Addressing the Needs of Parents, Relatives and Caregivers

Reducing Caregiver Stress When Future Planning for the Family Member

By Maggie Haag, LSW, CBIS, Frank L. Bird, MED, LABA, BCBA, and Mary Jane Weiss, PhD, BCBA-D

Over the last several years, a lot of focus and attention has been given to the very important topics of transition planning and services into adulthood for those with autism and intellectual disabilities. Supporting families, caregivers and the adolescent/adult child in connecting with adult services in the right way and in the right time frame has been an increasing focus for many families, advocates, and professionals.

Transition planning is not a simple, linear, or one-step process. It can be extremely difficult to assist families and caregivers to think about what will happen to their loved one post age 21. Many families have an understandably hard time facing the difficulty reality that school-aged entitlements will end, and the much less predictable and much more spare world of eligibility-based adult services will begin. Knowing where their loved will go and what types of services he/she may be receiving after age 21 is often almost all a family can bear to deal with during the transition planning phase. This process is so difficult and emotionally draining, that thinking far beyond the immediate placement issue can be dauntingly stressful. The paucity of services, the low quality of services, and the wait lists for services are formidable and discouraging.

Negative health effects and high levels of stress are common in parents of adults with autism (e.g., Shattuck, 2012; Smith, Greenberg, & Malick, 2012).

One of the elements of the planning that creates such stress is the extent to which it is discrepant from other parenting experiences and concerns. Most of the time, parents focus on establishing their typically developing children as adults, and then give little thought to how they will manage in their 40’s, 50’s, 60’s, 70’s and beyond. In the natural course of the life span, concern for children dissipates as children age. When the child has a disability, this worry and concern does not abate. In fact, it may increase, as parents begin to envision a world in which they personally are no longer able or present to monitor, advocate, plan, and ensure quality care.

At Melmark, we have identified several key considerations in this planning process. While many of these concerns focus

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Employers Supporting Parents Through ABA-Based Technology

By Angela Nelson, MS, BCBA
Executive Director of Family and Clinical Services
Rethink

Parents of children with autism spectrum disorder (ASD) are among the most distressed group and display more affective symptoms when compared with parents of both typically developing children and children with other developmental delays (Estes et al., 2009; Davis & Carter, 2008). Why is this? Could it be that many parents face daily behavioral challenges- intense tantrums causing high levels of anxiety and worry about what will happen at the grocery store, inappropriate communication and play behavior which prevents carefree playdates at the local park, or safety concerns causing parents to constantly be on high alert? Others face pressure to close the gap between their child’s skill deficits and other children his age. Some children have expansive skills but socially, they just cannot quite get to a point of making lasting friendships or are getting bullied every day of middle school. ASD isn’t one thing for parents. Each parent experiences it differently. One thing, however, which we’ve seen time and time again at Rethink, is that parents try their hardest to get help for their child while putting themselves second...or third...or fourth...or last.

The words “help” or “support” take on many meanings for parents of a child with ASD. Parents pursue help from educators to help their child learn, from healthcare providers to ensure their child’s wellness, and from extended family members to promote familial engagement. One area of support that parents often need is training - the true “how-to” so they themselves can generalize their child’s skills after the therapist leaves at the end of the day, after services are reduced, or even fill that primary role of “therapist” if their child does not receive direct therapeutic services. In a large randomized trial of children with ASD, Bearss and colleagues (2015) found that 48% of parents who underwent 24 weeks of behavioral training reported improvement in their child’s behavior as compared to 32% of parents who received 24 weeks of just basic education on ASD. Additionally, an overall improvement in behavior of nearly 70% for the training group as compared to 40% for the education-only group was measured by the researchers. Behavioral training included determining the function of their child’s behavior, implementing visual schedules, providing positive reinforcement for appropriate behavior, techniques for promoting compliance as well as new skills (e.g., communication and daily living) and how to maintain such gains over time. Direct instruction, video examples, practice activities, and role play with feedback were all used to promote parent skills. By contrast, parent education included sessions and manuals addressing evaluation, developmental changes in ASD, educational planning, advocacy, and current treatments.

Why is parent training so important? For one, Dr. Kara Reagon, Autism Speaks Associate Director for Dissemination Science, states that “It’s telling us that simply educating parents about autism isn’t enough. They really need help in the home and the community, and there’s a need for more effective parent training” (Reagon, 2015). Two, the need for generalization of skills as well as the fact that therapist-led services are finite in duration means parents must be involved early and often, and equipping them with tools and best-practice strategies can empower them to facilitate gains for their child on an ongoing basis.

Strong parent training significantly enhances a child’s overall learning experience, providing more teachable moments and consistency across all environments. What happens when a parent lives in a remote area, far away from a university or from agencies that are offering services? Or perhaps their child is receiving quality applied behavior analysis (ABA) services but their job prevents them from observing or receiving feedback from the therapist during therapy. Technology can provide a cost-effective, timely, and simple solution to address these challenges. Video modeling and performance feedback are effective methodologies to promote skill acquisition
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Essential Information: Respite Care for Families

By Amy Golden, MS, BCBA, Behavior Therapy Associates, Elizabeth Neumann, MA, BCaBA, and Suzanne Buchanan, PsyD, BCBA-D, Autism New Jersey

Many individuals with Autism Spectrum Disorder (ASD) require significant levels of support in home, school, and community settings. Due to deficits in social communication and interaction, compounded by restricted, repetitive patterns of behavior, many will not be able to keep themselves safe and need constant supervision, even as adults. This duty usually falls to already exhausted families who experience the daily stresses of intense caregiving demands and restricted activities. Research clearly suggests that respite is a lifeline for families, so it is vitally important that it provide the intended effects.

While the majority of literature to date has focused on the negative effects of autism on families, it is important to first note parents’ adaptive responses to its challenges. According to Bayat (2007), many families exhibit characteristics of resilience such as pulling resources together, feeling connected to one another, making meaning out of adversity, affirming their strengths, becoming more compassionate, and having a spiritual belief system. On a broader level, parents and other family members have often been the pioneers of new and expanded service provision options (Jacobson, 2000), research, and advocacy organizations. These accomplishments are noteworthy in their own right and even more so given the intense and constant demands autism places on family members.

Increased caregiving requirements are commonly reported by parents of children with any disability. Pisula and Kosssakowska (2010) found that mothers of children with autism spent an average of 9.5 hours per day caring for their child, compared to 5.3 hours for parents of typically developing children. This extraordinary amount of caregiving can take a cumulative toll. In fact, parents of adult children with autism reported that a main unmet need was “breaks from caring” (Hare, Pratt, Burton, Bromley, & Emerson, 2004, p. 431). To further quantify these demands, Smith et al. (2010) conducted an 8-day diary study which indicated that, compared to mothers of typically developing individuals, mothers of adolescents and adults with autism were three times more likely to experience at least one stressful event per day and had twice as many days with multiple stressors (p. 175). This consistent and pervasive stress may make everyday parenting tasks a challenge (Boyd, 2002).

Parents also reported altering their daily activities and life plans as a result of having a child with autism. Restrictions included less frequent attendance of religious services, reduced employment opportunities due to childcare issues, and less

see Essential on page 24
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Parent Empowerment Among Parents of Children Newly Diagnosed with ASD

By Laura L. Corona, MA, Stephanie A. Fox, MA, Melissa L. Rinaldi, PhD, and Kristin V. Christodulu, PhD, Center for Autism and Related Disabilities

Parents of children diagnosed with autism spectrum disorder (ASD) often report high levels of parenting stress and low levels of well-being and parenting self-efficacy (Karst & Van Hecke, a). The process of receiving an ASD diagnosis and accessing services can be particularly difficult and frustrating for parents (Moh & Magiati, 2012). Past research has demonstrated that providing parents of children with ASD information about the diagnosis through parent education programs and support groups can decrease parenting stress (Keen, Coupens, Muspratt, & Rodger, 2010; Tonge, Breereton, Kiomall, Mackinnon, King, & Rinehart, 2006). Parent empowerment, defined as the process by which parents gain access to resources, has been implicated as one factor influencing parent responses to challenges associated with parenting a child with ASD and is linked to positive outcomes including parent self-esteem and perceived control over the environment (Weiss, MacMullin, & Lunsky, 2015). Initial research has reported gains in family empowerment following participation in a support group (Banach, Judice, Conway, & Couse, 2010). The present study examined parent empowerment in the context of an education-focused group for parents of children newly diagnosed with ASD. Of interest were the relations among parenting stress, family quality of life, and parent empowerment, as well as whether participation in the program was associated with any changes in parent empowerment.

Individuals providing data for the present study were parents who participated in a five-session parent education program offered through a university-affiliated ASD resource center. The program was designed to provide information and resources to families of children who had been diagnosed with ASD within the last year. Sessions were facilitated by a licensed clinical psychologist, and a developmental nurse practitioner also participated in sessions covering medical topics. Sessions lasted two hours and were held approximately once per month. Each session highlighted a different topic, including an introduction to ASD, medical and developmental issues often associated with ASD, choosing interventions, accessing resources, and parenting at home and in the community.

Prior to their first program session, parents were asked to complete several questionnaires, including the Family Quality of Life Scale (FQOL; Summers et al., 2005), the Parenting Stress Index – Short Form (PSI-SF, 4th ed., Abidin, 2012), and the Family Empowerment Scale (FES; Koen, DeChillo, & Friesen, 1992). Parents completed the same questionnaires after attending all five program sessions. The FES was chosen to measure parent empowerment because it has been used frequently with parents of children with disabilities and focuses on parents’ perceived abilities to manage demands likely to be associated with parenting a child with ASD. The FES is divided into three subscales, measuring empowerment related to family life, child services, and community involvement. For instance, the ‘Family’ subscale includes items such as “I believe I can solve problems with my child when they happen.” The ‘Child Services’ subscale includes items such as “I am able to work with agencies and professionals to decide what services my child needs.” Finally, the ‘Community Involvement’ subscale includes items such as “I know what the rights of parents and children are under special education laws” and “I know how to see Empowerment on page 30

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The Daniel Jordan Fiddle Foundation Launches Endowed Fund to Focus on Lifelong Family Support

By Linda J. Walder
Founder and Executive Director
The Daniel Jordan Fiddle Foundation

The Daniel Jordan Fiddle Foundation, for nearly two decades, has focused its all-volunteer organization’s mission on every aspect of adult life from employment to the arts to health and wellness to residential and recreational endeavors. An integral aspect of the Foundation’s mission has always been to recognize and support the love, care and challenges experienced by family members in the lifelong journey of autism.

In September of 2016, The Daniel Jordan Fiddle Foundation will announce and launch the first endowed fund in the nation that will support the development of model programs, offer resources, and fund counseling services for family members and caregivers of adults diagnosed with autism. The Daniel Jordan Fiddle Foundation Adult Autism Family Support Fellowship and Resource Guide Fund will be established at Rutgers, the State University of New Jersey and will be administered by the Rutgers University School of Social Work.

The purpose of the Fund is to train graduate students to work as clinicians specifically focused on improving outcomes for the family members of adults diagnosed with autism, and to create a web-based resource guide for families, organizations and agencies as they serve and support adults. The Dean of the Rutgers University School of Social Work will annually name a group of graduate level Fellows to be known as The Daniel Jordan Fiddle Foundation Fellows, who will work in the field as direct care clinicians for family members of adults diagnosed with autism. The Fellows will also be responsible for compiling a web-based resource guide to be known as The Daniel Jordan Fiddle Foundation Adult Autism Resource Guide, which will include statewide and national resources to assist families, organizations and agencies as they navigate the often confusing and difficult paths to employment and financial and healthcare information to name a few, will also be included in the website guide.

According to Dean Cathryn Potter of Rutgers University School of Social Work, some of the goals of the Fund’s usage will be to develop new service benchmarks, share resources nationally and shift public perception that autism only affects children. The Daniel Jordan Fiddle Foundation values these goals and is proud to add this newest endowed program to our university-based endowed programs that focus on specific aspects of adult autism.

It is our intent that The Daniel Jordan Fiddle Foundation Adult Autism Family Support Fellowship and Resource Guide Fund will assure for decades to come that family members and caregivers of adults will receive the resources and clinical services they need.

About the Author
Linda J. Walder is the Founder and Executive Director of The Daniel Jordan Fiddle Foundation. Currently Linda and the Foundation Board are using their expertise in the field of adult autism and their collaborative spirit to create endowed programs at the nation’s finest universities that will assure a focus on areas that impact the lives of the diverse population of adults diagnosed with autism for generations to come. In 2014, The Daniel Jordan Fiddle Foundation established The Daniel Jordan Fiddle Foundation Adult Autism Research Fund at Yale Medical School and The Daniel Jordan Fiddle Foundation Transition and Adult Programs Fund that supports program development and implementation at The Daniel Jordan Fiddle Foundation Transition and Adult Programs at the University of Miami/NSU Center for Autism and Related Disabilities.
**It’s All My Fault!” Understanding Guilt in Parents of Children with ASD**

By Shuli Sandler, PsyD
Clinical Psychologist
Private Practice,
Spectrum Services

Guilt is a powerful emotion. It has both motivating and destructive effects. It can be seen as a moral conscience, directing us toward doing the “right thing.” Imagine a society where there was no sense of moral guilt - this could lead to a situation where there is anarchy. Our guilt allows us to do nice things for other people, to care for those in need, to support family members, and overall be “good people.” When taken to an extreme however, guilt can be incapacitating. It can make us feel bad about ourselves and take actions that are ultimately not in our own best interest. It can cause us to hurt those that we love. In this article, I will explore ways in which parental guilt can have both a positive and constructive effect, as well as a negative effect on parents of children on the spectrum.

Parents are in unique roles. They serve as the caregivers of a child and ultimately make all major decisions for the child throughout their development, and often into young adulthood. There is a tremendous amount of responsibility that comes with the role of being a parent, and with that responsibility can also come feelings of shame and guilt. This is true particularly when there is a worry that the parents have made mistakes with regard to their child. There is often a worry that these mistakes can have a long-term negative effect on the functioning of the child.

I believe that parents of children on the Autism Spectrum are more at risk for feelings of overwhelming guilt than their neurotypical counterparts. Often parents of children on the spectrum have important decisions to make and the stakes can feel very high. Research supports that early intervention for this group of children is of utmost importance, so these decisions can have a tremendous impact on their child’s level of functioning in the future (Greenspan & Wieder, 2006). The pressure to make these decisions at this time can increase levels of personal responsibility when any decisions are questioned. As a result, guilt and self-doubt can be extremely high for this group.

The following are four different scenarios that reflect common areas of guilt in this population:

1. **Scenario #1: Guilt over self-blame**
   
   Hank is an adorable 10 year old boy with Asperger’s Syndrome (AS). Hank’s father, Aaron, has always felt that Hank was very similar to him. They look alike, talk alike, and even share the same interests. Since Hank’s diagnosis, Aaron has worried that he was somehow responsible for Hank’s deficits. He feels guilty for the genetic endowment from him, as well as wonders if he has demonstrated some deficits in his fathering skills. Every time he hears a story about a child that talks before he does, he becomes quite defensive and angry, and underneath he is frightened and guilty.

2. **Scenario #2: Guilt over past mistakes**
   
   Jacob is a 21-year-old young adult male diagnosed with Asperger’s at the age of 18. Looking back over his childhood, he had many sensory difficulties, a lot of problems with motor coordination, and appeared to be quite anxious and perseverative. He also had a lot of compulsions and mood dysregulation. At the same time, he did have some friendships, although looking back, they did not quite appear to be on par with his peers. Many of his difficulties appeared to be anxiety related and his parents took him to many specialists in anxiety disorders, but they never quite felt like anyone “got Jacob.” When a specialist finally brought up the diagnosis of AS, there was both a relief at the diagnosis, but a frustration in the lack of information and treatments that “could have been.” Jacob feels quite angry about being misunderstood for so long. His parents feel guilty that they “should have known better,” yet don’t like the blaming and accusatory tone Jacob takes with them. There are frequent disagreements about this area and it remains an area of tension in their relationship.

**To Speak or Not to Speak Only English**

By Tamara Sterling, MS, CCC-SLP, TSSLD
Speech-Language Pathologist

As families of children with Autism Spectrum Disorders (ASD) become more culturally and linguistically diverse, they often seek clarity about bilingualism and its effects on their children’s communication patterns. They are apprehensive about speaking to their children in their language other than English (LOTEx) because they recognize the life barriers that stem from ASD and if they perceive that communicating in their LOTEx further worsens the situation, they are likely to minimize or stop speaking it (Yu, 2013). 61.8 million U.S. residents spoke a LOTEx in 2013; this is an increase of 2.2 million since 2010 (Camarota & Ziegler, 2014) and one in 68 individuals is identified as having ASD (Christiansen et al., 2016). Given the increased number of individuals who speak a LOTEx and the increased prevalence of ASD, it is imperative that professionals understand how bilingualism and ASD function together so that they can provide important and appropriate guidance to parents of children with ASD who speak a LOTEx.

According to Yu (2013), parents of children with ASD are advised by some physicians, speech-language pathologists (SLP), teachers, and psychologists to speak exclusively in English because doing so will boost language acquisition and reduce linguistic demands. This advice according to Ijalba (2016), is unethical, incompatible with evidence-based practice, and disadvantageous to families. It also refutes the American Speech-Language Hearing Association’s (ASHA, 2014) position on cultural competence and service delivery. ASHA encourages clinicians to demonstrate compliance to families’ linguistic and cultural preferences. Cultural competence is progressively important in service delivery and in responding to the demographic changes in the U.S. When professionals erroneously advise parents to speak “only English,” they often do this without considering the parents’ English proficiency. The Center for Immigration Studies revealed that, based on self-assessments from the U.S. Census Bureau’s 2004 American Community Survey, 25.1 million individuals reported that they “Speak English less than very well” (Camarota & Ziegler, 2014). How can parents bond with their child if they are encouraged to speak “only English” in light of their limited English proficiency? According to Ijalba (2016), caregivers use their most proficient language to interact and engage with their children in reciprocal activities such as having a conversation, reading a book, playing and problem solving. The parent-child interaction is interrupted when limited English proficient parents are told to speak “only English.” Ijalba (2016) goes on to explain that a parent’s role can shift from being the primary language model to that of exclusively being the person who provides care (i.e. only feeding and dressing). When this exchange is made, parents who speak LOTEx are limited in their capacity to engage in literacy activities and to have meaningful social-verbal interactions.

The language socialization paradigm (Oeh & Schlefflin, 1984 as cited in Kremer-Sadlik, 2005) explains that this “only English” advice exacerbates the desired social communication outcomes for children with ASD. How can they develop relationships, increase social acceptance, and effectively participate and function in society, if their families are being guided to dismiss speaking to them in their LOTEx? Kremer-Sadlik (2005) explains that this “only English” advice exacerbates the social communication challenges children with ASD. “Only English” encourages social isolation from parents, siblings, and caretakers and therefore results in lost cultural identity, obstructed bonding between parent and child, and severed attachment.

The language usage patterns that families elected to use with their child with ASD are also informed by their beliefs about bilingualism and its effects on learning development (Yu, 2013). These families’ concerns about bilingualism are uniform across the various sociocultural groups. They feel that it is best for their child with ASD to establish a strong foundation in English first and have proficiency in one language (English) because it is better than limited proficiency in two languages. They speak only in English at home because it is the language of the classroom and this would accelerate their child’s English language acquisition. Overall, they feel that bilingualism might complicate matters or further delay language development.

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See **Speak on page 16**
Psychiatric Problems Common in Siblings of People with Autism

By Ann Griswold, PhD
Spectrum

Psychiatric conditions crop up more than twice as often in families that include a child with autism as in the general population. That’s the upshot of the most sweeping study to date of mental health in siblings of children with autism.

The findings suggest that clinicians should look carefully for signs of other problems in relatives of people with autism.

Autism is known to share genetic roots with a range of psychiatric and developmental conditions. Researchers have shown that nearly half of siblings of children with autism have difficulties with attention, language, learning or mood even when they don’t have autism. These families are also at elevated risk for conditions such as schizophrenia.

“We wanted to see how these disorders aggregate in families and explore the possibility that there could be shared genes or shared environmental exposures driving these outcomes,” says senior researcher Alan Brown, professor of psychiatry and epidemiology at Columbia University. The findings appeared 1 June in JAMA Psychiatry.

Among siblings of people with autism, Brown’s team found high rates of seven childhood-onset conditions including autism, attention deficit hyperactivity disorder (ADHD) and learning disability. They also found that the siblings have higher rates of schizophrenia and mood disorders, among other mental health problems (see graphic above).

“This might help us identify offspring at high risk of not only autism, but other psychiatric conditions as well,” Brown says.

Paper Trail

The researchers examined the health records of 3,578 children with autism and their 6,022 full siblings, all of whom had been followed since birth as part of the Finnish Prenatal Study of Autism and Autism Spectrum Disorders.

The team also mined three national registries to match each child with autism to four typically developing children of the same sex, born in roughly the same year and from the same geographic area. The total included 15,353 children and their 28,149 siblings.

Roughly 37 percent of the siblings of children with autism have at least one psychiatric or neurodevelopmental condition, compared with about 17 percent of the brothers and sisters of controls. Intellectual disability in the children with autism confers no additional risk for their siblings.

The conditions that emerge in childhood — autism, ADHD, intellectual disability, learning disorders, tic disorders, conduct disorders and emotional disorders — are 2.5 times more common, overall, among siblings of children with autism than among siblings of controls.

see Siblings on page 30
Integrating ABA into Practice: Addressing the Misconceptions

By Ronald Lee, PhD, BCBA-D
Director, MA in ABA Program
William James College

The past few decades have seen drastic changes to the field of autism, at least in part due to changes in the defining characteristics/diagnostic criteria for Autism Spectrum Disorder (ASD).1 As a result of increasingly inclusive criteria, professionals in fields such as psychiatry, medicine, education, social work, clinical psychology, and applied psychology may be more likely to see ASD as part of the diagnostic make-up of populations they have typically served.2 Consequently, professionals in a wide range of related disciplines will benefit from incorporating Applied Behavior Analysis (ABA) principles and techniques into their treatment repertoire. Commonly referred to as “Reinforcement Theory” or “Learning Theory”, these are the principles of learning and behavior that have led to teaching and behavior-change procedures and are dependent on measurable dimensions of observable phenomena as the evidence of change.3 There seems, however, to be a barrier to including the principles and techniques of ABA within the treatment approach of practitioners outside of the field of ABA. Despite decades of research and thousands of applications supporting ABA as an evidence-based approach for educating and supporting providers to report on our progress and recommendations, this is what helped them acquire the services they need. Their brother is now able to maintain his level of support and community engagement. This in turn relieves the elderly mother some of her years of concern as to what is happening to her son when she is not attending to him, and concurrently relieves the siblings of the fear of the unknown of “what’s next.” 4 The power in ABA is the graphing of progress and the simple presentation of that information; frequently enough that families can quickly visually see if there is progress or regression. For a family with a daughter dually-diagnosed with Schizophrenia and Intellectual Disability: assisting the parents in obtaining guardianship by explaining the paper-work, procedure and their rights, we are now able to ensure the safety of the young lady’s well-being. Their daughter will now have consistent and thorough medical care that addresses both her behavior and psychiatric conditions with a coordinated team approach thatmelds the best of all possible care coordination.

For an elderly couple, trying their best to provide their severely aggressive daughter with a home to live in with her family: giving them support while on doctor’s appointments and in the community where they otherwise are afraid to take her on their own. Their daughter now not only

By Amanda Duva, BCaBA
and Terry Blackwell, BCBA
Services for the UnderServed Inc.

As a behavior specialist working in the home with the families of individuals with disabilities there is an exceptional opportunity to identify needs and concerns of not just our direct client, but also the family as a whole. While the primary focus is on the adult or child who needs support, it is inevitable that a professional relationship will develop with parents and siblings. If done well, a level of trust will be acquired. When this happens, you are now in the position where you can support the family and utilize that dynamic to further improve the lives of the household.

Often families of children with an intellectual disability suffer greatly in isolation from the ability to interact in community settings with other families and peers, due to the need to care for their son or daughter. When the therapist steps through the door; they represent for many the first and best chance they have to establish some normalcy in the family’s activities outside the home. Siblings often for the first time in years, find it “safe” to invite friends to come to their home to play. The parents and caregivers can breathe for a change, knowing that there is a function to behavior and that not every event needs to escalate into a full blown melt down crisis.

Ronald Lee, PhD, BCBA-D
addressing problem behaviors in people with ASD, numerous misconceptions of ABA continue to pervade both professional and lay communities. The purpose of this article is to identify a few common themes among popular misconceptions around ABA and to address the bases for them.

Misconception # 1: ABA is Simplistic

There are a number of misconceptions of ABA based on the premise that its principles and techniques are far too simplistic for anything more than changing and/or teaching simple, single responses. Many believe that the complexity of the interaction between the individual and his/her socio-cultural environment, neuropsychology, genetics, and other factors must be beyond the scope of an approach that reduces this complex constellation to the relation between stimuli and responses. Examples are evidenced in statements such as:

- “ABA treats all individuals alike.”
- “ABA does not take into account the uniqueness of the individual.”
- “ABA discourages or inhibits individual expression and creativity.”
- “ABA teaches children to behave as robots.”
- “ABA denies the existence of thoughts, emotions, personality…”
- “ABA is based on the work on reflexes done by Ivan Pavlov and John Watson.”
- “ABA does not address underlying causes/mechanisms.”
- “ABA is a set of procedures that can be learned over a weekend workshop.”

For example, discrete-trial teaching (DTT) is one of the most well-known ABA-based techniques and has been highly-effective in teaching skills to learners with ASD who have been resistant to other forms of instruction.4 DTT has been implemented on a wide range, resulting in critiques that an ABA is a “one-size-fits-all” approach and can appear simplistic to the naive observer. Although DTT may appear repetitive and unsophisticated, an applied behavior analyst will incorporate a variety of methods that address numerous behavioral principles concurrently, each of which might affect behavior in a different way. Indeed, the most effective educators, teachers, and mentors are those that navigate the interplay between numerous variables that can affect the behavior of the individual in the moment and in the future. Additionally, the applied behavior analyst will also shift from intensive and strict DTT approaches to looser, more naturalistic forms of instruction as the learner progresses. Unfortunately, applications of DTT and other ABA-based techniques by insufficiently trained practitioners will produce undesirable effects and this is no less true of teaching, therapy, counseling, medicine, or other professional disciplines. Only advanced and thorough training in the principles of behavior will expose the multitude of variables that

see Misconceptions on page 22
Evidence-Based Practice for Very Young Children with Autism
Delivering Family-Centered Services within a Community Program

By Jamie Winter, PhD, BCBA-D,
Cynthia Martin, PsyD,
and Catherine Lord, PhD
Center for Autism & the Developing Brain
Weill Cornell Medical College
New York-Presbyterian Hospital

Evidence from randomized controlled trials supports the efficacy of naturalistic developmental behavioral interventions (NDBIs; Schreibman et al., 2015) for young children with autism spectrum disorder (ASD). The Early Start Denver Model (ESDM; Rogers & Dawson, 2010) and Early Social Interaction model (ESI; Wetherby et al., 2014) are two examples of NDBIs. The ESDM is delivered through both one to one intervention and parent coaching, and ESI is a parent-implemented intervention.

NDBI-based models of intervention fuse the teaching principles of applied behavior analysis (ABA) with a developmental, relationship-based approach that is appropriate for very young children with ASD. Hallmarks of NDBIs include intervention delivered in settings that are typical of early childhood (e.g., home, playground, preschool), incorporation of child choice and following the child’s motivation, and the use of behavioral teaching principles.

Interventions that combine both developmental and behavioral elements may be effective for a broad range of children with ASD (Stahmer, 2014). Despite this evidence, access to treatment based on these models of intervention is largely restricted to university-based research programs and is not typically available within the local community.

Program Information
The Center for Autism and the Developing Brain (CADB) offers an early intervention program to parents and children in a community setting, at NewYork-Presbyterian Hospital. The program is publically available and uses a NDBI approach. These services are provided free of charge through the New York State Early Intervention Program (EIP), and delivered within a focused 6 month period. This is to allow the maximum number of families a chance to participate in the program.

In the local region, the majority of available community programs are based on see Family-Centered on page 31

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Increasing Psychological Flexibility When Parenting a Child with ASD

By Glenn M. Sloman, PhD, BCBA-D, NCSP
and Michael C. Selbst, PhD, BCBA-D
Behavior Therapy Associates

Parents and caregivers of a child with an autism spectrum disorder (ASD) are presented with extreme challenges and demands. Oftentimes, this begins immediately when the parent notices that their child is displaying developmental delays. Parents commonly experience a great deal of uncertainty, apprehension, and concern throughout the process of seeking evaluations, learning that their child has been diagnosed with ASD, exploring treatment options, and navigating educational and mental health interventions. These difficulties are combined with challenges such as overseeing home programming, ensuring adequate and appropriate schooling, planning for the future, and attending to the direct needs of their child. This places the parent in direct contact with circumstances that commonly result in high levels of chronic stress (Holly, Brown, Wikler, Simmons, 1975). Many of the challenges become obstacles to a healthy life of harmony between caring for their child, providing and managing ASD recovery treatments, being available for other important relationships (e.g., spouse, other children, friends), sustaining success in the workplace, and attending to their own well-being. Similar to others on the “front line” positions, these parents experience a lower quality of life and elevated depressive and anxious symptoms (Poddar & Urbii, 2015). Parents can become caught in the symptoms (i.e., excessively ruminating about the future, struggling with sadness) and attempting to reduce these avoidable and difficult thoughts and emotions at the expense of doing what is important to them. Given their responsibilities and worries, how can we help parents live a more meaningful, balanced life style?

Using Acceptance and Commitment Therapy (ACT) to Increase Psychological Flexibility

ACT is an empirically supported supplement to behavior therapy. ACT capitalizes on empirically supported treatments (behavioral activation, exposure and ritual prevention, mindfulness, etc.) to foster meaningful behavior change that helps someone find meaningful? Workability links long-term behavior patterns in the service of a more meaningful (i.e., valued) life.

Increasing PF is critical when helping parents remain fully connected (present) throughout challenging situations they encounter themselves and when caring for their newborn’s care are determined. And, eventually, the relationship with the partner and sexual intimacy returns. The role development of the new father has different issues. Goodman (2005) describes four phases. In the first phase, there is the expectations of how the newborn will be integrated in the family. Fathers have specific intentions on how it will be accomplished. Fathers, during this phase, desire an emotional involvement and deep connection with the infant. Then, comes phase two. Reality sets in. This phase is characterized by unrealistic expectations, frustration, guilt, helplessness, and inadequacy. During phase three, expectations are altered and new priorities are established. Fathers are redefining the role by negotiating with the partner, learning how to care for the infant, increasing their interaction with the infant, and they struggle for the need for recognition. All this helps the new dad create his personal role as the father. In time, fathers reap the rewards. The baby’s smile brings a new sense of meaning, completeness, and immortality.

At the time of their child’s autism diagnosis, parents have described their feelings as grief, relief or disbelief. According to Hutton and Caron (2005), 52% of parents felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame. At this moment, the hopes and dreams for this child are lost (Gargiulo & Graves, 1991). There is grief for the loss of the perfect child (Ellis, 1989). Therefore, it is common that parents go through the stages of grief. Mothers and fathers proceed through the stages at different rates, vacillate between stages, and may even go through them in a different order. The stages of grief for the parent of a child with autism, described by Naseef (2013), are denial, anxiety and fear, guilt, shame, depression, anger, and hope. The grieving has biological, intellectual, emotional and behavioral aspects. For those parents that felt relieved with an autism diagnosis, the diagnosis was a validation. They may have initially offered excuses for their child, but seeing the differences from their previous child or playmates helped them move through denial. They recognized “something isn’t right.” For those that are consume with disbelief, they may have been caught totally off guard. These parents may be unfamiliar with typical development. Their denial may be an unconscious avoidance of anxiety and cannot “hear” what is being told to them. The denial may be a coping mechanism while they mobilize their resources (Hutton & Caron, 2005).

So how does the mother adapt to the diagnosis of her child with autism? It goes back to Reva Rubin. The mother takes the diagnosis in. She seeks out ways to get her basic needs met. The need for information. The mother needs to understand what autism is, how her child is affected, and starts to realize its impact. In the second phase, she takes-hold. Much like when her child was a newborn, her focus is on the child and being a competent mother. She has a desire to take charge. It often is characterized as “Get out of my way” while I figure what this autism is and what we are going to do. Mom is very eager to learn. She needs others to accept her new role, to support and nurture her quest. The letting-go phase, described as moving the family forward as a unit, is a very crucial one. There needs to be resolution of individual roles, reassessment of relationships with their partner, and resumption of intimacy. This phase has a significant impact on the father.
Avoid Mistakes with Important Legal Forms

By Sharon Kovacs Gruer, Esq.

Many individuals have wills prepared, put their copies of the will away, and don’t think about their estate plan again. However, they should review their estate plan from time to time to make sure that their will and other legal documents, such as beneficiary designation forms and trusts, comport with their overall estate plan and goals.

With retirement accounts often comprising a large portion of a person’s assets these days, a beneficiary designation form can be just as important, or even more important, than a will. Beneficiary designation forms for retirement accounts may sometimes involve the transfer of an amount of money that exceeds the total sum of the assets covered by the will.

Some people do not fill in the beneficiary designation forms for their retirement accounts, assuming that these accounts will then go to the beneficiaries of their estate pursuant to their will. If there is no designated beneficiary listed on a beneficiary designation form, an IRA would usually go to the estate by the default provisions of the IRA custodial agreement, but in a much less tax efficient manner than if there had been beneficiaries listed. For instance, designated individual beneficiaries of an IRA have the ability to take out their minimum distributions over their own life expectancy pursuant to the IRS tables. If there are no designated beneficiaries, depending on the age of the account holder at death, the proceeds may have to be paid out over five years, or over the period that the IRS considers to be remaining life expectancy of the deceased account holder.

If a beneficiary is receiving public benefits, or is likely to need public benefits in the future, it may be advisable to have a supplemental needs trust created for that beneficiary, and list the trust on the beneficiary designation form. Otherwise, after the death of the account holder, it might become necessary for someone to commence a court proceeding (with the attendant fees and delays) to be able to collect the assets on behalf of the minor. If a trust is a beneficiary of all or part of a retirement account, the trust should be listed on the beneficiary designation form.

When a trust is listed as a beneficiary of a retirement account, it is best to review the trust to make sure that it meets the IRS requirements to permit the minimum distributions to be able to be “stretched” out and paid over the life expectancy of the beneficiary of the trust. If the IRS requirements are not met, then instead of being able to “stretch” the minimum distributions over the life expectancy of the beneficiary, depending on the age of the account holder at the time of death, the IRS would require that the retirement account be liquidated over five years or over the life expectancy of the deceased account holder.

Because of all the mergers and acquisitions of financial institutions these days, the financial institution’s copy of the beneficiary designation form may not be available after the account holder’s death. A bank may have taken over another bank and may not have all of the prior bank’s records. The bank may have no record whatsoever of the completed and signed beneficiary designation form, and may advise the family that there was no such beneficiary designation form on file. Without a designated beneficiary, the “stretch” of the minimum distributions could be lost. For that reason, it is a good idea to obtain a date-stamped copy of the completed form which is on file with the bank.

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Now accepting applications for admission
What Parents of Children with Autism Should Know About Abuse

By Nora Baladerian, PhD
Executive Director
The Disability and Abuse Project

It is true that parents of children and adults with ASD, if asked, will admit to having long-held fears that their child may become a victim of abuse. However, it is also true that when I have provided classes for parents of young and adult children with autism at Los Angeles-based Regional Centers (case management and support agencies for people with intellectual and developmental disabilities), few show up. Whereas the classroom may hold up to 200 people, class size is typically 12-15.

Some of these brave folks have told me, “I did not want to come. Abuse is on my mind every day. I feel so afraid. But I thought maybe I would learn something to help keep my child safer.” I understand. No one really wants to face the ugly reality of abuse—the fact that someone intends to harm to one’s loved ones. Yet, closing our eyes and hoping it won’t happen is not a power position, and does nothing to protect anyone.

In this brief article, I want to help parents know that any of them can take effective action to reduce the risk and impact of abuse. This is not the same as saying that I can show you how to make sure your child is never abused. We cannot eliminate disasters from happening. But, we can reduce the risk of it happening and enhance the individual’s outcome if it does.

The strategies that I have developed are detailed in a workbook for parents and other caregivers. This provides background information about abuse that I believe is essential for anyone seeking to improve the safety of their children.

There are a few mottos that I depend upon to transmit this information easily. The first is, “knowledge is power.” Thus, I provide information about perpetrators…those individuals who abuse. These can be males or females, old or young. For the great majority of those who experience abuse, the perpetrator is someone who either lives in their home, or is a welcomed visitor in the home, or is another type of care-giver, such as teachers, occupational or speech therapists. Statistics tell us that around 90% of the time, the perpetrator is someone the victim knows well, and often, the parents know well. The myth of a stranger jumping out from behind a bush is just that…a myth. That myth is much more psychologically comfortable for many, who just cannot believe that the abuser is, about 90% of the time, well-known to the victim and the family. It is important for parents to be aware of this fact, so that they can be helpful and believe their eyes and ears when abuse appears to have occurred. In the absence of recent research on the incidence and prevalence of abuse, the Disability and Abuse Project decided to conduct one. We received 7,289 responses nationally. Our 2012 National Survey on Abuse and Disability. The Disability and Abuse Project is focused on the responses of over 2,500 individuals with disabilities and their family members. The full report is available on our website for free download. Visit http://disabilityandabuse.org to get your copy.

Of course, hopefully one can act before abuse happens, yet in most cases, that is not what happens. I want the parents/caregivers to be able to respond effectively and quickly when abuse is discovered or disclosed.

I like to think of abuse as just another in a long list of things we wish would not happen in our typical, normal lives. We wish there would not be a tornado or earthquake, but still we make preparations in case this should occur. We do not close ourselves off to the possibility, but take recommended precautions that will help during and after the unwanted weather event. The motto in this regard is, “hope is not a strategy.”

My recommendation and practice is to have strategies for each phase of the abuse experience. Before, during and after. In the book, I provide examples of how to create an Individual Response Plan, an IRP. The IRP has two main sections for being informed and empowered.

One is for the individual with a disability (whether a child or an adult) and one is for the parent or caregiver. Both have much to learn about reducing the risk of abuse, creating a communication system so that the child and Disability Group can alert the parent or plan partner after abuse has occurred, as well as let the parent know they do not feel safe or good around certain people or in certain locations. The child with a disability

see Abuse on page 32

Mindfulness and ASD

By Laura M. Pascarella, LCSW
Manager of Clinical Services
YAI Autism Center

Over the last couple of years, mindfulness, in particular Mindfulness-Based Stress Reduction (MBSR), has been receiving more attention in the media. Mindfulness is often discussed as a new tool for managing life’s stressors and problems, and, perhaps, a better way of approaching our daily lives. Of course, mindfulness is really nothing new with its origin in Eastern-based meditation practices. However, more recently with autism spectrum disorders on the rise, the use of MBSR techniques is also beginning to receive more attention as an effective intervention for caregivers of and for people with autism spectrum disorders.

Different Ways to Cope with Stress

So what is mindfulness anyway? It is important to understand that mindfulness is not about trying to achieve a state of happiness all the time. But, as Jon Kabat-Zinn, an expert in mindfulness-based stress reduction, describes, mindfulness is “...moment to moment awareness, the complete ‘owning of each moment’ of your experience, good, bad or ugly.” The practice includes mindful awareness, which is an open-minded, open-hearted and non-judging awareness of the present moment, as well as types of sitting and walking meditation, body scans, Qigong (involving posture, breathing techniques, and mental focus), mindful eating and loving kindness concepts. It also incorporates specific attitudes of mindfulness like purposefully paying attention, non-judging, patience, using a beginner’s mind, trust, loving kindness, non-striving, acceptance of reality and letting go. Mindfulness is not teaching us ways to eliminate problems, but instead, different ways to think about and manage the ongoing stress and problems that arise. Research is showing that we can change our attitude, and thereby our relationship to our circumstances, in ways that can make a difference in our health and well-being.

Learning to Quiet the Mind

This practice is emerging as a growing trend in working with children, adolescents and adults with autism spectrum disorders. Learning to quiet the mind through meditation and breathing techniques and to listen to our bodies seems to help regulate emotions. By learning to pay attention in the present moment, people are able to reduce rumination. These techniques can be particularly effective in dealing with the anxiety and depression that can often accompany autism spectrum disorders. Research shows that depression and anxiety disorders are the most common psychiatric concern in autism spectrum disorders.

Mindfulness-based therapy has been found effective in reducing anxiety and depression symptoms. In addition, for some, learning to accept reality and to let go can have a profound effect on dealing better with everyday concerns. Tara Brach writes, “Radical Acceptance is the willingness to experience ourselves and our lives as it is” and emphasizes how mindfulness can help in this process. Exercises in paying attention, self soothing, noticing thoughts and breath awareness can be taught to people who need varying levels of support.

Helping Parents and Caregivers

Parents and caregivers of people with autism spectrum disorders can also benefit from these MBSR techniques. While all parents endure stress, we have learned that parents of children with developmental disabilities, like autism, are more likely to experience depression and anxiety. Using MBSR techniques can help. “Previous studies indicate that the majority of people who complete [Mindfulness Based Stress Reduction programs] report a greater ability to cope more effectively with both short- and long-term stressful situations, critical skills for parents of children with DD.”

One parent who practiced in a mindfulness group taught at YAI stated, the practice of mindfulness in her daily life gave her “a feeling of wellbeing and peace that [she] had never experienced in her past.” And another parent expressed, “mindfulness has been a transformative experience to awaken a centered and conscious life where a treadmill of challenges is turned into wisdom and opportunities.”

Practice, Practice, Practice

Practicing mindfulness in our daily life is really the only way to cultivate the practice. However, by actively practicing people can acquire techniques that can help them gain more control and be a positive

see Mindfulness on page 19
The Role of the Caregiver in Enhancing Job Skills in Individuals with ASD

By Kelly Imperial, MS  
Director of Employment Training Services  
New York Institute of Technology  
Vocational Independence Program

When parents think of what they want for their children, a fulfilling job is often included in their answer. Many caregivers want to see that their loved one can not only obtain a job, but maintain it long-term. This tends to be particularly difficult for those on the autism spectrum, as research indicates that long-term employment rates are less than ideal (Lorenz, Frischling, Cuadros & Heinitz, 2016). According to the U.S. Department of Labor, Bureau of Labor Statistics, approximately 12.1% of individuals with disabilities are unemployed (BLS, 2015). This is more than twice the national unemployment rate (BLS, 2015). Individuals with ASD and intellectual disabilities continue to battle barriers to employment and often struggle to acquire the necessary job skills needed to maintain gainful employment (Lorenz et al., 2016). Caregivers are often cognizant of these outcomes and many are mindful about how they may contribute to their son or daughter’s job skills; thus increasing the likelihood that he or she will be able to obtain and maintain employment. Recent studies have found the development and acquisition of professional etiquette and soft job skills to be crucial in determining whether an employee will be retained (Scott, Falkmer, Firdler & Falkmer, 2015). Despite having this knowledge, caregivers may still find that the road to employment can be difficult to navigate. They may feel torn between trying to insure that their loved one has a positive work environment and experience, while also not wanting to overstep boundaries and interfere with his or her independence. To be mindful of the latter, it is imperative that caregivers assist in the development of job skills at home. Various studies have identified which factors are crucial in determining whether a person will be able to maintain employment in the competitive workforce (Scott et al., 2014). Studies have found that having clear expectations, step by step directions, on-site support, a professional presentation and etiquette, and “soft” job skills best indicate whether an individual with ASD will be successful in the workplace (Lorenz et al, 2016; Scott et al., 2015).

Caregivers can play a large role in the development of these skills, many of which can be introduced at home at a young age. The research has found that the earlier these skills are introduced, the more likely the individual is to acquire them and later be employable (Dipeolu, Storlie & Johnson, 2014). Introduction of these skills can begin as early as the toddler years and extend throughout college. For example, when asking a young child to complete a task at home, providing step by step instructions can decrease anxiety and allow the child to find a sense of accomplishment in completing each task. Further, it is recommended that the child be provided with clear expectations (Lorenz et al., 2016). When assigned a task from either a caregiver or an employer, the individual may struggle with anxiety related to the successful execution and completion of the task at hand. However, the knowledge of how to breakdown tasks can serve the individual well. When asking to clean an object in the home, a sink for example, the caregiver can demonstrate what the sink looks like once it’s cleaned so the child has the visual of what a “clean” sink is. Leaving it up to the child to define “clean” can result in unclear expectations and later, undesirable results. Providing the step by step instructions in the form of a checklist can make instructions clearer and allow the child to transition from one task to the next smoothly (Moyer, 2011). Providing detailed instructions such as to how to clean the object, where to clean, and what cleaning ingredients to use can simplify what may appear as an overwhelming task. Providing these visual supports and mirroring the task can reduce anxiety and provide direction, which increases the likelihood of the task being finished successfully (Moyer, 2011). As the child grows, they may reasonably be expected to take on more complex tasks and mimic what an employer may expect of them in a paid position. Having already developed the skill of breaking down an assignment into step-by-step tasks and identifying the end result will serve them well in a traditional work environment.

soft job skills to be crucial in determining whether an employee will be retained (Scott, Falkmer, Firdler & Falkmer, 2015). Despite having this knowledge, caregivers may still find that the road to employment can be difficult to navigate. They may feel torn between trying to insure that their loved one has a positive work environment and experience, while also not wanting to overstep boundaries and interfere with his or her independence. To be mindful of the latter, it is imperative that caregivers assist in the development of job skills at home.

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Functional Skills Training for Individuals with Autism Spectrum Disorders

By Robert H. LaRue, PhD, BCBA-D, James C. Maraventano, EdM, BCBA, and Jenna Budge, MSW
Douglas Developmental Disabilities Center at Rutgers University

The acquisition and maintenance of functional skills are among the most important educational targets for individuals with intellectual disabilities. Functional skills are the skills we possess that allow us to take care of ourselves and function independently in our natural environment. For most of us, these skills are readily acquired through daily life experiences. For individuals with cognitive impairments, these skills may need to be explicitly taught. The acquisition of functional skills results in several favorable outcomes, including increased opportunities for community integration and better overall quality of life (Ayres, Lowrey, Douglas, & Sievers, 2011). In addition, functional skills allow individuals with disabilities to have more opportunities to access reinforcers and make choices in their daily lives, which has been shown to have positive effects on work completion and inappropriate behavior (e.g., Wannabe and Sturmey, 2003).

The goal of any educational program should be to prepare individuals to function as independently in their environment as their abilities will allow. Experts have noted that individuals with intellectual disabilities encounter a myriad of challenges as they transition out of school placements, including unemployment and placement in more restrictive programs (Ayers et al., 2011; Courtade, Spooner, Browder, & Jimenez, 2012). Consequently, researchers have argued that functional skills should be incorporated into students’ individualized educational programming and practiced on a daily basis. Ideally, each educational goal should be linked to a terminal skill that will be useful to the individual in the natural environment (Bannerman, Sheldon, Sherman, & Harchik, 1990; Favell, Favell, Riddle, & Risley, 1984). This should be accomplished through systematic assessment and planning which allows parents and practitioners to produce the best outcomes for this population.

What Are Functional Skills?

Functional skills refer to a broad range of abilities needed to navigate the demands of everyday life. Functional skills are often seen as a way to improve social and self-care skills, as well as academic skills. Functional skills are important for individuals with autism spectrum disorders because they help individuals acquire the skills they need to function in their communities.

References


Speck from page 8

Little is known about bilingualism and its effects on ASD. The emerging research is showing that bilingualism and ASD do not interact in a detrimental way that would give rise to a delayed or deviant profile of language acquisition (Reetzke, Zou, Sheng, & Katsos, 2015). Hambly and Fombonne (2011) compared the language and pragmatic skills of bilingual and monolingual children with ASD. They concluded that parents and caregivers of children with ASD should not be prevented from speaking with their children with ASD in dual languages because they do not experience additional delays in language development when compared to monolingual children with ASD. When the expressive and receptive language abilities of monolingual English speaking children with ASD and those of age-matched bilingual English/Chinese speaking children with ASD were compared, the results revealed that children with ASD have the linguistic capacity to be bilingual without experiencing impediments in their language development (Petersen, Marinova-Todd, & Mirenda, 2012). In a related research, Ohashi, et.al (2012) compared the severity of ASD related communication impairment, age of first words, age of first phrases, expressive and receptive language, and functional communication scores of bilingual (English or French and one more language) and monolingual (English or French only) children with ASD. They found no statistical difference between bilingual children with ASD and monolingual children with ASD on any of the language measures.

When the expressive and receptive language development of bilingual (English/Spanish) children with ASD were compared to that of age-matched monolingual (English) children with ASD, the findings, again, demonstrated that expressive and receptive language of bilingual children with ASD did not fall behind the monolingual children with ASD (Valicenti-McDermott, et al, 2013).

While there is a shortage of research about how bilingualism interacts with ASD, the studies that have emerged are revealing evidence that shows that bilingualism is not affiliated with language development challenges in children with ASD. This has clinical and educational implications. Health care professionals, Speech-language pathologists and other educators need to demonstrate increased cultural competence and engage in evidence based service delivery in order to be responsive to culturally and linguistically diverse populations. It is imperative that they are aware that exposure to two languages in the home environment does not have an impact on language competence in children with ASD. They should therefore advocate for families to communicate with their children with ASD in their LOTE and not speak only English.

Robert Robert H. LaRue, PhD, BCBA-D

James C. Maraventano, EdM, BCBA

Jenna Budge, MSW

students’ individualized educational programming and practiced on a daily basis. Ideally, each educational goal should be linked to a terminal skill that will be useful to the individual in the natural environment (Bannerman, Sheldon, Sherman, & Harchik, 1990; Favell, Favell, Riddle, & Risley, 1984). This should be accomplished through systematic assessment and planning which allows parents and practitioners to produce the best outcomes for this population.


For more information, please email sterling.tamara20@gmail.com.


Because of You

I almost lost my marriage because of you. It was the year my son named Jack was born, and you were born right along with him. At first, we had no idea. He was just a squirming chubby baby who didn’t sleep too well and hated to be swaddled and cried a little more than we expected.

Slowly, you made your presence known. The sleep got worse. The cries got louder. The quiet got quieter.

He was sick all the time; reflux and ear infections and a deep, barking cough. Then eighteen months later, on a gray day in early November, an official diagnosis of autism spectrum disorder.

I charged full-steam ahead. I wanted to read about you and research your symptoms and figure out the best plan for speech and occupational therapy and maybe some sign language and then integrated preschool and if we had time we should do music class because everyone knows music is great for kids who don’t talk a lot.

My husband, Joe, took the wait-and-see approach. He wanted to slow down and understand you. He wanted to be thorough before we jumped into anything.

I was right, he was wrong. He was right, I was wrong. I was frantic. He was methodical. I was raw. He was angry. Because of you, we were both lost.

Oh sure, we never fought about you specifically. Instead, we fought over who got more sleep and who spent more money and who did more housework; all while a wolf knocked quietly at the door—an interloper in the dark of the night.

Inside every marriage is a secret language, a private code of nicknames and jokes and memories. Some days are full of a thousand tiny hurts, followed by a million small recoveries.

Once you bared your long, yellow teeth in our house, the jokes ebbed. Our nicknames faded, and our attempts at recovery were dwarfed by the hurt. Most of our spousal dramas played out on our big tan couch, with one of us rocking and petting a fussing Jack.

I said I would look into—why can’t you just calm down? Calm down? Calm down? Something is really wrong with him. You know it’s true. I always hated that couch.

Because of you, our young marital ground was sliding beneath us, and separately we each battled the nagging feeling that the landscape of our little family was shifting for good. We were a statistic, a number, a plot line on the spectrum’s sloping bell curve.

Ever since November 3, 2006, you and I have been like two boxers in a ring, circling and jabbing, trying to gain whatever ground we can against each other. We are brother and sister at the end of a long, hot car ride, poking and needling and annoying and griping. We are the quintessential cat-and-mouse, and we take our turns chasing and hiding, hiding and chasing. I am
A new study aims to quantify effects of respite vacation experience on families with special needs

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having a child came to fruition. However, when it became clear that there were some serious delays in his development, they were initially very concerned and worried. They spared no expense or resources in obtaining an early diagnosis and enlisted the help of expert providers in diagnosing and treating Charlie’s Asperger’s. Ultimately, Charlie has done very well with these treatments, but Jane and Joe continue to feel a massive amount of guilt. For Jane, she feels some sadness and frustration that her son is not what she imagined. She is struggling to come to terms with the reality of some of Charlie’s limitations, but her biggest struggle is processing through her feelings of guilt over her own disappointments. “I know I have to mourn the loss of the child I imagined I would have, but I feel so terrible for ever having these kinds of thoughts. What kind of mother looks at her child and feels disappointment?” In her effort to shield Charlie from her feelings, she has become quite permissive with him. Even though she knows he will thrive more if she is better with boundaries, every time she sets them, she backs down more if she is better with boundaries, every time she sets them, she backs down more if she is better with boundaries, every time she sets them, she backs down more if she is better with boundaries. And so, they may miss something, Samantha feels she is under a microscope. In an effort to protect her, they may be hindering her own independent adolescent experience, including learning to explore and think independently from her parents as she fosters her own unique identity.

These scenarios reflect just some of the areas that trigger guilt in the parents of children with ASD. Parents of these children often take full responsibility for their own critical thoughts as well as holding themselves accountable for actions that are often not under their control. They may feel a tremendous sense of self-criticism and self-blame for what transpired. This may be masked behind a veil of anger or defensiveness. There may also be a lot of anger and disillusionment with “the system,” those that should have known and pointed them in the right direction, and also a lot of sadness and personal responsibility for the mistakes that were made. Parents may invalidate their own knowledge for fear of making mistakes and dealing with guilt afterward. This can lead to a basic mistrust of one’s own parental instinct, or the opposite, making rigid, inflexible decisions, and then second-guessing oneself.

Parents in this situation may be so overwhelmed by their own guilt, they may not know how to move forward in terms of taking the child’s progress and development moving forward. Unwittingly, they may make allowances for their child that may in fact not be in the child’s best interest, or may be blinded from accurately assessing the needs of their child, in an attempt to assuage the feeling of guilt.

After recognizing the presence and power of guilt, the next step is to try and work it through. We believe by understanding, exploring, and processing feelings, parents can begin to master them and feel empowered to use the guilt to set up the child for success. The guilt can be analyzed and understood in the context of the parents’ own struggles and conflicts, and therefore separated and contained from leaking into their interactions with their child. The feeling of guilt can be used as a powerful motivator to help the child achieve success. I use the metaphor of a river with a dam. By understanding the parents’ personal contributions, it can separate out the child’s individual needs from the parents own wishes, thoughts, and fears which can sometimes contaminate their parenting style. Awareness in this case breeds success.

In my own work with those on the spectrum, I find it helpful to see the work in the context of the entire family. This enables parents to have their own parent meetings with me where they spend time thinking about their own actions with their children, and whether they are acting in what they know (but self-doubt) to be their own parental instinct, or if they are acting out of a personal sense of guilt. I find these sessions to be at least as important as the work with the child. We all have guilt. At times, it mobilizes our ability to demonstrate our feelings of caring and empathizing with those we love. At other times, it can feel like it inhibits us from doing what is best for those same people. Ultimately, it is within our power to find the right balance and model it to our children. And if we don’t, we apologize, try again, and model that it’s OK to make mistakes - yet another valuable lesson!

Shuli Sandler, PsyD, is a clinical psychologist. Among her areas of focus in her practice are children and adolescents with ASD and their families, as well as those who are experiencing a variety of difficulties in school, and young adults struggling with issues of achieving independence. Dr. Sandler has offices in midtown Manhattan with Spectrum Services and Teaneck, New Jersey. She can be reached at shulisandlerpsy@gmail.com.

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Building Capacity in Pre-Service Teachers to Collaborate Successfully with Parents of Children with ASDs and Related Disorders

By Dr. Vanessa Tucker, PhD, BCBA-D
Pacific Lutheran University

The experience of raising a child with a disability is, without a doubt, qualitatively and even quantitatively different from raising a typically developing child. Educators must develop a better understanding of the experiences of families in order to promote successful and long-lasting collaboration. Educators are in a unique position to make or break this experience through their interactions with parents. While it is not possible for everyone to “walk in their shoes” of parents, it is entirely possible to increase understanding, empathy and better practices right from the start. Educators may, in absence of good guidance in training, inadvertently contribute to break downs in collaboration.

Assumptions

Collaboration is the process of coming together to mutually contribute to problem solving. There are a number of ways that educators unknowingly contribute to collaboration breakdowns (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004). Assumptions about what parents should be doing, based upon what typical parents can do (when they have the resources) is one source of conflict. Challenging behaviors due to breakdowns in social-communication, sensory issues or past learning and reinforcement history can cause serious division. Educators may develop the expectation that parents have far more responsibility for their child’s behavior than it reasonable to expect. Assumptions about the child’s behavior being a direct result of lax parenting or overindulgence can lead to blame—in this world view, the parent is responsible for the child’s behavioral excesses. The unfortunate result is, in the worst case scenario, an absolutism from building positive behavior support strategies in school, as the “cause” is assumed to be within the home.

Equality in Collaboration

Successful collaboration is fostered by all members of a team coming to the table adequately prepared and able to contribute to educational planning. Educators are in a privileged position of being “insiders” into the process—they are employed members of the LEA (Local Education Agency). When the IEP meeting is convened the ratio of parent to educational staff is heavy on the “district side.” The district members have access to information by virtue of their day to day work, often many days in advance of the meeting. It is common for parents to report that the first time they saw the IEP was at the meeting. This marginalizes parents from truly participating in the process.

Parents’ expertise can sometimes be discounted in the IEP process. The unwritten assumption may be that a school professional’s degree trumps the parent’s unique and intimate knowledge of their child. Degrees and titles can intimidate parents and lead to deference to professional authority (Wellner, 2012). This phenomenon results in a loss of valuable information and input from families who have known, lived and developed incredible expertise in the care of their child (Hess, R.S., Molina, A.M. & Kozleski, E.B. 2006). This form of “professional dominance,” still common in the medical and educational fields, can serve to create dissonance between educators and parents. Parents want and need to feel respected and honored for what they bring to the collaboration effort.

The IEP Meeting

Related to this is the tone and tenor of the IEP meeting. Educators may not realize that the way they conduct meetings can make or break the collaboration experience. IEP meetings are stressful for parents due to the medical model that continues to pervade Special Education. The terminology used in evaluation and IEP proceedings can be foreign and overwhelming. Parents and caregivers have to reveal much information about their child’s health and development than typical parents. Deficits and behaviors are often necessary to discuss as a springboard for educational planning.

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force on their wellbeing.

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Cameron L. Neece Department of Psychology, Loma Linda University, Loma Linda, CA, USA Journal of Applied Research in Intellectual Disabilities 2014, 27, 174–186
Reducing Stress from page 1

on the quality of the placement and the nature of support services needed, we also have identified some common ancillary concerns that are also crucial. Because the transition planning process is so stressful, important topics that need to be discussed with every family that often get overlooked are guardianship and end-of-life planning. Individuals with certain diagnoses such as Down syndrome and other intellectual disabilities or neurological disorders are living longer and fuller lives than ever before. It wasn’t long ago when parents of children with certain disabilities could expect to outlive their child. Now, the need for guardianship is largely established and it is generally put into place. While many families go through the process of obtaining guardianship for their loved one, however, they do not always plan ahead to when they will no longer be able to be that person’s guardian any longer. Additionally, because aging caregivers have not always planned for what will happen when they can no longer make decisions for their loved one, their wishes for their loved one’s end-of-life care can go unknown by others, leaving those decisions in the hands of people who may not know those wishes.

Guardianship Considerations

Some families feel that once they have obtained funding and found permanent housing for their loved one, they have solved all of the issues in regard to what will happen to their family member when they are gone. While their family member may have more support in place than individuals without funding or housing, many important decisions in regard to treatment still need to be made, including end-of-life planning.

Families can choose to obtain guardianship or power of attorney (POA) of their loved one with special needs. They can also choose to refrain from obtaining guardianship or POA, but remain extremely active participants of their loved one’s treatment team. Explaining and supporting the family’s choice is a key ingredient in family support services. In each of these cases, it is extremely important for families and providers to prepare and have a plan for when families/caregivers/guardians are no longer able to make decisions or be active members of the treatment team.

It is important for provider agencies to initiate, revisit, and support this conversation with families, to not only consider what will happen when the guardian or primary caregiver is no longer here, but what will happen if that person is still here, but no longer able to make decisions for their loved one.

Families do not always consider that there may come a time when the aging caregiver will need their own POA or guardian. For example, if a mother has guardianship of her adult child with a disability, but the mother falls ill and is no longer able to make decisions for her child with a disability, the burden for decision making for both the mother and the child will fall on another family member such as a sibling. If planning for this type of situation has not taken place with the family, it can cause a lot of undue stress on the sibling who is now responsible for making decisions for two family members, especially if the sibling was not an active member of the treatment team for his/her sibling with a disability. This can cause hardship and an interruption in needed services for the sibling with a disability, such as needed medical care, which may require the signature of a guardian even if the person lives with a provider agency full-time.

Provider agencies, like Melmark, can support this discussion and process by making this a part of the regular conversation at treatment team meetings. By educating families about the need to make these types of decisions, and supporting them through the process of trying to make these decisions, added stress and difficulty surrounding the passing or incapacitation of a caregiver can be avoided for both the person receiving services and for other family members. Provider agencies need to support families so that they are prepared to ensure that the care for their loved one goes uninterrupted, and that service agencies are aware of the wishes for their loved one.

End-of-Life Planning

End-of-life decisions and planning are not easy subjects to address for anyone, and is something that likely needs more discussion across all populations. This is particularly important, however, for individuals with intellectual disabilities who may be unable to express their own wishes to those who do not know them well.

Family members, caregivers and/or guardians may have very specific wishes for the end-of-life care for their loved one with a disability; however, they may not share those wishes with the providers who are responsible for carrying them out when the time comes. As mentioned before, parents and caregivers may not have planned for their loved one to outlive them, but the odds are that they will.

End-of-life planning, while a very personal decision, can be viewed as a treatment team decision just like everything else. These decisions should include input from the interdisciplinary team (IDT), which includes the individual, family, caregivers, physicians, nurses, case managers, and anyone else that important to the individual. It is important to include the IDT in these decisions so that everyone who plays an important role in the individual’s life is aware of and can support the end-of-life care that is desired. This is a topic that needs to be discussed with every family before these decisions actually need to be made. When this topic does not get discussed, an individual can end up in a situation where someone other than a guardian or caregiver needs to make an important decision regarding ongoing medical treatment. Without the knowledge of the wishes of the family and individual, or a thorough knowledge of that person’s care plan, decisions are made with the best information available to the team at the time. While decisions may be made with the best interests of the individual at heart, they may not align with the wishes of that person. A goal of end of life planning is to avoid facing a situation where a decision must be made, the person cannot express their wishes, and no one in the room knows the wishes of the individual and/or their family. This is also a situation that can easily be avoided by planning carefully.

Summary

While ongoing guardianship and end-of-life planning decisions are difficult conversations to have, they are extremely important and can prevent more difficulty than they create in the future when important decisions need to be made.

Provider agencies should take the lead in addressing these important topics with individuals and their families, to ensure that service interruptions do not occur as a result of a guardian being unable to make decisions, and to ensure that end-of-life
New CDC Funding Will Expand Knowledge About Children with ASD

By The Centers for Disease Control and Prevention (CDC)

Over the next five years, CDC will invest more than $27 million to carry out a new phase of the Study to Explore Early Development (SEED). SEED is one of the largest studies in the United States to help identify factors that may put children at risk for autism spectrum disorder (ASD) and other developmental disabilities. Understanding the risk factors that make a person more likely to develop an ASD will help us learn more about the causes.

SEED includes three groups of young children (3-5 years of age) – children with ASD, children with other developmental disabilities, and children in the general population. Detailed information is collected from children and their mothers about the child’s development and health, the mother’s pregnancies, and the family’s health. Blood and saliva specimens are also collected. The three groups of study participants are compared to better understand genetic and environmental factors related to having ASD, health conditions among children with and without ASD, and the range of developmental and behavioral characteristics in children with ASD.

CDC has previously funded two phases of SEED. Over 5,000 children were enrolled in the study during these earlier phases. “We are so grateful to the thousands of families across the United States who have participated in SEED and made possible this critical work to better understand the complex risk factors for autism,” said Cynthia Moore, MD, PhD, Director, Division of Congenital and Developmental Disorders, CDC’s National Center on Birth Defects and Developmental Disabilities.

In the upcoming phase, CDC will fund five study sites to conduct SEED 3 so that more children can be enrolled in the study. This will enhance the ability of researchers to perform in-depth analysis of research questions that require large numbers of participants. In addition to funding external study sites, CDC will also conduct the study as a sixth site (Georgia SEED). Altogether, the six SEED 3 sites will enroll over 2,500 children.

CDC will also fund a central laboratory (biorepository) where the blood and saliva samples will be processed and stored, and a data coordinating center to provide a centralized location to hold the study.

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Linda J. Walder, Esq., Joins Autism Spectrum News Editorial Board

By Staff Writer
Autism Spectrum News

Mental Health News Education, Inc. (MHNE), publisher of Autism Spectrum News (ASN), is proud to announce that Linda J. Walder, Founder and Executive Director of The Daniel Jordan Fiddle Foundation, has become the newest member of the ASN Editorial Board.

Linda J. Walder is the Founder and Executive Director of The Daniel Jordan Fiddle Foundation (DJF), a national autism organization focused on adults. The mission of the all-volunteer run organization is to develop, advocate for and fund programs that create innovative ways for the diverse population of adults diagnosed with Autism Spectrum Disorders (ASD) to participate in and contribute to community life. The Daniel Jordan Fiddle Foundation Signature Programs co-developed and funded by the DJF Foundation can be found throughout the United States and include residential, vocational/employment, educational and recreational opportunities that are blueprints for replication in grassroots communities throughout the world. In addition, Linda is recognized as a “social entrepreneur” who has created and brought to fruition a wide range of informational resources, public policy, and most recently has pioneered a collaborative vision with outstanding universities to establish endowed programs assuring in perpetuity that there will be research, programs and support systems focused on adult autism. The first of these endowed programs are The Daniel Jordan Fiddle Foundation Adult Autism Research Fund at Yale Medical School and The Daniel Jordan Fiddle Foundation Transition and Adult Programs at the University of Miami Center for Autism and Related Disabilities. Linda and the DJF Board of Trustees are planning for several more endowed programs to be announced in 2016. The vision of the DJF Foundation is for all adults diagnosed with autism to have opportunities that honor their individuality, strengths and talents. This is the wish that Linda had for her own son Danny who passed away at age 9 and in whose memory The Daniel Jordan Fiddle Foundation is named. The website can be found at http://djfiddlefoundation.org.

Linda has received numerous honors for her volunteer work heading up DJF that have included a Russ Berrie Award for Making a Difference, the Jefferson Award for Public Service, and honors from the New Jersey Coalition of Inclusive Ministries and ASAH, New Jersey’s association of special education private schools and agencies. Linda also received Redbook magazine’s “Strength & Spirit” Award and was featured, as one of the five most inspirational women in the United States. She has been recognized before the New Jersey legislature for her humanitarian efforts that “exemplify a standard of excellence towards which others should strive.” In September 2011, Linda received the “Seeds of Hope” award for her leadership in the field of Autism and was featured in NJ Monthly Magazine’s September, 2011 issue. In March 2012, United States Senator Robert Menendez honored Linda with the “Evangelina Menendez Trailblazer Award,” for her pioneering work on behalf of the Autism community. In 2013, Linda was the first recipient of Autism Spectrum News’ “Beacon of Hope Award.” In 2014 Linda was awarded the “Classic Woman Award” by Traditional Home Magazine for her philanthropic efforts.


David Minot, Associate Director of MHNE and Publisher of Autism Spectrum News stated, “Linda has been an unofficial advisor and friend to Autism Spectrum News for years and is the driving force behind countless top notch programs and initiatives across the country that are providing adult individuals with autism vital opportunities to achieve the best most productive lives possible. I look forward to working with Linda to enhance the content of Autism Spectrum News by addressing issues related to the growing adult population with autism through education. I know I speak on behalf of the entire Board at MHNE in praising Linda’s work and welcoming her to the ASN Editorial Board.”

To see the full listing of the Autism Spectrum News Editorial Board, visit www.mhnews-autism.org/editorial_board.htm.
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are in effect during the seemingly simplest of teaching procedures.

Misconception #2: ABA is Not Generalizable

A second category of misconceptions speaks to perceived limitations on the general- ized or applicability of an ABA-based approach. ABA is perceived to be useful in 1) specialized settings, 2) with specific pop- ulations, 3) for certain types of behavior, or 4) for a limited time and 5) only as long as ABA treatment persists. For example:

- “ABA is only effective for severely im- paired individuals and cannot/should not be used with higher-functioning people with disabilities or neuro-typically-de- veloping people.

- “ABA is only applicable for severe prob- lem behavior like aggression but not for bizarre behaviors like self-injury, psy- chotic speech, or delusions.”

- “ABA is only useful for teaching simple responses or self-care skills.”

- “ABA can’t be used to teach complex or abstract behavior like language, problem-solving, and understanding of concepts.”

- “ABA is a laboratory science and tech- niques cannot be carried over into real-world settings.”

- “ABA can produce changes in behavior but those changes don’t generalize outside the treatment setting.”

- “ABA techniques are unnatural or con- trived, and so they don’t mimic the real world.”

Although ABA has had its largest impact in the field of autism and developmental disabilities, it has also been effective in a diverse range of fields addressing prob- lems on the individual, organizational, and community-level. This includes, but is not limited to, clinical/mental-health settings, business and ethics, industry, clinical and applied health psychology, and education. The be- havioral analogue of Industrial-Organ- izational Psychology, Organizational Behavior Management (OBM), is one of the most rapidly growing subfields within ABA. Despite great differences in the set- ting of work and target populations, applied behavior analysts in the fields of OBM and ASD rely on the same basic principles of learning and behavior change. Ultimately, this suggests that more examinations be made for demonstrations of the effective- ness of ABA in fields and settings other than ASD.

Misconception #3: ABA is Unethical

A third category of misconceptions consists of criticisms based on the idea that ABA-based approaches are unethi- cal, harmful and should not be used. Pro- ponents are explicitly anti-ABA and their dialogue is designed to elicit contempt of ABA. They argue:

- “ABA is dependent on the use of shock or other uncomfortable and aversive stimulation.”

- “ABA makes children dependent on ed- ible reinforcers, and children don’t learn for the sake of learning.”

- “Reinforcement is bribery and an un- ethical practice.”

- “ABA is like animal training and is inhumane.”

- “ABA practitioners seek to control people.”

The care and rights of the individual cli- ent are at the fore of the practice of applied behavior analysts. Prior to the field of ABA having established its own code of profes- sional ethics, the Association for Behavior Analysis adopted the American Psycho- logical Association code of ethics to guide professional practice. The role of ethics continues to be of paramount importance to the field and is a required component for the continuing education of all nationally certified behavior analysts. Unfortunately, some criticisms of hu- man-rights violations are based on cases in which behaviorally-based interventions have been implemented without appropri- ate or sufficient oversight, resulting in neg- lectful or abusive conditions. Additionally, the phrase “behavior modification” has been used synonymously with non- ABA-based techniques such as sedative medication, shock-therapy, and frontal lobotomies and its pejorative sentiment now also includes ABA. Although the history of the practice of behavior therapy in- cludes the misuse of behavioral techniques, these make up a small minority of cases that have been illustrated through decades of applied, clinical, and experi- mental applications resulting in meaning- ful change. Ultimately, much anti-ABA sentiment have little to no facts to support them and are gross overgeneralizations.

Conclusions

Applications in the field of autism have demonstrated the extent to which ABA is an important component to intervention. Although misconceptions and criticisms of the field of ABA are generally based on some version of fact, they rarely ap- ply on any level greater than superficial appearance and/or for more than a small number of cases. Moreover, it is becom- ing increasingly relevant to clinicians and educators to receive advanced training in ABA as the field of ASD changes. As the need and demand for ABA services increases, it is critical that professionals with a comprehensive understanding of the principles of behavior are prepared to fill that need.

Dr. Ronald Lee is the director of the Master of Arts (M.A.) in Applied Behavior Analysis (ABA) program at William James College. For more information, please visit http://www.williamjames.edu/academics/ counseling/applied-behavior-analysis/ap- plied-behavioral-analysis.cfm.

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The Intermingling of Tech and Therapy

By Ladislas de Toldi
CEO and Co-founder
Leka

The iPhone and iPad is commonly touted as today’s go-to therapeutic tool, specifically when dealing with children. With monitored screen time, it enables the development of learning, literacy, and physical and fine motor skills. Apple even has research speaking to this fact, proving that the iPad has positively affected student learning and test scores. Similarly, it’s been employed in therapy sessions as a communication device, choice board and a vocabulary builder.

While it’s great seeing this level of integration of tech, especially with children (as they are, after all, digital natives), there’s more to tech in therapy than the iPad—in fact, there has to be. Applications within tablets create limited man-machine interactions, meaning the most a child can get out of any given app is restricted by the app itself. The interaction eventually becomes static and a child’s development is more closely associated with the device itself rather than the child’s surroundings—a crucial element when addressing the needs of children with developmental disorders, such as autism, Down syndrome or cerebral palsy.

In order to engage and enable children with developmental disorders to live the exceptional lives they deserve, we need to think a bit outside the box.

The Case for Social Robotics

Developments in robotics today are simply astounding. While we aren’t quite at the level of creating androids known in Philip K. Dick’s Do Androids Dream of Electric Sheep?, we’re making advancements in other areas. We have dancing robots representing nations, Hanson Robotics and Hiroshi Ishiguro Laboratories recently debuted Sophia, a synthetic android, and Boston Dynamics made headlines with its Atlas prototype, showing the robot squat, move objects, and pick itself up after being knocked down.

One field that’s currently burgeoning is social robotics, where robots are designed as autonomous humanoids capable of interacting and communicating with humans. The applications are varied, with one in particular being that robots, when designed and implemented appropriately, can make for excellent communication and education intermediaries for children—and adults even—with special needs.

It is known that children with developmental disorders—especially children with autism—feel comfortable around robots as their actions are more much predictable than humans. And it’s not just humanoid robots—some studies (Kozima, Nakagawa, & Yasuda, 2007) show that designs that mix human characteristics (such as eyes or human-like movement) with simple robotic elements facilitate lasting engagement. A robot is programmed to respond in a certain way, and to an extent their reactions are limited—at least, when employed in a therapy setting, they should be! Children with autism and other developmental disorders tend to shy away from other children and caregivers for the simple fact that humans are unpredictable—and what one cannot predict they fear. With robots, it’s all preprogrammed, and children learn that certain inputs will always yield certain outputs, making the robot an approachable and curious tool to capture the attention of children.

And attention is key—without it, breaking through and making progress with a child is nearly impossible. Kids love toys, kids love gadgets, and when designed properly, a robot is a toy. Suddenly, children are no longer dreading sessions with a therapist—they’re looking forward to playtime. Securing interest, however, is only half the battle. Social robots, when employed in a therapy environment, need to engage children effectively in order to build on progress and help children become the exceptional people that they are. Interactions between a child and any robot must be guided by a professional. When guided, they can be used towards motor skill, social, communication, and spatial awareness development. In short, games or activities should be constructed around the use of a robot to reinforce a child’s social and cognitive learning.

We also cannot forget that, if technology in the form of a robot is used as a tool in therapy, it is also likely capable of collecting data on child-robot interaction—which is key. It’s an added benefit to the use of social robotics, as while a robot can be

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attends medical appointments and receives medical attention as needed, but also goes to the store with her parents and to the park. For a single working mother with an adult son who is capable but is fearful for him to be out of her sight: showing her how he can independently help out in the home and complete chores that he just does not have the time in the day to get to herself. She and her son now have more time available to go out to the store together and he can make his own lunch, rather than his mother having to come home from work to make him something to eat.

These area a few real time case examples of the power of Applied Behavior Analysis (ABA) done well. Lives changed and destiny shaped. The work itself is rigorous. The rewards of seeing the changes described above are extraordinary. The task confronting us as a field now is to take what we know, and that is considerable, and foster an environment that recognizes best practices and aligns reinforcement to providers willing to step up the plate and take a swing at doing behavior programs that create accountable progress.

As professionals in the field, there are times when the need shifts by identifying that the needs of the adult or child we were brought in to help are directly related and an effect of the needs of the family. At the end of the day, families and caregivers are the ones that must maintain the improvements and live in vivo with the treatment effect. When they feel supported and understood, positive effects are highly likely on the day-to-day life and opportunities for the adult or child with disabilities we serve.

Amanda Duva, BCaBA, is a Behavior Intervention Specialist and Terry Blackwell, BCaBA, is Chief Operating Officer at Services for the UnderServed Inc. For more information, contact Vivian Attanasio at vattanasio@sus.org or visit www.sus.org.

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After the diagnosis for the father, there is a parallel to Goodman’s phases. During the first phase, the father still has the desire for an emotional involvement and deep connection to the child. Reality needs to be confronted that the degree of involvement and his emotional connection to the child is in jeopardy. The expectations he originally had for this child may be unrealistic. The dad has feelings of frustration, disappointment, guilt, helplessness, and inadequacy to be able to “fix” this problem. In the next phase, he must alter the expectations, establish new priorities, redefine his role, negotiate with his partner, learn to care for this child with autism, realize the increase in the needs for this child, and may struggle for recognition of his contributions. The final phase, reaping rewards, has some uncertainty, similar to when this child was a newborn. There is a new sense of meaning, and completeness and immortality needs to be redefined. Much like the arrival of a newborn was a life-altering event, the diagnosis of autism is life-altering. The key is moving beyond the crisis to taking on the challenge.

So parents of newly diagnosed children, I give you the advice that I give new mothers: (1) Take care of yourself. You need to have your needs met in order to be available to your child; (2) Give love and attention to the siblings so there is no resentment or jealousy; (3) Maintain and nurture the relationship with your partner. You will need their support and love; and (4) Do not create a job no one else can fill. You may know your child the best, but others can help and lighten the load.

Like the birth of a child, the diagnosis of a child with autism gives rise to an intense devotion to your child. The newborn and autism can become the center of your universe. Just remember, if you make this child the center of your life, you will lose those relationships with everyone around you. Make the needed adaptations. The road will be easier if you are not alone.

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www.mhnews-autism.org
participation in community events (Lee, Harrington, Lewis, & Newschaffer, 2008). These limitations were also present when families attempted to engage in recreation and leisure activities, such as the need to extensively prepare for simple trips, a lack of free time to relax, and great difficulty taking family vacations (Hutton & Caron, 2005).

Siblings of individuals with ASD are also negatively affected by the extra responsibilities of their brother or sister’s needs. They have reported concerns regarding safety, additional caregiving responsibilities, and limited access to their parents’ attention (Harris & Glasberg, 2003). Yet, when parents perceived the burden to be high, the formalized care of the child with autism (as they often must be), they may have limited availability to meet the siblings’ needs (Abelson, 1999).

Not surprisingly, parents are at risk of both physical distress (e.g., poor sleep) and psychological distress exacerbated by extreme stress, anxiety, fear, and guilt. Marital difficulties, fears about safety, and financial worries over autism intervention are just a few of the specific concerns frequently shared in the literature. Of most concern is the possibility of a higher risk of abuse and neglect as well as the impact of parenthood of all children in the family (Abelson, 1999). Clearly, there is a “body of evidence documenting marked quality of life decrements in families of children with autism” (Lee et al., 2008, p. 1158). Services for alleviating these stresses are warranted to mitigate potentially damaging effects on both individual family members and the family unit (Manning, Wainwright, & Bertness, 2011).

While there are few well-controlled studies on the effectiveness of respite, many studies have evaluated parents’ perceptions of the support respite offers. Chan and Sigafoos (2001) concluded that use of respite care was associated with reduced parental stress in a majority of participating families. There is a clear consensus that parents who have more support available to them report reduced stress (Harrington & Caron, 2005). Furthermore, while the primary benefit of a respite program is to allow parents a break, it can be extremely rewarding, it may also produce stress and fatigue. These side effects may impact relationships between respite providers, families, and individuals with autism as well as other aspects of their lives. Although it may seem there is never enough time, taking care of oneself should be considered a priority in order to be able to care for anyone else. Making time for yourself, participating in stress reduction activities like exercise, and utilizing respite when necessary are a few ways to stay strong and committed to this important role. Effective respite provision may afford the opportunity to take care of oneself more easily.

Families may wish to have a basic training tool and share essential information about their loved one with autism by using the Individualized Respite Care Guide: A Resource for Families and Providers, available free of charge. Download at www.autismnj.org/publications or call 800.4.AUTISM to obtain a copy. It is designed to be of use whether you are a professional, an extended family member, or friend. This guide and the family/provider communication forms may be used as one component of a comprehensive respite provider training program.

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References


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Liberty POST is approved by the New York State Education Department and the New York State Department of Health to provide professional services to children ages birth to 5 years old for evaluations, special education, speech-language therapy, occupational therapy, physical therapy, social work, service coordination, and audiometry. Liberty POST clinicians possess significant experience and expertise in providing ongoing therapy services and evaluations, in group and individual settings in the clinic, homes, daycares, and preschools. They work in a collaborative model to provide services to children with developmental delays, behavioral challenges, and a wide variety of diagnoses among them: Autism Spectrum Disorder, Down Syndrome, Cerebral Palsy, Muscular Dystrophy, medical conditions, prematurity, and apraxia.

About Liberty Resources

As one of Central New York’s most diverse and trusted human service agencies, Liberty Resources is well established as a leader in providing services in many areas: mental health treatment, substance use disorder (SUD), services to individuals with intellectual disability, community-based children and youth services, and early childhood diagnostic and pediatric therapy services. Headquartered in Syracuse, New York, Liberty Resources employs over 1,000 professional staff providing shelter, treatment, assistance, counseling and support to nearly 12,000 individuals and families. Providing an array of services to individuals, children and families, Liberty Resources strives for excellence in all areas – as an employer, service provider, and a corporate citizen of the communities served – across New York state, as well as a significant presence in Texas. For more information, visit http://www.liberty-resources.org.

About Liberty Post

Liberty POST offers high quality early childhood diagnostic and pediatric therapy services (psychology, physical, occupational, speech therapy) for children from birth to age 5. Liberty POST is a partnership between Liberty Resources, Inc. and private early childhood providers. With licensed and/or certified professionals in all areas of development, from physical to mental and emotional, Liberty POST has the expertise to help children, and families, discover and reach their fullest potential. For more information, visit http://liberty-post.com.
Keeping It Together When Faced with an Autism Diagnosis

By Laura Henderson, MA, BCBA and Nicole Pelliciari, MS, BCBA

CNNH

Your child has been diagnosed with Autism—now what? Many parents feel as though they are finally able to answer some of the questions they have had regarding their child, but still feel confused, overwhelmed, and frightened about what to do next. Parents are their child’s best advocate and have the most to be fully informed of what the appropriate next steps are.

Next steps can be confusing and overwhelming when presented with a variety of approaches that have been found useful in treating individuals with an autism diagnosis. Parents may be faced with various recommendations, such as ABA therapy, speech therapy, feeding specialists, neurologists, etc. However, being unfamiliar with these areas of treatment, where they are located, and who should provide each service, can be daunting to a family with a newly diagnosed child. It is common for families to be given a list (aka “the list”) of resources that they can independently reach out to. However, scheduling the appropriate evaluations can be time consuming, intimidating, and, sometimes, defeating. In addition to seeking out and understanding treatment, medical insurance is a key factor in this equation. This is a significant consideration when attempting to get treatment services for your child or your spouse, overeating, staying in bed all day, etc.

Getting “hooked” by unhelpful and unproductive thoughts and feelings may lead parents astray from whom they want to be as a parent. Likewise, this will likely become unhelpful and unproductive for their child with ASD. Thus, it is easy for parents to slip into becoming the parent they swear they never were going to be when experiencing stress, etc.

There are various ways to foster greater PF, specifically among parents of a child with ASD. Within the ACT model, we can use the ACT matrix based on Dr. Kevin Polk’s protocol (2014). The ACT matrix helps clients identify thoughts, feelings, sensations, values, and behavior through noticing and sorting. When using the matrix, we notice what shows up by acknowledging it and then sorting if the experience is within our outer experience (i.e., in the world of the five senses, something that we can see, hear, touch, taste or smell) or within our inner experience (i.e., in the world of the mind or language which includes our thoughts, feelings, beliefs). For example, inner experiences may include the thought, “It is my fault that my child has no friends” or “It is so unfair that my child has ASD.” This contrasts the outer experience such as noticing the behaviors you are displaying when you are with your child, your spouse, your child’s teacher or therapist, your own behaviors when experiencing stress, etc.

Additionally, the ACT matrix can help the parent sort whether their behaviors are associated with the experience of moving in the direction toward what they value (i.e., that which they have identified as important and meaningful to them) versus behaviors associated with moving away from the discomfort and stress associated with unwanted internal experiences. Examples of the former may include sitting and reading with your child, modeling and reinforcing desired social skills, scheduling and attending therapy appointments, scheduling a play date for your child, working out at the gym, getting a restful night sleep, remaining calm, etc. Conversely, behaviors that may move one away from what is important and away from comfort may include yelling at your child, arguing with your spouse, overeating, staying in bed all day, etc.

Getting “unhooked” by unhelpful and unproductive thoughts and feelings may lead parents astray from whom they want to be as a parent. Likewise, this will likely become unhelpful and unproductive for their child with ASD. Thus, it is easy for parents to slip into becoming the parent they swore they never were going to be when experiencing the stress associated with raising a child with ASD. For example, parents may think, “This intervention is too hard,” or, “Life is so unfair, why do I have to do this,” leading them to temporarily try the intervention or implement it with a consistent integrity. Alternatively, it is important to slow down, be mindful by noticing how their thoughts try to push them around and prevent them from doing what is valued by them (i.e., helping their child), and be present in the moment.

There are various ways to become more psychologically flexible and therefore become “unhooked,” including using relaxation techniques (taking a deep breath from the belly and pressing your feet firmly into the floor; slowly “smelling the pizza” and slowly “blowing out the candles”); talking about their thoughts and feelings with a confidant (spouse, friend, therapist); looking at the situation with humor; acknowledging and accepting that while there is currently no cure for ASD, there is a lot they can do to demonstrate care, support, and steps to help their child improve their skills; assist their child who may be showing an interest in artistic expression; noticing which of their child’s characteristics are extremely difficult or impossible to change and focusing on what they can do to help their child improve; etc.

In this manner, those working with caregivers to increase PF may help parents gain greater perspective to avoid reacting to a stressful situation, respond more creatively, increase their own mental health, and enrich the relationship they have with their child.

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References


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family member.

Upon receiving “the list,” how does one go about identifying appropriate service providers who are ethical, effective, and within a reasonable proximity to their home? Often times, parents share they will “Google” treatment providers, seek out feedback from other parents, or use various online “medical” resources that can be found on the internet. We advise our families and families reading this article to reach out to resources, which can provide information that is both ethically sound and legally correct. In the state of New Jersey, for example, we often utilize the following parent advocacy groups SPAN (Statewide Parent Advocacy Network - http://www.spanadvocacy.org), FACES 4 Autism (http://facesautism.org), a support network for families with autism, Autism New Jersey, and Autism Speaks. Each of these resources have clinicians, volunteers, and team members who are well versed in the diagnosis of Autism and who can assist in the process of attaining ethical and effective treatment.

Sometimes, having a diagnosis and knowing where to seek out ethical and effective treatment can bring relief. Along with relief, diagnosis coupled with where to attain treatment can bring awareness to matters that were questionable. A diagnosis can lead parents to an appropriate treatment plan. This treatment plan may begin as young birth through the 3 months and see Diagnosis on page 32.
Recreational Skills - Recreational skills typically involve an individual’s engagement with objects, activities, people, places, or things that are interesting, rewarding, relaxing, or enjoyable. For most individuals, recreational activities are acquired without specific training as a part of typical development. Exercising (e.g., running), playing games/sports (e.g., bowling, soccer, playing “Tag”), or interacting with preferred items (e.g., playing video games or reading a book) are learned by most without any specific teaching. Alternatively, individuals with intellectual disabilities may require formal teaching strategies to develop repertoires of appropriate leisure-time activities.

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to a decrease in stress and thus a healthier life both physically and psychologically for these individuals.

One known stress reliever is taking respite vacations. Results of numerous studies reveal that family vacations contribute positively to family bonding, communication and solidarity (Lehto, 2009). Studies have also shown that families with special needs are limited in these vacation opportunities (Amet, 2013), thus lessening the amount of recreational activities and family interactions. This increases the amount of stress among these families with special needs. While few experiences may exist, many barriers inadequately influencing the quality of these vacations also exist. Amet’s 2013 study categorized these barriers into five areas: 1) child’s disability, particularly with regard to behavior, 2) lack of suitable holiday structures, 3) financial limitation of the family, 4) lack of empathy from surrounding communities towards the disabled child and his or her family, and 5) general state of exhaustion of the parents (Amet, 2013).

The Autism on the Seas Foundation is embarking on a new scientific study aimed to investigate the effect of the organization’s vacation experiences on families with special needs, with specific regard to alleviating the aforementioned barriers with respect to quality of life, family solidarity, and stress. This study will consist of a survey containing both Likert-type scale and open-ended questions regarding the Autism on the Seas vacation experience. The survey will be distributed to vacationers post vacation.

Further research of the Autism on the Seas Foundation hypothesizes that, by alleviating the aforementioned barriers, the Autism on the Seas vacation experience will have the following effects on parents of individuals on the spectrum:

1. Increase quality of life for families with special needs - self-efficacy skills in participating in recreational/community activities with their child
2. Create a social network for families with special needs
3. Create a positive family bonding experience thus alleviating stress for families with special needs

We believe it is critical to provision accommodating vacation options and programs for families with special needs that feature:

1. A unique opportunity for families with special needs to vacation with adequate support from professional volunteers, thus alleviating stress levels with regards to behavior stated in barrier 1
2. A unique opportunity for families with special needs to travel in Autism-Friendly Certified structures, thus alleviating the lack of suitable holiday structures stated in barrier 2
3. A unique opportunity for families with special needs to travel with the assistance of multiple grant programs (provided by the Autism on the Seas Foundation), thus alleviating some financial limitation stated in barrier 3
4. A unique opportunity for families with special needs to travel with the support of one another, thus creating a social network for these families, thus alleviating the lack of empathy from surrounding communities towards the disabled child and his or her family stated in barrier 4
5. A unique opportunity for families with special needs to travel with trained and professional volunteers who offer many respite sessions, thus alleviating some of the general exhaustion of parents stated in barrier 5

Alyssa Soohoo, MAT, is a Doctoral Student at Teachers College, Columbia University and Board Member of the Autism on the Seas Foundation.

Autism on the Seas (AotS) was founded in 2006 as a niche travel company that organizes and staffs cruise and land resort vacations for families and adult guests with special needs, including autism spectrum disorders, Down syndrome, cerebral palsy, and other cognitive and intellectual developmental impairments. For more information, visit www.autismontheseas.com.

References


Liberty Resources Announces Expansion of Service Area Through Recent Acquisitions

By Staff Writer

Autism Spectrum News

Liberty Resources, parent company of Liberty POST, announces the recent acquisition of Manhattan-based Watch Me Grow, a pediatric sensory gym and speech language center. This addition demonstrates Liberty Resources’ commitment to expanding the interdisciplinary team approach to early childhood diagnostic and related therapy services throughout New York State.

Liberty POST is the largest provider of childhood diagnostic and pediatric therapy services for children from birth to age 5, in the state, offering services in Buffalo, Rochester, Syracuse, and the Hudson Valley region, and now New York City. Liberty POST is a division of Liberty Resources, one of Central New York’s largest human service agencies, providing a wide array of services to clients and families across New York State and in Texas.

“Liberty POST has been a people-centered provider of special education and related therapy services for more than five years,” states Liberty POST President John Torrens, PhD. “The addition of Watch Me Grow enables us to leverage the tremendous capabilities of Liberty Resources to expand our footprint and deliver services in a more cost effective way.”

John Torrens, PhD
President, Liberty POST

Shirael Pollack, MSPT
ED and Founder, Watch Me Grow

Watch Me Grow will continue to offer center-based, school-based and in-home therapy, evaluations, as well as group programs including social groups and camps, at their two Manhattan locations (Upper West Side and the East Village).

The day-to-day operations of Watch Me Grow will be continued to be led by Executive Director and founder Shirael Pollack, MSPT. Pollack, a Goldman Sachs 10,000 Small Business program alumni, has decades of experience as an operator in the pediatric physical therapy industry. She will also be responsible for acquiring and opening new pediatric therapy centers both locally and regionally.

“The affiliation with Liberty Resources provides us with the resources to serve more families and special needs children with a larger platform of therapies and settings,” said Pollack. “I am delighted to be working with John Torrens, the Liberty POST regional directors, and Liberty Resources management team improve and increase our services and offerings to the pediatric community in NYC and beyond.”

Liberty Resources has also recently purchased Rochester-based Communication Center for Hearing and Speech. These acquisitions add nearly 100 professional staff to the more than 1,000 Liberty Resources workforce.

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Job Skills from page 15

It is also beneficial to coach the individual on how to manage unexpected situations. Often the stress of a transition or unexpected occurrence can contribute to difficulties in self-regulation, particularly in those with ASD (Moyer, 2011). Poor self-regulation during an unanticipated work event can hinder job performance and at its worst, result in termination.

Practicing how to respond appropriately in these situations can begin in the early years. While these skills may already be developing for school settings, a caregiver can demonstrate how an employer may expect their staff to respond in a professional setting. Identifying possible stressors and coping mechanisms can reduce the likelihood of inappropriate responses and behaviors in the workplace. Often these can be similar to the coping mechanisms the child is utilizing in his or her school setting. Problem-solving skills will be useful in the world of work, as employees are likely to encounter issues which need to be resolved quickly and with as much assistance (Scott et al., 2015).

Being mindful of stimuli in any potential work environment is helpful as well, as an environment with a lot of sensory stimuli can cause a distraction and influence the individual’s ability to complete the tasks as assigned. Identifying how the child or young adult can manage an uncomfortable transition or distraction at work can help decrease anxiety, resulting in a more comfortable and confident employee.

Additionally, difficulty navigating social interactions in the workplace continues to hinder the work performance of employees with ASD (Lorenz et al., 2016). An individual’s ability to professionally communicate verbally and nonverbally with their supervisors and colleagues greatly influences the likelihood of maintaining employment, particularly amongst those with ASD (Brown & DiGaldo, 2011). Further training in these areas can be provided by demonstrating how interactions differ in the workplace versus between friends or acquaintances. Role-playing these interactions and allowing the child to see how social and professional interactions differ can be helpful in teaching professionalism. Practicing how an employee might approach a customer or a supervisor can be done via role-plays and by displaying the appropriate behavior. These interactions should be practiced often to instill positive, professional behaviors in the same way that mock interviews may later be utilized.

Further, sharing experiences from one’s own professional environment can expand the child’s knowledge of the expectations at work versus at home or school. It can be confusing for a child or young adult to determine why some behaviors are unacceptable in a work environment, but are fine in others. Providing examples as to why and what constitutes a professional can also enlighten the child to know what “being professional” actually means. This is especially important in terms of mirroring appropriate professional dress and hygiene. The child can practice identifying different styles of professional dress and its purpose.

Identifying the roles of employees at frequent establishments can begin to show a child what responsibilities are expected of staff and how the establishment is run with the support and work of each and every employee. The goal should be to generate excitement over future work opportunities and teach children and young adults about the value of all positions. It is recommended that caregivers pose questions to the child to generate thoughts about why the employees behave the way they do. Asking why a server checks in a mid-meal or why a sales associate asks if help is needed can generate discussions on what it means to be an employee. What is their role? This can also be a time to discuss the important of “soft” job skills, such as punctuality, a positive attitude, and work ethic. A child may be asked what he or she thinks might happen if their waiter or waitress took a long break while working or what might happen if a store’s staff were late to open the store. Understanding the cause and effect of these actions can further introduce the important of soft job skills and how they affect others. Providing feedback and praise to a child who can identify staff members and how they contribute to the business is likely to result in positive feelings about the workforce. Thinking early on about possible job interests can make planning for the future that much easier.

While navigating the path to employment can be challenging at times, caregivers can provide support beginning early on which can be continued as their loved one prepares to enter the competitive workforce. While the statistics on employment for those with disabilities can be daunting, the research also indicates that the acquisition of business etiquette, task-by-task checklists, and soft job skills greatly influence whether an individual will remain successfully employed (Scott et al., 2015; Lorenz et al., 2016). By promoting these skills early on, caregivers can provide support and take additional steps towards the future success of their loved one.

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References


As the nation’s leading evidence-based publication for the autism community, *Autism Spectrum News* provides an affordable and cost-effective opportunity to reach a large targeted autism readership with an immersive community distribution in print in addition to a fast-growing online readership.

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For more information, please contact David Minot at (508) 877-0970 or dminot@mhnews.org
of individuals supporting children with ASD (Catania, Almeida, Liu-Constant, & Reed, 2009; Digennaro-Reed, Coddig, Catania, & Maguire, 2010; Leblanc, Ricciardi, & Luiselli, 2005). Video modeling and feedback can be delivered remotely and conveniently. At Rethink, an educational technology company that provides web-based resources to educators and parents, we’ve been able to work with parents across the world, providing them with opportunities to not only watch/mimic short clips of skilled clinicians teaching a myriad of skills, but also to deliver teleconsultation to provide feedback on their therapeutic skills (live or taped), clarification/redirection during incorrect performance, reinforce progress, and assist with objective progress monitoring. When parents learn to promote skill acquisition and effectively address inappropriate play behavior or communication, play dates, trips to the grocery store, and everyday family life become a reality.

Due to successfully reaching and supporting a wide range of families through Rethink, we began partnerships with companies, large and small, to offer the resources and tools to their employees. Parents of children with ASD and other developmental disabilities are now able to access parent training and participate in individualized parent coaching via teleconsultation at no cost to the employee and no eligibility requirements. Why bridge this gap between parent training and employers? In the age where ABA services are still costly and difficult to acquire, this model provides an opportunity that many parents would not otherwise have. Both employers and employees experience the impact on job performance, attendance, and overall bottom line due to the demands and stress of having a child with ASD. Caring for a child with a developmental disability can lead to up to 250 hours of lost work time and $3,000 - $5,000 in lost productivity. As it relates to employment decisions, 58% of parents surveyed did not take a job, 23% did not take a promotion, and 53% worked fewer hours to accommodate needs of their child (Baker & Drapela, 2014; “Therapies for Children with Autism Spectrum Disorder,” 2012). Ironically, Baker and Drapela (2010) found that workplace participation is actually associated with increased social support and decreased feelings of isolation, improved self-esteem, and an identity outside of being a parent of a child with a disability. If employment is a protective factor, something needed to happen to address this predicament experienced by so many parents.

Rethink is doing with employers, contact Rethinkbenefits.com, (877) 988-8871, or visit www.rethinkbenefits.com.

References


CDC Funding from page 21

data. Finally, CDC will fund a site to work jointly with CDC to design and conduct a brief follow-up study of children enrolled in the first phase of SEED (SEED 1). The follow-up study will help CDC researchers better understand the long-term health and development of children identified as having autism at younger ages. The children from SEED 1 will be teenagers at the time of the follow-up study. “This SEED 1 follow-up study is an important first step in ensuring that we have the necessary information to support children with autism as they grow into adolescence and adulthood,” said Dr. Moore.

Awardees*

• University of Colorado Denver/Anschutz Medical Campus (SEED 3)

• Johns Hopkins University (SEED 3 and also central laboratory and biorepository)

• University of North Carolina at Chapel Hill (SEED 3 and SEED 1 follow-up study site)

• NEW: Washington University in St. Louis (SEED 3)

• NEW: University of Wisconsin System, Board of Regents (SEED 3)

• Michigan State University (SEED Data Coordinating Center)

*CDC serves as a site for both SEED 3 and the SEED 1 Follow-up Study

To learn more about ASD, please visit: www.cdc.gov/autism. To learn more about SEED, please visit: www.cdc.gov/SEED.

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used as a tool, it can also be used as a measuring device to monitor progress over time. Robots can be outfitted with a variety of sensors to track how children touch and manipulate a robot, how long it takes for a child to respond to a question or action, or how long a child is able to maintain eye contact. This data can be tracked and shared with researchers as well to offer further insight into the potential role of social robotics in therapy.

Robots Over Humans?

The idea of using robots with children, particularly children with autism, isn’t an entirely new concept—it has been around for a number of companies today who operate in this still growing space. That said, it isn’t a field without its critics.

There’s a concern that if robots are used in therapy sessions, especially with children who are still developing their own identities, it could create a preference for robot interaction over human—which, yes, could be problematic. However, it’s important to note that a child’s use with a robot is guided. The robot is a facilitator, not the sole therapeutic conduit used in treatment. Research conducted by Kersdin Dautenhahn and Ian Werry (2004) of the University of Hertfordshire support this notion (and for more on this subject, read about the Aurora Project, an ongoing series of studies on the applications of robots as therapy tools for children with autism).

Unlike an iPad, a robot, especially one that encourages interaction via games and activities, is grounded in use by its immediate environment. When used side-by-side with a therapist, the human element is still present, and when used as a toy with other kids, the human element becomes even more prominent. Children in today’s age are digital natives, born in an era of ubiquitous technology, and the use of robotics opens a gateway to communication with other humans. Robots don’t replace human interaction—they supplement it.

To kids, robots are toys, and if they’re able to facilitate treatment and bring children together to play activities, and are proven to be effective therapy tools, then we should consider incorporating them into standard practice for children with developmental disorders. What do we have to lose?

References
Empowerment from page 6

to get agency administrators or legislators to listen to me.”

Data from 69 parents (42 mothers, 27 fathers) who participated in the program between July 2014 and April 2016 were included in the present study. All parents had a child with ASD between the ages of 18 months and 9 years who had been diagnosed with ASD within approximately the last year. Analyses first examined how parent empowerment was related to parenting stress and family quality of life. Correlations indicated that parenting stress was negatively associated with parent empowerment related to the family (r = -.70, p < .01), parent empowerment related to child services (r = -.32, p < .01), and parent empowerment related to community involvement (r = -.35, p < .01). This suggests that parents who report higher levels of empowerment reported lower levels of parenting stress. A multiple regression demonstrated that empowerment related to the family was most closely associated with parenting stress (β = -.69, p < .01). After accounting for empowerment related to family life, neither empowerment related to child services nor community involvement accounted for any additional variance in parenting stress.

Next, analyses examined whether parents reported higher levels of empowerment following participation in the parent education program. Paired samples t-tests indicated that parents reported higher levels of empowerment on all three subscales following the program compared to prior to their participation, indicating that empowerment related to family life, child services, and community involvement all increased (See Figure 1). Due to the absence of a control group in the present study, this increase in empowerment cannot be directly attributed to parents’ participation in the program. However, future research may be directed at answering this question.

The present study documented relations among parenting stress, family quality of life, and parent empowerment. In particular, higher parent empowerment is associated with lower levels of parenting stress and higher family quality of life. Parent empowerment specifically related to family life was most closely associated with parenting stress and family quality of life, emphasizing the importance of parents’ perceptions of their own abilities to manage the day-to-day challenges often associated with parenting a child with ASD.

Further, the present study provided preliminary evidence that parent empowerment increased over the course of an education program focused on providing information about ASD, interventions, and services.

The results of the present study must be considered preliminary, as no control group was included in the design. As a result, it is not possible to conclude that parent empowerment increased as a direct result of the parent education program. In addition, because parenting stress, family quality of life, and parent empowerment were all measured at the same time, it is not possible to conclude that one causes the others. However, the present study does suggest that parent empowerment may be a useful target of intervention. It is possible that enhancing parents’ empowerment – that is, their perceptions of their own abilities to manage the demands of parenting, accessing services for their child, and advocating within the community – may have a positive impact on their quality of life and levels of stress. Future research more closely examining these questions is an important step in improving the lives of children with ASD and their families, particularly in the often overwhelming time following an ASD diagnosis.

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For more information about this research, contact Laura Corona at lcorona@albany.edu.


siblings from page 9

Only one condition examined in the study, substance abuse, is not associated with autism. Most siblings of children with autism were diagnosed earlier than the siblings of controls. “If you’re a parent of a kid with autism, you’re going to be more attuned to a variety of behavioral abnormalities,” Brown says.

If clinicians were to systematically look for signs of other conditions in these siblings, they might spot them even sooner, says Stelios Georgiadis, assistant professor of psychiatry and behavioral neurosciences at McMaster University in Hamilton, Ontario, who was not involved in the study.

It would be interesting to assess whether early diagnoses in these siblings will have ten access to treatment and improve their outcomes relative to the siblings of controls, who receive a diagnosis later, Georgiadis says.

Stable Estimates

The “impressive” number of participants sets the new work apart from previous analyses, says Sally Ozonoff, vice chair for research in psychiatry and behavioral sciences at the MIND Institute at the University of California, Davis, who was not involved in the research.

Using a nationally representative sample rather than recruiting families, the researchers skirted possible bias toward more severely affected families, who are more likely to participate in autism research, Ozonoff says.

The new study offers “stable and valid estimates of the prevalence of psychiatric and neurodevelopmental disorders in the siblings, which is really helpful,” she says.

Registry data aren’t perfect, however. Some of the siblings might have had conditions that went undiagnosed, particularly because diagnostic criteria for autism have changed over the years, Ozonoff says. The researchers also did not independently confirm the diagnoses.

These factors, Ozonoff says, may explain the markedly low rate of autism in the siblings of children with autism. Only 10.5 percent of these siblings had an autism diagnosis in the study, compared with an earlier estimate of 20 percent for the younger siblings of children with autism.

Reducing Stress from page 20

care is carried according to the wishes of the individual and family.

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Brown’s team plans to tap into the Finnish registries again to see if any of the undiagnosed siblings received a psychiatric diagnosis later in life. “These siblings are quite young. It may be that we see bigger effects over time,” Brown says.

This article was originally published on Spectrum and is reprinted with permission. You may view the original article, published 23 June 2016, at https://spectrumnews-autism.org/news/psychiatric-problems-common-in-siblings-of-people-with-autism/.

References

Family-Centered from page 11

structured discrete trial (DT) interventions with limited parent involvement. The goal of the CADB program is to create a combined parent and child approach to empower parents while providing evidence-based practice to the child. This intervention takes place in group and individual settings at both the clinic and the child’s home with the goal of improving the child’s social communication, imitation, play skills, motor skills, personal independence, and behavior.

Components of the Intervention

Group classroom setting - Intervention is provided at CADB in a group setting of 6 children, for 6 hours per week. This is in an effort to replicate and extend research published on the effectiveness of ESDM in group preschool settings with peers (e.g., Vivanti, Dissanayake, Zierhut, Rogers, & Victorian ASELCC Team, 2013; Vivanti, et al., 2014). Children follow a program of small and large group activities including art, gym, snack, and toy play. Each child’s individualized objectives are embedded into the teaching within these developmentally appropriate activities, and teaching is carried out by a team including psychologists, educators, speech-language pathologists, occupational therapists, and interns/externs. Parents observe the classroom sessions through a one-way mirror to learn strategies to carry forward outside of the classroom setting.

Individual intervention - Individual child and family sessions are also provided to improve the child’s skills across all domains of development. In this way, parents are supported in carrying out embedded teaching within their family’s daily routines. Parents and caregivers spend 3 hours per week in parent coaching sessions with a therapist and their child, observing and practicing naturalistic teaching strategies. These sessions take place weekly in both the clinic and the home settings. The goal of this time together is for the clinician to work alongside parents and caregivers to teach strategies that they can embed in their child’s natural daily routines in the home and community, such as mealtimes, book reading, and playing outdoors. For example, during a bath time routine, the therapist might show Allison’s parents how to get Allison to look at them and make sounds to request before pouring warm water from a cup onto her open hands, which she enjoys. During this same bath routine, the therapist may also work with Allison’s parents to teach Allison how to take off her own socks before bath time, and to tolerate nail cutting.

Related services such as speech and occupational therapy are also part of the CADB program, if a child qualifies for these services through the EIP.

Family components - Parents of children in the program also participate in a weekly support group and a weekly psychoeducational group session. Psychoeducational sessions led by a psychologist are used to share information with parents including about ASD symptoms, intervention options, use of visual supports, and how to manage challenging behavior. Psychoeducational sessions are also aimed at increasing parent competence in supporting their child’s continued development and in advocating for services to further their child’s growth.

Support group meetings focus on discussion topics of importance to the families and are facilitated by a psychologist or social worker.

Transitions and Maintenance

As children and families complete the 6 month program, they are provided with assistance in transitioning to other local services, whether they are continuing in the EIP or transitioning to a special education preschool setting through the Committees on Preschool Special Education (CPSE). Following their 6 month participation in the intensive EIP, families are invited to attend weekly hour-long parent and child groups that are held simultaneously in order to continue to provide psychoeducation and support to parents, and group-based intervention to the children.

Future Directions

We are currently developing a research study to examine the feasibility and effectiveness of this community intervention program. Pilot data have shown treatment effects in all child developmental domains, with largest gains in the areas of language, play, and behavioral regulation.

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must be taught what to do during an abuse and some strategies for evading abuse as well. Both should become knowledgeable about steps that should be taken immediately following an abuse experience, for the best possible outcome for the victim and the family members.

Using the before, during and after format, and practicing the IRP skills monthly, individuals and families (and other care-giving situations such as foster care, group home living, independent living) can enhance their safety. And, if abuse does occur, can enhance their well-being even though it happened. It is most likely not possible to eliminate abuse as an individual or family member with planning and creating strategies for increased safety, the reduction of risk is a worthy goal.

Diagnosis from page 25
continue on through the school age years. The act known as IDEA (Individuals with Disabilities Education Act) was initially developed in 1975 to ensure free and appropriate education for children with disabilities and is federal law. The act was revised in 2006 to include Part B covering school-aged children through adults up to age 22 years. IDEA was revised a second time in 2011 to include Part C covering infants and toddlers through three years of age.

In short, IDEA, Part B provides parents with their rights as the parent of a child with special needs to be informed of and included in the evaluation of their child, academic placement of their child, and meetings regarding their child’s progress and development. Part B indicates parental consent is required in order for services to be offered, maintained, or stopped. IDEA, Part C states families of children with developmental disabilities are entitled to an evaluation to determine eligibility for an individualized family support plan (IFSP) as well as early intervention services that include a variety of developmental goals for their child including but not limited to communication, fine/gross motor, and self-help. Additional information on IDEA may be found at http://idea.ed.gov.

Outside of IDEA families may require private services in the form of ABA therapy, speech therapy, physical therapy, or occupational therapy where insurance may or may not be utilized or the treatment may fall under the category of a “non-covered service”. Related services for individuals with an autism diagnosis are often covered on a weekly basis. In turn from week to week families may be facing high co-pays, high deductibles, or costly self-pay fee schedules. Parents are often paying hundreds, even thousands of dollars, for services with providers whom they trust or to wait for appointments through their in-network provider, which may have providers that are not as experienced or have the rapport with the child. It is not uncommon for families to share with us they have experienced sleepless nights worrying about receiving appropriate and effective treatment and covering the cost of these therapies.

Families should contact their health insurance companies and speak with a representative knowledgeable about their particular plan, as well as the services the insurance offers for the specific diagnosis. Families are also encouraged to reach out to the billing department in the organization where their child is receiving treatment, as these individuals may have contacts within the designated insurance company who can efficiently assist with the process. Families can also independently contact board certified clinicians at the BACB (Behavior Analysis Certification Board) via the board website www.BACB.com. The site lists credentialed clinicians, their contact information, and their location. Families can search by clinician name, zip code, state, or country and inquire as to what costs for ABA therapy are, as well as, if they are covered by insurance.

Once a provider is located, families are encouraged to ask the clinician/team about his/her experience, as not all individuals credentialed in ABA or other related services have the same experience or specialties. Parents are encouraged to convey concerns to the therapist and be an active member of the child’s treatment team.

The writers of this article are Board Certified Behavior Analysts and would like to dedicate this section to helping parents know what to look for in order to create a successful ABA therapy environment. Parents please be sure the following are including in your child’s ABA therapy program:

- A positive rapport between your child, you, and their therapist.
- Time for “work” and time for “play.” Discrete trials should not make up the entire child’s programming. Children with autism require so much more, such as development of appropriate leisure skills, appropriately playing and interacting with family members, and successfully completing community outings.
- Observation of your child’s sessions with the therapist. This is an opportunity to see how your child interacts with the therapist and an opportunity for you to observe the therapist in order to generalize these skills across settings.
- Organized program goals, data collection to document goals, plans, behavior information, etc.
- Regular meetings (monthly, bi-monthly) with the therapist to review analyzed data and gain an understanding of what that data means for treatment and program implementation.

When a family is given a diagnosis of autism or other developmental delay, the individual(s) with the diagnosis often requires an abundance of care and attention. This can leave little time to spend with other family members such as other children or significant others. Parents often worry where they will find the time and patience for others. The ability to be flexible is a valuable skill. This means one parent must be prepared to leave an event while the other stays with the rest of the family, setting aside specific days and times to spend with other children in the family, setting aside time for yourself, designating time for you and your spouse or friends. If other family members do not reside locally, ask a friend or neighbor. Accepting the help and not making additional work for yourself is also important. For instance, do not clean up your house just because you asked a neighbor to watch the children while you run to the food store; run to the food store because the house will still be standing when you return home.

Parents also expressed significant concern for their children with special needs for when their children become adults there is no longer a guardian to care for them. Some of the parents we spoke with in preparing for this article are parents of non-verbal children or parents of children with limited cognitive abilities. Parents expressed fears of their child being taken advantage of, getting hurt, or simply not having their day-to-day needs met properly in a way that maintains their integrity. Preparation for the future was emphasized. Parents shared while it is “unsettling” and “scary” to think about, preparations such as guardianship and wills should be prepared even when the child is young. This is one way to assist in ensuring your child’s needs can be met to the best of your ability when you as the parent are no longer here to meet them.

This article has discussed quite a bit about therapies and services for individuals with Autism or other developmental disabilities. However, we also want to emphasize the importance of allowing time for yourself and your family outside of therapies. It is easy to get caught up in and focus solely on your child receiving as many therapeutic services as possible. Receiving appropriate and good quality services regularly is important. That said, it is important to maintain balance and understand quality of life for all family members is equally as important.

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This experience is painful, stressful and may result in parents feeling blamed for their child’s disability. Most educators will never walk in their shoes. Without this first-hand knowledge, how can we build understanding and empathy in educators? In order to create a more meaningful experience I developed what we now call our Expert Parent Panels. This is a group of dedicated volunteers who come each semester to speak with my students in various class settings, with the goal of reaching each cohort/group at least once in their training program. These parents are typically raising a child with ASD (and in some cases, more than one) and are interested in changing the course of assumptions and misunderstandings pre-service teachers at risk of making.

Panel Basics:
Preparation and Recruitment

Pre-service candidates are prepared for this experience by reading several assigned articles regarding best practices in collaboration as well as examining their own assumptions about collaboration with families of children with ASDs. Candidates come prepared with a set of individual questions that have been developed for the class session. Examples of the questions that have been posed by candidates as well as main questions asked by faculty to the panel are available upon request from the author.

Panel experts are recruited from a variety of sources including word of mouth, social media and personal/professional contacts in the community at large. The panel experts are typically highly motivated and come with various positive and negative experiences. Every one of them has a story to tell. They are not given any training other than a basic agenda of the panel as well as preparation for the questions they will be asked. This is intentionally done in order to preserve the uniqueness of the stories and input they choose to provide.

Panel Activities
Panelists begin together as a group and are asked to introduce themselves. This is moderated by the faculty in charge of the class. The panel members are then asked to share specific experiences where they felt collaboration went well, followed by experiences where things were less than successful. This first activity usually takes about 30 to 45 minutes depending on the size of the panel group. Panel members then break away with small groups of candidates for private interviews. The entire experience lasts approximately two hours. Candidates write a paper describing their findings as well as creating a plan for collaboration based upon panelist input, lecture and readings.

Mutual Benefit
The Expert Parent Panels have received positive reviews from both groups. In follow up surveys, candidates repeatedly identify this experience as one of the most powerful in their program. Many have written, post-certification, to report that they see parents much differently and work to advocate for better understanding and respect during collaboration. The panelists keep coming back due to the benefits they see from the process. They enjoy socializing with these new educators and have reported that this process has helped them to “heal and move forward in the parenting experience” with their child (Private Communication, Expert Panelist, 2015).

Moving Forward
Educators and families alike are called to collaborate in the process of educating children and young adults with ASDs. This process can benefit from understanding and empathy. Powerful articles and readings can contribute as well as input from educators and faculty who have experience. I would advocate that incorporating the voice and presence of parents and caregivers adds tremendous value to the pre-service training experience. While it certainly doesn’t mirror walking in the lived experiences of parents, it does go a long way toward better collaboration and rapport.

References


Legal Forms from page 13

so your family has proof of what was pro
bank or other institution, and keep that
stamped copy in a safe place, vided to the

Other common issue is that many
people execute a health care proxy nam-
ing an agent to handle their medical care
if they cannot do so, but they neglect to
have an open and candid discussion with
the person they nominate as agent about
their end of life wishes. Since the agent
would be the one to make such decisions
if you cannot communicate, it would be
prudent to let the agent know your wish-
es, and make sure that he or she is willing
and able to carry them out. Sometimes a
fail has an objection to the principal’s wishes
and would not carry out the wishes of the
principal. If you have the conversation with
the agent, you would hopefully become
aware of such an issue, and may want
to choose a different agent. However, if
there is no communication, you may not
realize that your agent would not carry
out your wishes. It is also a good idea to
discuss your wishes with the rest of your
family, not only your agent, to minimize
later discord.

We have seen people who have set up
supplemental needs trusts for their chil-
dren or other beneficiary who receives
public benefits, but who have not coor-
dinated their estate plan to ensure that all
the assets they intend to bequeath to the
beneficiary would go to the supplement-
nal needs trust. Some may have accounts
that are “payable on death” (“p/o/d”) or
“transfer on death” (“t/o/d”) to the ben-
eficiary, which mean that upon their
death, the accounts would be distribut-
ed directly to the beneficiary, and not to
the supplemental needs trust. This could
advise that the account is not transferred
into the trust, then the trust provisions do
not govern the co-op shares. It is import-
ant to have the correct trusts prepared,
but just as much care should be taken
to make sure that the trusts are prop-er-
ly set up and that the assets are titled
correctly.

One should look at the will, trusts, asset
list, how the assets are titled, the beneficia-
ry designation forms and other legal docu-
ments to make sure that the estate plan is
integrated, that all the documents work to-
gether, and provide for the results that one
wants to achieve.

Functional from page 26

Social Skills - An individual’s ability to
function in today’s community is, to a
large extent, dependent upon their ability
to interact with others. Social skills are
the skills necessary that facilitate interac-
tion and communication with others. Un-
der normal circumstances, social rules and
restraints are developed without specific
training. However, for individuals with
intellectual disabilities, specific teaching
strategies may be necessary to develop ap-
propriate social behavior, such as respect-
ing personal space, perspective-taking,
conversation skills, turn taking, sharing
with others, asking for or offering to help,
giving an appropriate greeting, and giving/-
accepting compliments.

Behavior Management Skills - The abili-
ty to be integrated into the community is
often directly dependent on the absence of
maladaptive behavior. Specifically, the
presence of problem behavior significant-
ly limits an individual’s ability to partic-
itate in functional activities. Effective,
fuction-based behavioral intervention
is imperative for improving outcomes in
individuals with intellectual disabilities.
Behavioral intervention should involve a
systematic plan that includes antecedent
strategies to prevent the occurrence of
problem behavior, the reinforcement of
alternative, pro-social behavior, and strat-
egies for responding to problem behavior
(e.g., extinction). In terms of functional
behavior management skills, individuals
should be taught to make choices and state
their preferences, functional communica-
tion, and self-management techniques.
A task for a break, attention, preferred items
and activities), in addition to various strat-
egies for managing their own behavior (i.e.,
self-management techniques).

It is important to note that this list of
functional skills is not all encompassing.
In fact, functional skills span a wide vari-
dy of domains, are specific to an individ-
ual’s natural environment, and are more
than just what an individual needs to sur-
vive. These skills are essential to achiev-
ing independence and can significantly
affect quality of life for both an individual
and their caregivers. More specifically, if
an individual is unable to perform these
skills, their rights of self-determination,
self-management, and self-advocacy are
limited, which can lead to the development
of restrictive environments with fewer op-
portunities for choice and produce greater
strain for caregivers.

Conclusion

The development of functional skills for
individuals with ASD is, arguably, one of
the most important goals for any parent or
practitioner, leading to immense benefits
for the individual. Individuals who have
learned functional skills have the ability
to be more self-sufficient than those who
have not. The acquisition of func-
tional skills affords more choices in life
and lessens the need for assistance.
Functional skill development allows the
individual to be more integrated with his
or her community and increases opportu-
nities for gainful employment and volun-
teer work. Social skills are developed
without specific training. As parents
and practitioners, we should question
the need for each goal being ad-
dressed. Is this skill important? Is this
skill going to make a meaningful dif-
ference in 10 years? Will this skill make
the individual more independent at some
point in the future? If the answer to any
of these questions is no, then we need to
seriously consider why the goals are being
targeted. All too often, goals are selected
for the wrong reasons (e.g., because other
students in a classroom are working on
these goals), which can lead to the loss of
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