THE PARENTING CHALLENGE: SELECTING TECHNOLOGY AND NON-TECHNOLOGY INTERVENTIONS FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

By

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ABSTRACT

Autism is a Spectrum of Disorders (ASD) that affects 1 in 88 children. The issues and decisions parents face are almost insurmountable depending on the child's diagnosis, available interventions, the knowledge of parents, proximity to professionals and interventions, financial resources, and the individual needs of the child. There is no cure for ASD; it persists over an individual's lifetime. As a result, the role of parents is expanded and direct caregiving, decision-making, and supervision continue into the child's adult years. Parents find themselves involved in advocacy, education, intervention planning, and technology selection and use. Most parents actively seek interventions to help their children with ASD gain functional, behavioral, social, and academic skills. Without supportive parents or caregivers, many children with ASD are unable to function independently, and the quality of their lives is greatly diminished. This article describes technology uses in ASD and parental concerns. Findings from this descriptive study reveal the technologies parents are using, the needs and issues of families, and demographic data. Participating families were recruited from online discussion groups and through the assistance of the Interactive Autism Network (IAN) Project at the Kennedy Krieger Institute, Baltimore, Maryland.

Keywords: Technology, Autism Spectrum Disorders, Texas, Parental Selection.

INTRODUCTION

The number of children diagnosed with Autism Spectrum Disorders (ASD) continues to increase. Current statistics from the CDC's Autism and Developmental Disabilities Monitoring Network (ADDM) indicate that 1 in 88 children have an Autism Spectrum Disorder (Autism Society of America, 2012). Deficits in three areas are found in individuals with ASD; their degree of impairment in these areas varies in scope and intensity. The areas are communication/language, social interaction, and behavior (restrictive and/or repetitive behaviors are common). Many individuals with ASD have average intelligence; some possess exceptional skills in specific areas (artistic talent in music, drawing, and painting, detailed and accurate recall from long-term memory, computational ability, spatial organization, etc…), others are borderline in their intellectual ability, and some are mentallyretarded.Variationsinintelligence, communication/language, social interaction, and behavior are commonly observed, and these factors make it necessar y for intervention planning to be flexible, consistent, and individualized. This paper addresses variations in ASD, technology, needs and issues of parents, and demographic data.

Variations in ASD: Communication/Language, Social Interaction, and Behavior

Many individuals in the spectrum have difficulty understanding, interpreting, and using language in a social context. They may not understand language in face-to-face encounters, but they may excel at communication through technology tools like email, IRC sessions, and conference calls (O'Neil, 2008). Language is critical; it is an important part of academic and social success; it empowers learners and allows them to become actively engaged in their world. It also enables them to create and maintain social networks and

manipulate their environment in order to get the things they want and need.

Individuals with ASD have social skills deficits; they may not be aware of or process the subtle queues, reactions, and body language of others. They require explicit instruction in these areas to help them become better at "reading" and understanding people. Many individuals with ASD desire social interaction, but are unable to initiate or maintain dialogue, remain on task in conversations, effectively demonstrate turn-taking, or fully understand pragmatic language. They may perseverate on an item, event, or action or talk obsessively about a single subject or a narrow range of subjects. They may ask the same question repeatedly or ask inappropriate questions. They may have auditor y processing problems which limit their ability to listen effectively, engage in reciprocal conversation, and determine the level of interest of those around them. They may be socially inappropriate because they are unaware of social conventions regarding personal space and appropriate behaviors. They may discuss inappropriate information because they are unable to discern appropriate audiences and contexts. Structural and functional differences in their brain affect their ability to implicitly learn to read facial expressions, sense the discomfort of others, or empathize with others. Individuals with ASD are said to lack "Theory of Mind;" they are unable to understand that others have different thoughts, feelings, beliefs, knowledge, desires, and needs from their own (Baron-Cohen, 1995; Baron-Cohen, 2008).

The atypical social behavior demonstrated by some individuals with autism may be linked to their perception of their environment (O'Neil, 2008). If the environment is confusing or difficult to tolerate, repetitive motor movements and sounds (humming, squealing, or shaking) that seem bizarre to others may be a way of coping with excessive noise, fear, or discomfort. Often, self-stimulator y behaviors are often a mechanism for calming an overly active sensor y system (hypersensitivity). Many times the individual with ASD has Sensor y Integration Dysfunction, and this makes it difficult or impossible to efficiently process and respond to sensor y information. Visual, auditory, and tactile information is often confusing and difficult to sort, filter, and interpret. Poorly coordinated vision and motor systems present an additional burden which may make coordination, balance, and the execution of motor skills problematic. In an effort to compensate, the individual with ASD engages in self-stimulator y behaviors that are not always socially acceptable. These behaviors can cause social rejection, isolation, loneliness, and increased stress and anxiety in social situations. Sensor y issues are a tremendous issue in ASD; the latest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) has been updated to include sensor y processing issues.

Children with autism can present a broad range of clinical features including abnormalities in development, neurological problems affecting their sensory/motor systems, seizure disorders/epilepsy, cognitive dysfunction, impairments in adaptive behavior, ADD or ADHD, digestive disorders, visual processing problems, and an aberrant regulation of emotion (Bregman, 2005; National Autism Center, 2009; Reiss, 2009). Core symptoms associated with autism include an inability to see the "big picture" or thinking in detailed pieces rather that understanding the larger context. Additional symptoms include problems with reciprocal social interaction, rituals and compulsions, motor abnormalities, abnormal language and communication, and aberrant emotional expressions like anxiety and depression (Reiss,

2009). The risk factors for the development of autism include neurogenetic diseases like Rett and Fragile X Syndromes.

Technology and ASD

Technology tools can be used to address the variability in ASD, because they can be programmed to address many levels of user need. The needs of novice, intermediate, and expert learners can be addressed. Along with leveling, software can be programmed to collect and report performance data. Technology offers flexibility, the ability to individualize content, anytime, anywhere access, and engaging and motivating presentations. Computer programs can track a student's

progress, deliver immediate feedback, and present learning scenarios that are consistent and visually appealing. Messages, interactions, and instructional content can be repeated as often as needed without pressure or stress, a variety of skills (academic, social, functional) can be taught, the learner has locus of control, makes choices relative to the rate of the presentation, makes choices on branching sequences in the programs, and navigation. Some packages also allow the user to select options, choose characters, and create identities. Parents and caregivers need to understand the benefits and shortcomings of software and hardware in order to make informed choices. They need to have the opportunity to try tools, evaluate them, and review objective sources for product reviews, critiques, and uses before they make investments in technology which may or may not be beneficial. In order to be effective, technology tools must be consistently applied, they must match the instructional objective, they should be thoroughly evaluated, and they should be woven into a well-designed instructional and therapeutic program that is motivating and individualized to meet the needs of the learner.

Oberleitner, Ball, Gillette, Naseef, and Stamm (2006) identify types of technology and ways it can be used by families affected by ASD to lessen to pressure that can lead to Posttraumatic Stress Disorder. The authors mention Telehealth, distance education, information technology, video conferencing, and computer software as useful tools for families. Telehealth or telemedicine was mentioned as a way to provide synchronous consultations between patient and provider through video conferencing. By using telemedicine, medical information can be electronically shared after it has been reviewed. Safeguards must be in place to secure the information. Distance education was mentioned as a vehicle for providing information on state-of-the-art treatment techniques and educational programs to families in rural, remote, or isolated areas who do not have easy access to providers and services for intervention planning. Information technologies were mentioned as ways to increase communication, aid information seeking, process data, gather pertinent information, and conduct research. They provide an avenue for advocacy and information sharing over the Internet. Interactive websites, video libraries, listservs, and message boards are examples. Video conferencing provides two-way Interaction across different geographical locations. The interaction can be archived for later access and review. Computer programs can facilitate learning by providing practice, reviewing concepts, and delivering instruction and feedback on language and social skill development.

Pennington (2010) reviewed research on Computer-Assisted Instruction and teaching academic skills to students with ASD. The review of literature included studies conducted from 1997 to 2008. A total of 15 studies were selected because they met the inclusion criteria for analysis: published in a peer-reviewed journal from 1997-2008, experimental or quasi-experimental design, description of the manipulation of independent variables that used CAI, a description of data collection procedures on the targeted academic skill, and the identification of at least one participant as having ASD. The 15 studies involved the acquisition of literacy skills, and single subject research designs were most frequently used. The author indicates that there is a limited body of research on CAI and ASD, and more study is needed before CAI can be deemed an evidence-based practice. Even so, Pennington indicated that CAI showed promise as an intervention, because each study analyzed reported student improvement in the area targeted.

While CAI and CAL (Computer Aided Learning) have the potential to be efficacious when they are well designed, thoroughly tested with children diagnosed with ASD, supported by teachers and parents, used to help learners gain new skills, structured, and incorporated in a well-designed curriculum, the development of software and its use with children diagnosed with ASD is limited (Kimball & Smith, 2007; Moore, McGrath, Thorpe, 2000). Computer-mediated learning requires additional study; it may fill gaps in a student's knowledge and his ability to develop and generalize skills in his areas of deficit: social skills, communication, rigidity of thought, Theory of Mind.

In order for students to benefit from CAI and CAL, computerized systems should be created based on core deficits in autism, use accepted pedagogical practices, and be evaluated by cognitive assessments performed by educational experts and practitioners (Moore, McGrath, Thorpe, 2000).

The demand for more technology in the field of autism is even higher than in the past. Video modeling is an application of technology which uses realistic contexts to teach learners with ASD procedures, processes, and social skills. The National Autism Center (2009) provides evidence that Video-Modeling (VM) is a promising technique for reducing some skill deficits in ASD. Improvements in conversation and play skills, perspective taking, social communication, and spontaneous requesting have been reported after the use of video modeling (D'Ateno, Mangiapanello & Taylor, 2003; MacDonald, Clark, Garrigan & Vangala, 2005; Nikopoulos & Keenan, 2007; Owen-DeSchr yver, Carr, Cale & Blakeley- Smith, 2008).

Learning tasks may be presented at or above the user's level of proficiency. In research studies where VM was used as the primar y inter vention without other components, children studied acquired motor and verbal play sequences and generalized targeted skills across settings and peers (D'Ateno, Mangiapanello & Taylor, 2003; MacDonald, Clark, Garrigan & Vangala,

2005; Nikopoulos & Keenan, 2007).

There have been notable advancements in the field of technology designed to aid the learning process of children with autism. Electronic Screen Media (ESM) is one video-based technology used to engage autistic children. In a study by Mineo, Ziegler, Gill & Salkin, (2009), ESM was used to systematically compare the appeal of four types of video-based electronic screen media. Findings indicated that all types of stimuli included in the study held the students' visual attention reasonably well for a short period of time. Opportunities for students to see themselves portrayed on the screen generated greater gaze duration than viewing another person on the screen (Mineo, Ziegler, Gill & Salkin, 2009). The engagement of the autistic child is important in the educational process.

When teachers are able to engage students, the students retain more information, exhibit more focused attention, and actively participate in the educational experience.

Technology is also used to aid communication - one of the biggest challenges facing children with ASD. Another challenge is social interaction; children with ASD have problems interacting and socializing with their peers. This problem is addressed through Photovoice, a technology that uses photography to promote interaction. Students are given a theme and asked to capture pictures. After the pictures are taken, students choose the pictures they want to share with their classmates. Group interaction facilitates discussions about the pictures and their relationship to designated themes (Carnahan, 2006). This activity allows students who would ordinarily isolate themselves, to contribute to the discussion. For students, the Photovoice and discussion process increases involvement in group activities by removing language barriers, structuring the learning task, and incorporating student interests (Carnahan, 2006). This process was also tested on teachers. The teachers were able to share their experiences, learn from each other's strategies, and brainstorm ideas for future interventions for their students with ASD.

Activity schedules are another form of technology used to promote the independence of autistic children. The latest studies have paired activity schedules with computer technology to teach autistic children. Activity schedules delivered on the computer may increase learning through the combined used of video, sound, dialogue, imager y and words used as instructional stimuli (Stromer, Kimball, Kinney & Taylor, 2006). Activity schedules help learners in the spectrum manage their time, complete designated tasks independently, and follow through without distractions. Activity schedules combined with other instructional supports and enhanced with multimedia software significantly increase learning for individuals with ASD (Stromer, Kimball, Kinney & Taylor,

2006).

The increasing numbers of children diagnosed with ASD

have increased the need for research, development, and funding. According to Kimball & Smith (2007), an Autism Technology Grant Fund would create an avenue to pool money from different sources and apply the funding to projects designed to focus solely on the development of tools for teaching individuals with ASD. This would encourage research and make it possible to apply more technology to the needs of children with ASD.

With mobile technology on the rise, more research is needed to evaluate apps, test the effectiveness of smaller display screens, and inform the Autistic Community of the most effective tools for fostering communication, social skill development, and academic achievement. Successful technology outcomes for children with ASD include: skill acquisition and retention, social interaction, inclusion, and effective communication. These can occur if the most appropriate technology which matches the learning outcome is selected, it is included in a guided, mediated, and structured environment, staff support is present, technology training is given to teachers on an on-going basis, administrative support is present, and transition planning is addressed (Hutinger, 1996).

Goals of the Study

The purpose of this exploratory study was to discover the interventions used by families across Texas to help improve the lives of their children with ASD and to identify the needs and issues of parents raising children with ASD in Texas. The research questions for this descriptive analysis included the following:

I) What interventions are used most frequently by families with children in the Autism Spectrum in Texas?

ii) What technologies are used by families to address the problems faced by their child with ASD?

iii) What are the demographics of the families in Texas caring for children in the Autism Spectrum?

Method

This descriptive study was conducted to discover the technology and non-technology interventions parents were choosing for their children with ASD. This exploratory study received approval from a university human subjects review panel.

A survey was developed, statistically analyzed, piloted, and placed online to gather data from families in Texas with children in the Autism Spectrum. Survey Monkey was used to create and house the survey, and securely store the results. An Informed Consent Form preceded the survey, and participants were invited to contact the investigator with questions or concerns. An email address was given for participants to contact the investigator for final survey results. The recruitment of participants was supported by the Interactive Autism Network (IAN), which publicized the survey on its list of Autism Studies in Texas. Additional efforts to secure participants were made through face-to-face meetings at local autism societies and online discussion groups that focused on A SD. Permission was gathered from moderators of discussion groups and presidents of local Autism Societies.

Results

A total of 307 surveys were completed, and the respondents that identified Texas as their state were filtered. A total of 219 responses (71%) were usable and further analyzed to answer the research questions. The majority of responses were from mothers of children diagnosed with ASD. Fifty-seven percent of the mothers were employed outside their homes in nurturing and non-traditional roles. The most frequently reported professions were Teaching, Nursing, Administrative/Secretarial, Sales, and Supervision/Management. There were reports of non-traditional professions as well: CEO, CPA, Usability Website Designer, Pediatrician, President of a software company, and a Radiation Therapist. Respondents were generous with their information; high numbers of responses appeared for a majority of the questions. Survey results were analyzed using the tools in Survey Monkey, SPSS, and Microsoft Excel. Simple frequency distributions answered the research questions. Completed surveys came from residents in 85 cities across the state of Texas. The largest number of responses came from San Antonio, Plano, Houston, Dallas, and Austin, respectively.

Non-Technology Interventions Most Frequently Used by Parents

Families across Texas are employing a combination of therapies, instructional programs, and other strategies to improve their child's functional level and quality of life. Biomedical, behavioral, and other therapy interventions are used simultaneously. The most commonly reported interventions were Speech Therapy, Occupation Therapy, Sensory Integration Therapy, Social Stories, ABA Language and Behavior Therapy, and Vitamin/Nutritional Supplements as shown in Table 1: Non-Technology Interventions Used by Parents. The table was created by Survey Monkey.

Technology and Other Interventions Used by Families

Families reported using the following technology interventions: video games, educational programs on the Internet, educational software (CAI/CAL), listening programs, Neurofeedback, the computerized version of Nambudripad's Allergy Elimination Techniques (NAET), the ComfyLand Computer Program, EdMark's Reading Program, and Brain Training Therapy.

Other interventions included Early Childhood Intervention/Preschool Programs for Children with Disabilities (ECI/PPCD), dietary modifications, play therapy, music therapy, counseling programs, physical activity through Special Olympics, social skills groups and training programs, feeding therapy, yoga, and more. Families were actively using a host of non-traditional interventions and techniques to improve the quality of life for their children with ASD.

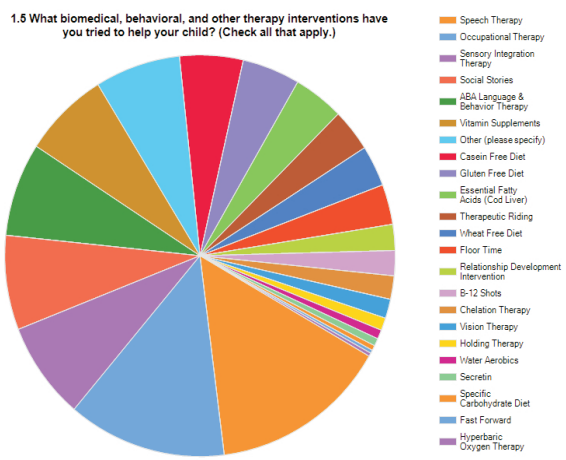

Table 1. Non-Technology Interventions Used by Parents

Needs and Issues of Parents Raising Children with ASD

Comments from parents of children with ASD indicated that they face a myriad of obstacles and challenges. The most common problems their children demonstrate include: frustration, problems with changes in routines, lack of attention, constant need for reminders, anxiety, difficulty transitioning, problems with motor planning, difficulty organizing and executing, humming and other noises, sleeplessness, auditor y processing problems, and self- stimulatory behaviors. Additionally, the parents reported difficulty because of the perceptions of others and a lack of understanding from individuals with whom they come in contact. Parents reported needing help coping with their child's non-compliance, communication deficits, aggression, and self-injurious behavior. The majority of parents indicated that their life was difficult and they faced stress, sadness, and overwhelming financial challenges. Most respondents were willing to tr y alternative therapies to help their children. When parents were asked what they wanted others to know about their life with ASD, the following comments summarize the responses:

"He looks normal, and I love that you think he isn't really autistic. It's a huge compliment to me that he is doing so well. But he needs reminders and a little management to keep it together in social situations and busy settings. Please do not assume I am a witch or a bad mother or mean person when I speak to him firmly in a louder than normal voice. He has auditor y processing problems, and he will not hear me unless I do this using very simple, direct words. Please do not tell me to relax and ignore him. If I had relaxed and ignored him, he would still be beating his head on the ground and screaming 12 hours a day. He would not be talking. Please try to understand even though you aren't seeing it. You don't want to see the autism. It's not pretty."

"For the public to stop judging us and labeling our kids as bad kids or poor parenting. It is a major challenge raising kids on the spectrum, and we do the best we can and especially when there aren't any other forms of support for us. Instead of judging us, tr y asking if we need help."

"Stress is never ending. Just when you move through one problem or crisis, another one pops up. We need people to help with everyday care issues. One size fits all programs do not work. We need help early on when they are young so that they maybe won't need it later."

"It is a 24/7 job regardless of where I may be. The financial and marital stress from having a child with ASD is more than any other type of stress I've experienced. There is no such thing as a "good night's sleep;" we may never be "empty nesters" and the worry about what will happen to her when we are no longer able to care for her is constant."

Demographics

According to the families surveyed in Texas, their children with Autism were mostly commonly given the following diagnoses: Autistic, PDD-NOS, and Asperger's Syndrome. Most of the children were diagnosed with Asperger's Syndrome or diagnosed as Autistic, and their mother indicated that they were high-functioning. Mothers of children diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified indicated that their children functioned at a medium level (not high with more normal skill sets or low with below average skill sets). The majority of mothers (84.8%) indicated that their children were males; the earliest diagnosis occurred when the child was 1 year old and the latest diagnosis occurred at 25.4 years of age. Diagnoses were typically made by a team of professionals in 28.1% of the cases. In 25.5% of those surveyed, a diagnosis was made by a clinical psychologist or by a school psychologist 17.9%. In the remaining families (28.5%) a diagnosis was made by a psychiatrist or developmental pediatrician.

Effectively assessing a child with autism requires knowledge about the shared characteristics of the disorder as well as unique characteristics of the individual (Shriver, Allen & Mathews, 1999). Observations should take place in home and school to determine a number of factors related to the diagnosis. The psychologists should interact with the child to determine the extent of the child's deficits, and he or she should give the child a direct skills assessment which may assist with effective instructional planning and establish strategies and methods for evaluating and monitoring progress (Shriver, Allen & Mathews, 1999).

Educational Level of Parents

Mothers of children in Texas affected by Autism reported being between the ages of 35 and 44 (53.3%), and more than 95% of them used the Internet regularly from their home to research information on Autism Spectrum Disorders. These mothers relied on their local Autism Society for information, and many attended local conferences on ASD - 19.9% attended state and national conferences to gain additional insight and information on ASD. The majority of these mothers have attended college (27.4%), are college graduates (26.5%), or holders of advanced degrees (21.8%).

Stress Levels

Survey responses indicated that mothers were educated, they were using the Internet to find intervention options, and they were under stress. The majority of respondents (58.8%) reported a high level of stress, while many others (38.9%) indicated that their stress level was at a medium level. Only five (2.3%) indicated that their stress level was low. See Table 2 Stress Levels Reported on page 8. In addition, parents were asked how having a child with ASD affected their level of stress. The majority (94.9%) indicated that having a child in the spectrum increased their level of stress. See Table 3 Increased Stress Levels on page 8. All tables were created by SurveyMonkey.

Conclusion

Families across Texas are seeking both non-technology and technology-based interventions to help their children with ASD gain functional, behavioral, social, and academic skills. Most families are simultaneously participating in a variety of interventions in an effort to improve their child's condition. Families surveyed are under stress, but generally healthy. They find life challenging as they select technologies and interventions to try to improve their child's condition. The simultaneous use of a variety of interventions is understandable. Parents desperately want to improve their child's chance to live a quality, fulfilling, and independent life, and they engage in a variety of therapy options in order to give their child

that chance. This does raise an interesting question. How will the families know which interventions are responsible for any gains their child achieves? Perhaps an interaction effect among the therapies is responsible for progress that may be reported. Families need to carefully select non-technology and technology-based interventions and carefully evaluate and log their child's progress in an effort to understand which therapies are contributing to their child's success. Carefully tracking interventions by establishing baseline data on performance, and then adding another intervention and tracking the result of the combination may be a good way to determine if a single intervention or combination approach is working. Families want progress, and that is understandable, but it is important to evaluate to understand which options are producing gains. By using a single intervention, determining its impact, and gradually adding another option, parents may be able to make more informed choices and provide better recommendations to other families.

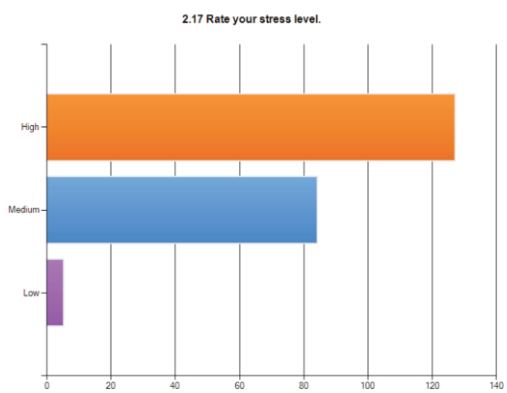

Table 2. Stress Levels Reported

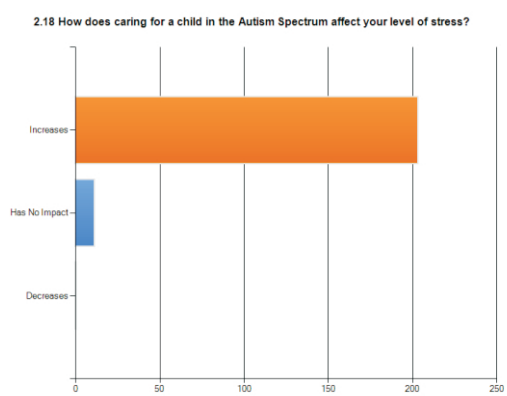

Table 3. Increased Stress Levels

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