes a peace of mind that children with Autism can learn and that their families can grow together to help the children with Autism be successful.

## **CHAPTER 5**

### **CONCLUSIONS AND LIMITATIONS**

Autism is a disorder that falls into several types and is still in the early stages of exploration, therefore little is known about the cause of autism spectrum disorders. It appears that there is a genetic component involved with autism, yet the actual source of the disorder has not been linked to a specific gene or environmental factor.

Parents and students are protected by the government in the United States with the Individuals with Disability Education Act of 2004. This means that in the United States a child with a disability that attends a public school should have accommodations made for them and extra services available when they are needed to assist in the child's ability to be successful in school. The first part of the rights explains that the child should be given a free and appropriate education that does not cost the family anything. Although the child may need extra help with learning to communicate, the cost of that extra instruction will not cost the family anything. The child should have a fair evaluation that truly addresses whether the child has a disability and what accommodations must be made to keep the child successful as they progress through their education. The Individual

Education Plan (IEP) should be completed by the same group of professionals that determined the child's disability as well as the parents of the child. When the child is old enough and able to participate, the child's own goals for their education should also be included in the IEP. The child should also be allowed to continue their education in the least restrictive environment, which means that they should be allowed to stay in general education classes when accommodations can be made to keep the child successful in the class. Parents should be included in the goals and practices that the school is using to help their child. They should learn how the school has been successful in meeting the goals in the IEP so that the parents can continue those things in their home. And finally the school and parents need to have safeguards set up so that everyone understands what happens when the child no longer has a disability or has passed the age of 18. Both the parents and school need to understand what happens in those situations. The other part of safeguards is that parents need to know what they can do if they do not agree with the IEP that the school set up and when the school is not responsible if the parent still does not accept an IEP.

The prevalence of autism around the world is still growing and is the most diagnosed disorder around the globe. In Saudi Arabia 1 in 100 children are diagnosed with an autism spectrum disorder and according to the CDC 1 in 88 children are diagnosed across the world. The different types of autism include Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, Rett Syndrome, and Childhood Disintegrative Disorder. Each one shows signs differently and at different times during development. The social impairment, stereotyped behaviors, and



communication problems are seen in most types of autism. Rett Syndrome appears only in girls but autism as a whole is more common in boys than girls.

Several different treatments are used to help manage some of the characteristics of autism but no actual cure for the disorder exists. Applied Behavioral Approach is used to help cope with issues that come with autism and help them be as successful as possible. Other types of therapy are also used that show a potential to help with some characteristics of autism. They have learned that early intervention and parent involvement are both key to helping children with autism. Since autism symptoms appear by age three on average, starting early is really helpful to get them verbal and successful. It is also helpful when the parents want to work with their child at home so continue giving them the best chance of success.

### **LIMITATIONS**

This project may have been limited in that there are so many resources about autism that it can be difficult to pick out the best sources. Another possible limitation could be that thoughts about autism are continuously changing as more research is conducted. There may be some issues with the handbook as it is translated into Arabic. When words are translated, at times the meaning is altered. A person with a professional background in translating should be utilized in the translation process for the handbook. In addition, because not much is known about autism, people in Saudi Arabia may not have the background understanding of the disorder.

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