Families, Technology, and Children with Autism Spectrum Disorders

Demetria Ennis-Cole, Ph.D.
Demetria.Ennis-Cole@unt.edu
Associate Professor
University of North Texas
3940 North Elm Street
G150 Discovery Park
Denton, Texas 76207

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Abstract

Autism, a spectrum of neurological disorders, persists over the lifetime of an individual. It affects 1 in 88 children. Individuals with Autism Spectrum Disorders (ASDs) have problems with communication, behavior (restrictive and repetitive), and social interaction. In the past, ASDs were poorly understood and not well publicized, but now, public service announcements, blogs, magazines, newsgroups, radio programs, a host of websites, and journal articles on ASDs are prevalent. As a result, many families are aware of the signs and the types of interventions that are available. Parents face a number of significant challenges and stressors as they seek inventions, plan for the future, obtain resources, balance the needs of all children in the family, and work through each day’s events. Deficits in social skills, communication, and behavior are found in varying degrees in individuals with ASDs. Co-morbid conditions, lack of Theory of Mind, and varying levels of intelligence are present as well; families use a variety of technology and non-technology interventions to mitigate deficits. This work explores some of the challenges of parents (things parents wish others knew about their life), the technologies parents select, their concerns about technology, and demographic data.

Introduction

Several pervasive developmental disabilities are included in the Autism Spectrum: Autistic Disorder, Pervasive Developmental Disorder - Not Otherwise Specified, and Asperger Syndrome (Center for Disease Control and Prevention, 2012). Children with ASDs may have additional challenges: depression, conduct disorders, sensory integration dysfunction, feeding issues, learning disabilities, anxiety disorders, ADD/ADHD, repetitive movements (stimming), obsessive compulsive behaviors, motor skill difficulties, seizure disorders/epilepsy, impairments in adaptive behavior, an aberrant regulation of emotion, discomfort with eye contact, late onset of speech, difficulty expressing empathy, as well as problems with communication, social interaction, and behavior (Loeber & Keenan, 1994; Madsen, Kaliouby, Goodwin, & Picard 2008; Myles & Simpson, 2002; Portway & Johnson, 2005; Reiss, 2009). The combination of any of these is a recipe for parental stress and anxiety, and many studies on parents of children with ASDs report stress, higher levels of stress than parents of children with other disabilities, persistent stress throughout the child’s lifetime, increased depression, restrictions of roles and activities, marital stress, and diminished physical health (Fleischmann, 2004; Ingersoll & Hambrick, 2011; Myers, Mackintosh & Goin-Kochel, 2009; Pisula, 2007; Stoner, Bock, Thompson, Angell, Heyl & Crowley, 2005; Shu 2009).

One promising tool for enriching the lives of families struggling with ASDs and co-morbid conditions is technology. Broadly defined as any electromechanical device which helps users accomplish work, engage in leisure pursuits (entertainment), learn new content (education), or both (edutainment), some technologies used with learners diagnosed with ASDs include: video-modeling, iPads, iPod Touch, laptop computers with Internet Access, DVD Players, virtual environments, augmentative and alternative communication devices, CAI, PDAs, e-Books, Nintendo DS, Wii, and a host of other devices and tools. Many parents of children diagnosed with ASDs are using technology to help their children gain academic, listening, and social skills. In addition, they are using technology to manage their child’s time, remind the child of critical daily activities, help the child develop leisure pursuits and build communication skills. Understanding the needs of families can create a platform for inclusion, acceptance, and technology integration for teachers, administrators, instructional designers, and therapists.
Purpose

The purpose of this exploratory investigation was to acquire insight about parents’ challenges with an Autistic child, examine demographics, and identify technologies used. In order to gain experience for further inquiry, the following questions were asked:

1.) What do families wish others knew about their life with a child in the Autism Spectrum?
2.) What technologies are used by families to address the problems faced by their child with an ASD?

Theoretical Foundation

This inquiry is situated in Adult Learning Theory – specifically experiential learning based on the work of Dewey, Piaget, Kolb, and Lewin. Adult learners in this study are parents of children with ASDs, and they learn to understand their child and discover the child’s unique needs and interests by direct interaction with the child. The parents learn to work with their child by doing so, and they reflect on the strategies that worked as positive reinforcement, the methods of discipline that were effective, and the educational experiences that were most successful. Parents’ gain knowledge of the therapies and instructional strategies that work and those that do not by observing their child, trial-and-error, the child’s behavior, and their own internal gage of the amount of progress they witness in their child. The parents’ learning is based on their personal and environmental experiences, and it requires active involvement, problem-solving, analytical ability, and memory. No teacher is present; the parent learns from direct experience rather than lecture, conversation, or readings.

Methodology

Participants

Parents in Texas who have children diagnosed with Autism Spectrum Disorders (ASDs) were invited to complete an online survey in an attempt to determine parental challenges and the technologies used. In order to gain information, a survey was created, reviewed by statisticians, pilot tested, and placed online. After gaining IRB approval, the link to the survey was sent to electronic newsgroups whose focus was ASDs. The survey had four sections: Background Information, Demographics, Physical and Behavioral Characteristics of the Child with ASDs, and Educational Options. Survey responses were gathered from 2008-2010 using a snowball sample technique which began from links posted on three known sources: online discussion groups that focused on ASDs, the Interactive Autism Network which publicized the study on its list of Autism Studies in Texas, and the TARA Website. In addition, families were recruited through face-to-face meetings at local Autism Societies and through word of mouth.

Coding Responses

The parents’ responses were reviewed for themes using content analysis (Miles & Huberman, 1994). The primary coder made a list of tentative themes, and two additional coders reviewed responses. As a result, the original themes were revised, combined, and expanded until there was agreement. Once the themes completely captured all the concepts in the data, parents’ responses were inductively reviewed again; sorted into primary and secondary themes, and the number of statements reflecting a primary and secondary theme were clustered and tallied. As an example, one primary theme was training, and it included parents’ references to an awareness of ASDs, family knowledge of ASDs, teacher and parent training.

Findings: Challenges of Parents: (Things They Wish Others Knew)

A total of 307 individuals completed surveys. Those were filtered to include only those respondents who indicated that they resided in Texas. Demographic data from those surveys along with the open-ended answer to the question, “What do you wish others knew about your life with a child in the Autism Spectrum?” were analyzed using SurveyMonkey and Excel. Exactly 220 responses were reviewed; 195 open-ended answers were coded by multiple reviewers and those presented an interesting story. The shortest response was five words: “Just how difficult it is.” The longest response was about 1.125 pages, and it contained 1,210 words. The coders came to agreement on 19 themes: need for family support, hard/difficult, unfair judgments, reasons for tantrums, kids with ASDs need patience, kids with ASDs need understanding, cost, worry, isolation, exhaustion, stress, frustration, need for structure, endless issues, insurance, training, positive descriptors, negative descriptors, and N/A (not applicable).
A majority of respondents mentioned at least one theme in their answer (53.3%). Two to five themes were mentioned by 30.8% of the respondents, and 15.9% made comments that could not be placed into any of the identified themes. An example of the latter: “I have noticed quite a few parents (in my area) who must think it’s ‘in’ to have a child who is autistic and have diagnosed their children on the Internet. They have completely turned me off from attending parent classes in my local area.” Many studies on parents of children with ASDs identify parental stress, heightened risk of mental health problems, chronic health conditions, a lower quality of life, difficulty obtaining services, inadequate service delivery, lack of collaboration, increased depression, anxiety, and other negatives as themes that emerge from parental perspectives on life with a child with an ASD (Fleischmann, 2004; Stoner, Bock, Thompson, Angell, Heyl, Crowley, 2005; Pisula, 2007; Shu, 2009; Ingersoll & Hambrick, 2011). The six most commonly reported themes are listed below.

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Theme #1: Parenting a Child or Children with an ASD is Very Hard/Difficult

Many factors contribute to a difficult life with a child (or children) diagnosed with ASDs. Some factors are tantrums or meltdowns on the part of the child, self-inflicted injury, over stimulation, sleep deprivation, and flight or fight (Fleischmann, 2004). Often, an unmet physiological, biological, or emotional need that cannot be verbalized causes the child to become frustrated and have a meltdown. Parents struggle with meltdowns, therapy selection, education, feeding problems, and other issues (Ivey, 2004; Starr, Foy, Cramer & Singh, 2006).

An individual with an ASD may pick his skin severely or inflict other forms of self-injury by punching, hitting, or biting. These are reactions to anger, stress, or frustration, and they can create stress on parents. Many individuals with ASDs have either an over-active (hypersensitive) or under-active (hyposensitive) sensory system that causes them to react to pain, sound, and noise differently than their neurotypical peers. In a classroom setting, an individual with an ASD may simultaneously hear lights humming, coughing, others talking, the A/C, the pencil sharpener, and the teacher talking and have difficulty filtering these sounds. Difficulty filtering and adjusting to noise and other stimuli may make it uncomfortable to be in certain settings - florescent lighting, loud noises and crowds can make a setting painful and overwhelming. These problems necessitate extra planning, avoidance of some settings, and Occupational Therapy determine and address sensory integration dysfunction and other issues. Normal appliances can have a similar negative effect – noise from a microwave, dryer, or vacuum may cause a person with an ASD to become fearful and react by covering his ears, running away to escape the sound, or screaming.

Problems getting an adequate amount of rest have been reported in children with ASDs, and these problems are more severe and more frequent than those found in typically developing children (Cotton & Richdale, 2006; Hoffman, Sweeney, Lopez-Wagner, Hodge, Nam & Botts 2006; William, Sears & Allard 2004). If children with an ASD are not rested, they are more susceptible to frustration and a loss of control. When children do not sleep well, their parents do not either. This further complicates life, and all of the above coupled with a lack of support and respite, little understanding from family and friends, isolation, and worry, make the life of a parent extremely hard and difficult. Some of the parents expressed these sentiments:

“IT’s hard! He looks almost fine since he is high functioning and cute. When he acts up, people are inclined to think it’s a behavior problem and not ASD overload.”

“HOW HARD IT IS TO DO ‘NORMAL’ ACTIVITIES. EVERYTHING IS A STRUGGLE.” (This response was typed in capital letters.)

“I wish others knew how hard it is to receive no extra help.”

“It is a very challenging and difficult experience. And it is especially difficult to see that your child desperately needs your help to learn and develop.”
“It is hard but we try to make things as normal as possible, so don’t look at him like he is strange when he waves and asks your name… just smile and wave back.”

Parents’ lives are also difficult because their child has varying degrees of deficit in three areas: communication/language, behavior (restrictive and repetitive), and social skills. The child with an ASD may be non-verbal or have problems with expressive or receptive language or pragmatics (practical use of language). The child may also exhibit delayed echolalia (repetitive use of words or phrases from television programs or stories) as a substitute when he knows he should respond, but does not know what to say. Delayed echolalia is also used to make a request or protest an action. Communication problems make it difficult for the child to get his/her wants and needs met by making appropriate demands within the environment. The frustration resulting from language deficits and the need for professional assistance adds to the challenge of parents.

The child with ASDs may engage in restrictive or repetitive behaviors. They may have a special area of interest, learn everything about that area (trains, Old West, History, Mine Craft, SimCity, or other), and constantly repeat things about that narrow area. This makes communication with others difficult, because constant and repetitive conversation about the interest is unwelcome. The individual with an ASD may not understand that others have different interests and passions (Theory of Mind – Baron-Cohen 1995; Baron-Cohen 2008), and do not want to hear about a single interest repeatedly. Attempts by others to display boredom and disinterest are not perceived very well by the individual with an ASD. Quite often, they fail to effectively read body language or facial information describing another person’s level of interest. Repetitive behaviors are known as self-stimulatory behaviors (shaking, noises, flapping, peeling paint from the walls), and they are used for calming or reacting to boredom or stress. Sometimes self-stimulatory behaviors appear strange, and the individual that engages in these behaviors may be misunderstood, isolated or ridiculed by his neurotypical peers.

Social skills are another area of deficit prevalent in individuals with ASDs; direct instruction, modeling, and multi-level support are needed to address this shortcoming. Same aged peers can provide the role modeling necessary for demonstrating and shaping appropriate behavior, and that can build social acceptance and foster collaboration. Supportive teachers that understand the disorder, are knowledgeable, and supply consistent positive reinforcement and patience can nurture social skill development, encourage peer-to-peer collaboration, and reinforce appropriate behaviors. Care should be taken to make sure all personnel (instructors, paraprofessionals, and aides) are well-trained and experienced, because untrained paraprofessionals can impede social skill development and acceptance and create confusion and overdependence (Zager & Shamow, 2005). Family support is critical for emotional balance, academic achievement, communication, physical needs, and general development and progress. Multi-level support systems can help individuals with ASDs function and learn appropriate behaviors and social skills. Support systems neutralize the isolation, anxiety, and depression of those with ASDs. (Brewin & Renwick, 2008; Marshall, 2002; Muskat, 2005; & Rayner 2005).

Theme #2: Parents’ Positive Adjectives Describing Their Child and Their Life

Parents used positive adjectives and phrases to describe their child. The literature is full of negatives in the lives of parents, but the second most populated theme contained positive messages where parents have accepted their child, love the child, regard his/her care as a “blessing,” and feel that the child is a “gift.” The most common descriptors in this theme were “loving,” “sweet,” and “beautiful, gift, and wonderful child.” Hastings, Kovshoff, Ward, Espinosa, Brown & Remington (2005) report the measurement and analysis of positive perceptions of parents of children with ASDs. In addition to stress, both fathers and mothers identified positive perceptions about their child and his impact on themselves and other family members. Some of the comments:

“We are not “sorry” he is the way he is- he is a bright, loving child who is the joy of our lives’ he simply has some challenges, as do we all.”

“Frightfully demanding, but it evokes a love you will never know.”

“I am just trying to accept my child for who he is and help him grow. I love him.”

“While it is the most difficult thing my husband and I have had to go through, it is also very rewarding. These children are so loving and giving. They are extremely smart.”

“He is lovable and has so much to offer if give [en] the chance and the oddities were acceptable to all children.”
Theme #3: Stop Judgmental Observations

Parents reported that they were doing their best, and they reported resentment to the comments and stares they receive from family members, friends, and onlookers when they are out in public and their child misbehaves. Parents reported that they do not appreciate the stares and judgments of others who react to them as though they are bad parents, lack the ability to administer discipline, or permissively deal with their child. Some quotes from parents are included below:

“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 isn’t any other form of support for us. Instead of judging us, try asking if we need help.”
“I wish others would try and see him as I do- an individual with gifts and strengths who can be loving and kind if given an opportunity. If they would attempt to communicate rather than judge they would find a person worth the work of getting to know!”
“A day in the life; don’t judge when you see me handling tantrums, etc. in public. You have no idea what we have to do to manage the situation.”
“Do not judge others if you think there is nothing wrong with their child. Our daughter is high functioning, but very tall and big for her age. Almost 7 but looks like 10. It is a double blow as she acts younger than her age, but looks older than her age.”
“That they walk in our shoes before judging.”

Theme #4: Negative Adjectives for Life with a Child with ASDs

Several parents used negative adjectives to describe their life with a child diagnosed with an ASD. The most frequently used adjectives were lack, sad, and depressing and demanding. Lack was expressed in terms of resources, available professionals to provide assistance, and support from families, friends, the school system, and insurance providers. Reflections reported include the following:

“That being a single mom with 1 Autistic Child and another with traits is difficult and that we don’t have many resources here in our town.”
“I guess I wish that people understand how sad it is to grieve your child on sometimes a daily basis. Having a child with special needs is grueling on a marriage, which is fairly common knowledge.”
“The toll it takes on a family, the fights we have with insurance to get coverage for services, the therapy that is needed to cure it.”
“You’re given this diagnosis and pretty much sent on your way to figure it out for your child. The school district gives the minimal amount of therapy so you must figure out the rest on your own.”

Theme #5: Training is Needed

Parents expressed the need for training on ASDs and supportive services at many levels: child, parent, family, community, and teacher/school personnel. Both private (immediate and extended family) and public spheres (community, businesses, and school systems) of life are reflected in the different types of support needed. According to the respondents, some of their family members and friends need to be trained on the characteristics and behaviors of children with an ASD. Community members and business personnel need training on the importance of inclusion for individuals with ASDs, teachers need effective strategies for working with children and adults with ASDs, and parents need training on behavior and social skill development. Some of the comments that reflected the need for training are listed as follows:

“What goes on at home. To my friends we seem like a normal family. Some think E. is just spoiled, they don’t understand what a meltdown is like for her and for us.”
“That he isn’t retarded; he has at least average intelligence, but it is a matter of teaching him in a way that he can learn.”
“He wants to have friends, yet other families don’t teach their children to be good mentors to these children.”
“That just because an individual has a diagnosis of Asperger Syndrome does NOT necessarily mean they are “higher” functioning than an individual with a diagnosis of PDD-NOS or autism…their symptoms are instead manifested differently.”
“I would [like for] people to understand what it is like raising a child with autism and we need more services through the school district support with the behavior, and social training for the child and parents.”

“That he is not mentally retarded, and that he has normal intelligence. That he won’t GROW OUT OF IT, Grandma!”

Theme #6: Stress is Present

The stress experienced by parents of children with ASDs persists throughout the child’s lifetime and manifests itself in an increased risk of depression, restrictions of roles and activities, marital stress, and diminished physical health (Fleischmann, 2004; Ingersoll & Hambrick, 2011; Myers, Mackintosh & Goin-Kochel, 2009; Pisula, 2007; Stoner, Bock, Thompson, Angell, Heyl & Crowley, 2005). Stress was the sixth theme into which the highest number of respondents’ comments fell. Some reasons cited for stress were marital, financial, psychological, and emotional pressure. Stress results from the child’s behavior, level of functioning, educational needs, interventions, parental expectations, worry about the child’s future, and the need to make provisions for the child after the demise of the parents. Parents expressed doubts about the safety of their child with an ASD, and they had a tendency to be overprotective. As a result, they tended to limit their child’s independent skill development (Ivey, 2004). Many parents feel isolated, and the constant demand of finding and financing programs to help their child leaves many with little time to recharge themselves and few outlets for relaxation and enjoyment (Fleischmann, 2004). Several comments were indicative of this:

“That it’s harder than it looks, that even if he looks normal at first glance, there are so many aspects to it once you get to know him. It’s very draining financial wise and that it has an effect on my marriage, and not always a good one either.”

“The feeling of isolation from the rest of the world and the worries associated with raising a child in this day and age increase three fold making stress unbelievably high.”

“How stressful it is not having personal and/or school/state/federal resources/assistance; how psychologically oppressive it is to feel that our child’s future depends SOLELY on our research, our interventions and our decisions – there is really no one professional to turn to for information and guidance.”

“The constant worry about time running out to recover your child – am I selecting the right therapies? The right supplements? What have I missed that could be the key to help my child? It is a low-level chronic stress that never goes away.”

“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.”

Nineteen themes emerged from the responses (195). The number of themes suggests that life for parents is complex and multifaceted and necessitates simultaneous attention to many issues. The six most frequently identified themes were discussed, but other themes included worry, the endless obstacles, and the need for understanding and compassion for children in the spectrum. Many parents reported using technology to address some of the issues and challenges they face.

Technologies Parents Select

Technology tools have the benefit of being able to individually address different needs and different levels of functional capability. They can provide flexible presentations, repetition, individualization, motivation, locus of control, prompting, fading, visual lessons and modeling, and record keeping. Parents of children diagnosed with an ASD are using technology to help their children gain academic, listening, social, time management, leisure, and communication skills. Researchers have discovered that computer use with learners diagnosed with ASDs increases competence in speech (receptive language), and other areas (social, behavioral, and cognitive), improves attention, motivates the learner, and reduces problem behaviors (Cramer, Hirano, Tentori, Yegnayan & Hayes, 2011; Dettmer, Simpson, Myles, Ganz, 2000; D’Ateno, Magiapanello & Taylor, 2003; Escobedo, Nguyen, Boyd, Hirano, Rangel, Garcia-Rosas, Tentori & Hayes, 2012; Gentry, Wallace, Kvarfordt & Lynch, 2010; Hourcade, Bullock-Rest & Hansen, 2012; Hetzroni & Tannous, 2004; Kagohara, 2010; MacDonald, Clark, Garrigan & Vangala, 2005; Meehling, Gast & Seid, 2009; Moore & Calvert, 2000; Muskat 2005; Myles, Ferguson & Hagiwara 2007; Tartaro & Cassell, 2007). Parents across Texas reported using the following technologies to help their children gain functional, language, and academic skills: video games, assistive technologies, educational software (CAI/CAL – Ed Mark’s
Technology Concerns

Technology can offer many benefits to both children in the Autism Spectrum and their parents. However, it cannot be considered a panacea to mitigate all skill deficits. While it has tremendous positive potential, it should be used with restriction. This is important for all children, especially those with ASDs. They may become obsessive about the hardware and software they use often, and they may model behaviors and actions they see and use language they hear in games and programs. This can have devastating consequences when real life clashes with the animated and surreal presentations the children see. In addition, they can become so comfortable in created reality (Lego StarWars, Super Mario Brothers, Pokemon) that they flee face-to-face encounters. While the games in and of themselves can be very entertaining, the constant use of them can keep the child from learning other important lessons and social skills. A balanced approach is advocated at all times; technology should provide both entertainment and academic skill development. Technology is highly visual and motivating; it should be incorporated into academic work to balance the “boredom factor.” Reading assignments on the iPad and visually presented worksheets can be very motivating and help the child persist through academic work. Screening programs from the Internet and game consoles (Wii, PS3, Nintendo DS, DVD, etc…) is important for all children, especially those with an ASD. Rating systems and monitoring software should be used regularly to make sure children with ASDs are not exposed to inappropriate, crude or offensive content. Children diagnosed with ASDs may not understand the language and motives of others (Little, 2003), so it is particularly important that parents and teachers provide extra control and monitoring to make sure they are protected from cyberbullies, pedophiles, and negative influences on and offline.

Demographics of Survey Participants

Between 2008 and 2010 respondents generously shared their technology choices, needs and issues. Only respondents who indicated that they resided in Texas were included in this analysis (220 responses). All of these responses were from mothers of children with ASDs (100%), and the diagnoses their children received most frequently were Autistic (45.0%), Asperger Syndrome (25.0%), and PDD-NOS (30.0%). Most of the time, a team of professionals performed the diagnosis, followed by a Clinical Psychologist, a Psychiatrist, and lastly a Developmental Pediatrician or School Counselor/School Psychologist. The majority of children were male (85.8%); ASDs affect more males than females (Center for Disease Control and Prevention, 2012). Most mothers (90.7%) reported that their child with an ASD was physically healthy. When asked about the race of their child, most mothers reported that their child was Caucasian (77.7%), Hispanic (15.0%), and African American, Asian, or Native American (7.3%). The most frequently reported age range of the mothers was 35-39 (30.1%); this was followed by 40-44 (21.8%), and 45-49 (17.1%). About 57.3% of the mothers indicated that they were employed outside their home in the following careers: Teaching, Nursing, Administrative Assistant/Secretarial, Sales, and Supervisory or Management positions. Many non-traditional job titles were reported: President of a software company, Usability Website Designer, Pediatrician, Radiation Therapist, Chemical Processing Technician, CPA, CEO, and others. Household income rounded to the nearest dollar: $50,000-59,999 (11.1%), $40,000 - $49,999 (10.1%), $100,000-$109,999 (8.7%), $80,000 - $89,999 (8.2%) and $170,000 - $179,999 (8.2%). Insurance coverage for some of the child’s interventions (58.7%), and an annual estimate of $1,000 - $9,999 (42.8%) was reported for “out-of-pocket” intervention expenses.

Conclusion

Children with ASDs have a lot to offer the world. They need multi-level support systems that are flexible and evolve as they grow and change and technology to help with academic, social, and behavioral challenges. In addition, parents of children with ASDs face many obstacles; they need effective technology tools, strong systems of inter-family and intra-family support, understanding, and training to help them help their child. This study provided insight on the parental perspectives and technology use of families in Texas who are living with and loving a child in the Autism Spectrum. It sets the stage for further research on the stress of families, their needs, and the implications of technology.
References


