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## 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  
**Melmark**

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 difficult 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 one 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

*see Reducing Stress on page 20*

### 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 last-

ing 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 parental 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

*see Supporting Parents on page 29*

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## Essential Information: Respite Care for Families

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

**M**any 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



Amy Golden, MS, BCBA



Elizabeth Neumann, MA, BCBA



Suzanne Buchanan, PsyD, BCBA-D

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 Kossakowska (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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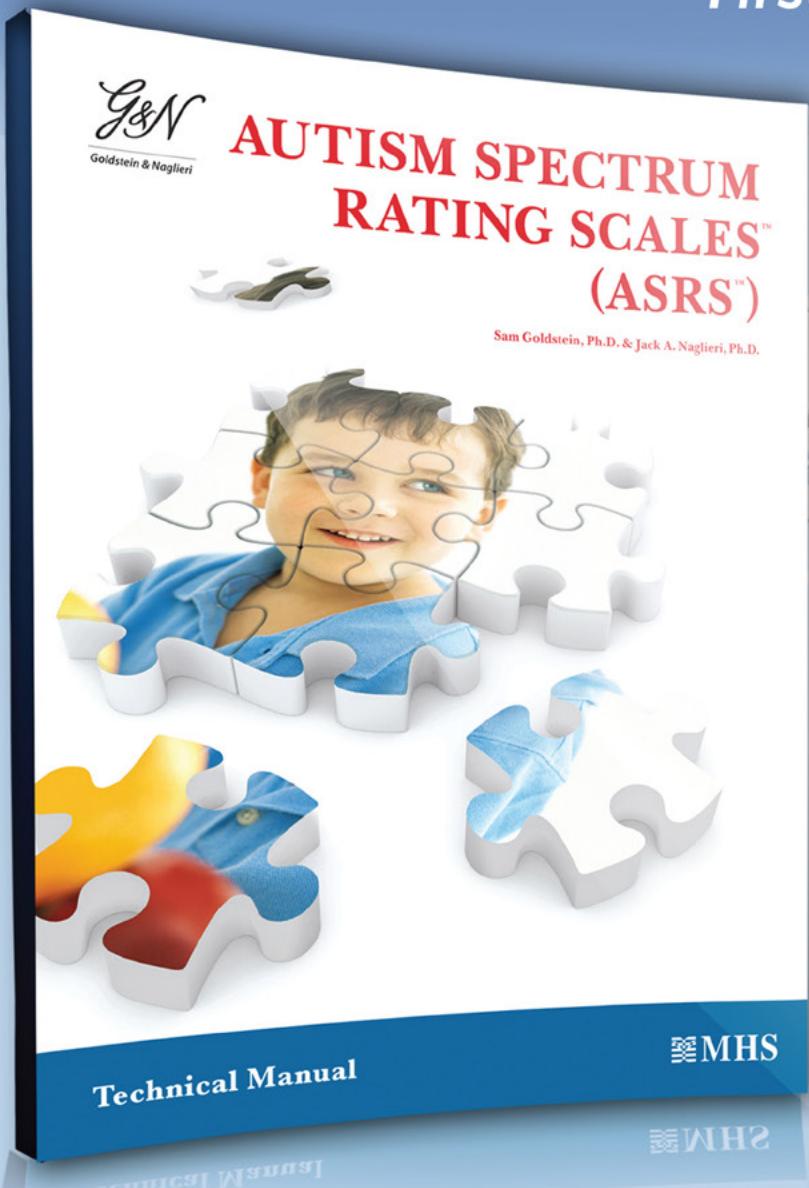
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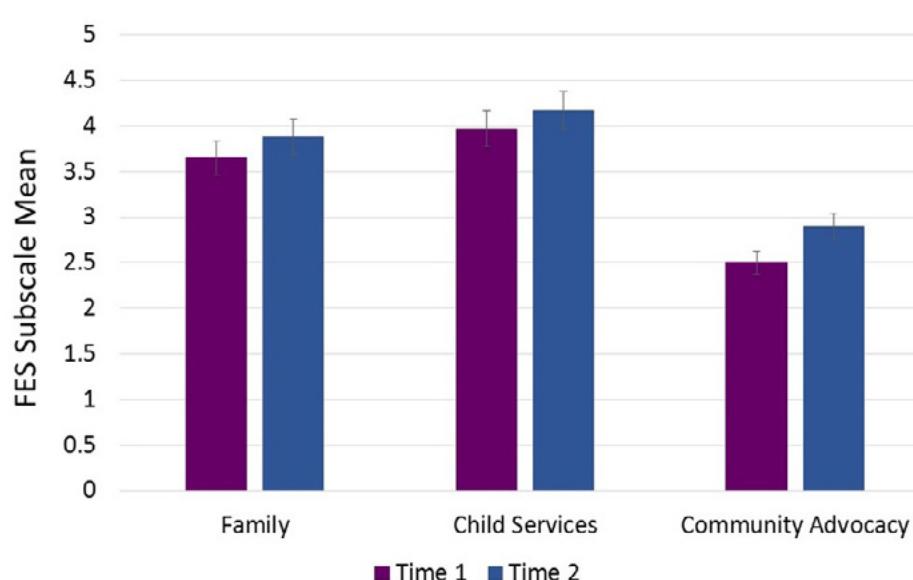


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## Parent Empowerment Among Parents of Children Newly Diagnosed with ASD

By Laura L. Corona, MA,  
Stephanie A. Fox, MA,  
Melissa L. Rinaldi, PhD,  
and Kristin V. Christodulu, PhD,  
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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, 2012). 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, Couzens, Muspratt, & Rodger, 2010; Tonge, Brereton, Kiomal, 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, Iudice, 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, 4<sup>th</sup> ed., Abidin, 2012), and the Family Empowerment Scale (FES; Koren, 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

*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.



Linda J. Walder

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 Univer-

sity 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 Sup-*

*port 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.

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## This is what an adult living with autism looks like!

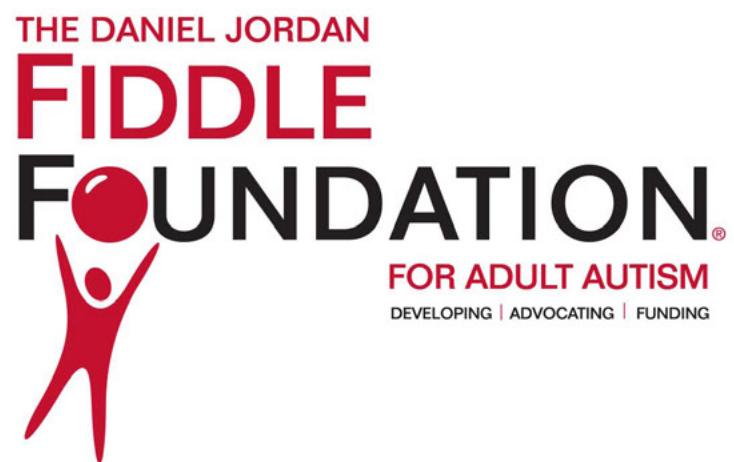
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## “It’s All My Fault!” Understanding Guilt in Parents of Children with ASD

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

**G**uilt 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



Shuli Sandler, PsyD

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 (Green-span & Wieder, 2006). The pressure to make the “right 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:

**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 comparison between Hank and himself, he becomes quite defensive and angry, but underneath he is frightened and guilty.

**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.

**Scenario #3: Guilt over negative thoughts:** Jane and Joe are a highly ambitious couple. They have both had highly successful careers in the areas of law and finance. They met later in life, and struggled to conceive initially due to Jane’s advanced maternal age. After Charlie was born, they were so happy and so relieved that their dream of

*see Guilt on page 18*

## To Speak or Not to Speak Only English

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

**A**s 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 (LOTE) because they recognize the life barriers that stem from ASD and if they perceive that communicating in their LOTE further worsens the situation, they are likely to minimize or stop speaking it (Yu, 2013). 61.8 million U.S. residents spoke a LOTE 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 (Christensen et al., 2016). Given the increased number of individuals who speak a LOTE 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 LOTE.

According to Yu (2013), parents of children with ASD are advised by some physicians, speech-language pathologists (SLP), teachers, and psychologist to speak exclusively in English because doing so will boost language acquisition and reduce



Tamara Sterling, MS, CCC-SLP, TSSLD

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 2013 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 a communicator to that of exclusively being the person who provides care (i.e. only feeding and dressing). When this exchange is made, parents who speak LOTE are limited in their capacity to engage in literacy activities and to have meaningful social-verbal interactions.

The language socialization paradigm (Och & Schleffelin, 1984 as cited in Kremer-Sadlik, 2005) explains that language and socialization are integrated. Children are socialized through language and are socialized to use language. Preventing them from communicating in the

home language could lead to socialization deficits. “Only English” contradicts 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 LOTE? 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 with misperceptions about bilingualism. 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.

*see Speak on page 16*

# Psychiatric Problems Common in Siblings of People with Autism

By Ann Griswold, PhD  
Spectrum

**P**sychiatric 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.

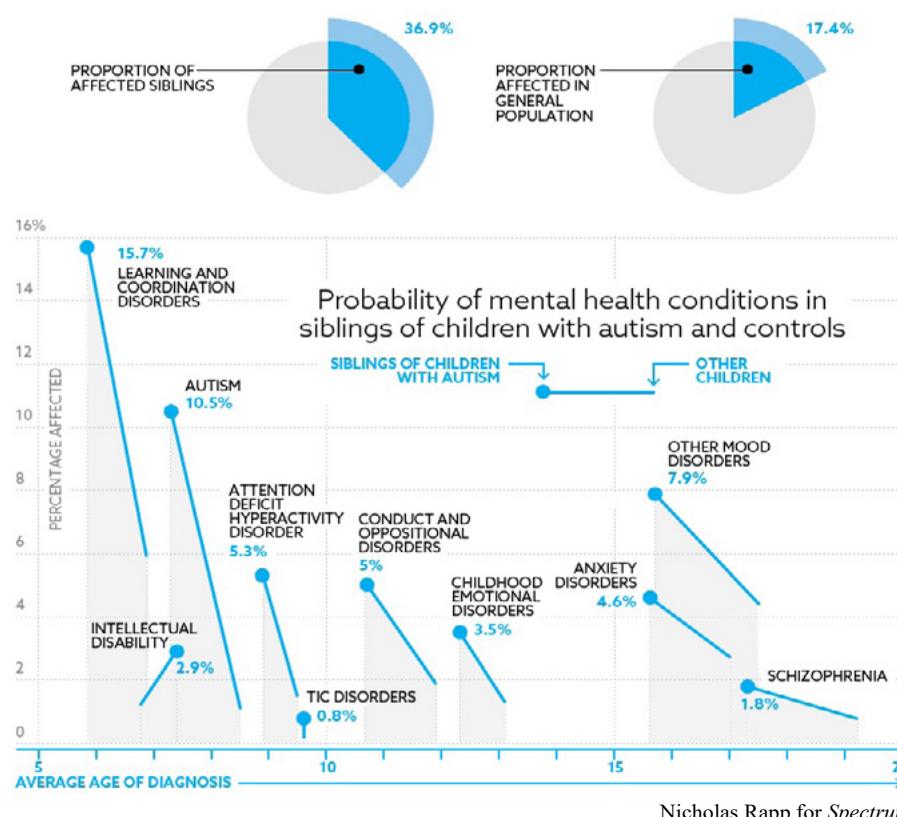
The findings suggest that clinicians should look carefully for signs of other problems in relatives of people with autism.

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.<sup>1</sup>

Among siblings of people with autism, Brown's team found high rates of seven

Likelihood of psychiatric conditions in siblings of children with autism



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

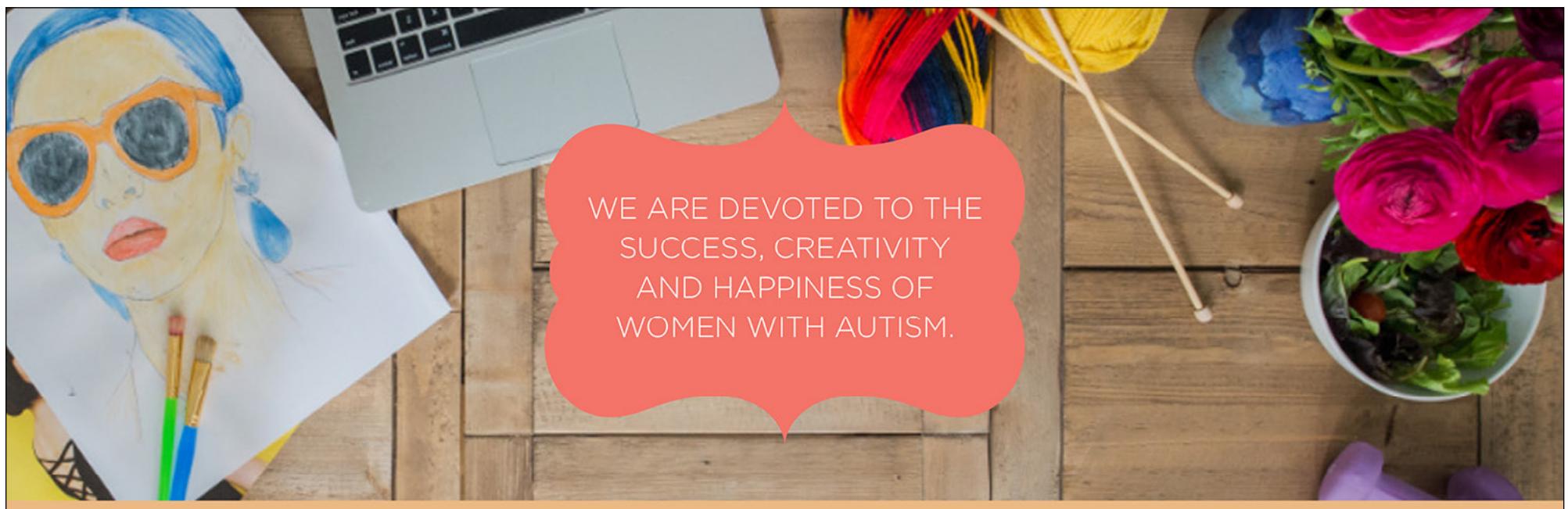
The researchers examined the health records of 3,578 children with autism and their 6,022 full siblings, all of whom had been followed since birth as part of the Finnish Prenatal Study of Autism and Autism Spectrum Disorders.

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*



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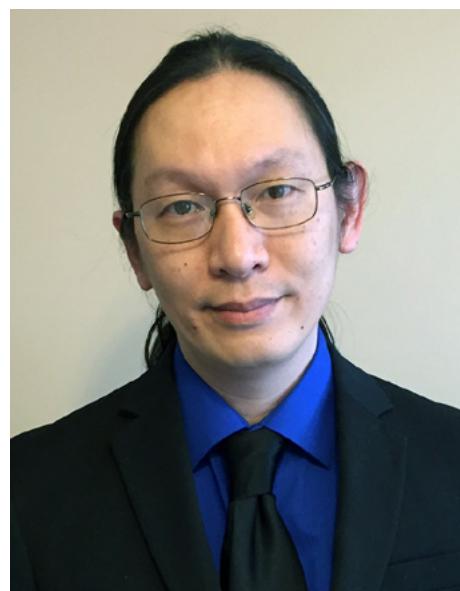
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- The expertise of a friendly staff person
- A community

## 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 has seen drastic changes to the field of autism, at least in part due to changes in the defining characteristics/diagnostic criteria for Autistic Spectrum Disorder (ASD).<sup>1</sup> 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.<sup>2</sup> 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.<sup>3</sup> 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



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, neurophysiology, 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.<sup>4</sup> 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 techniques in education, therapy, counseling, medicine, or other professional disciplines. Only advanced and thorough training in the principles of behavior will expose the multitude of variables that

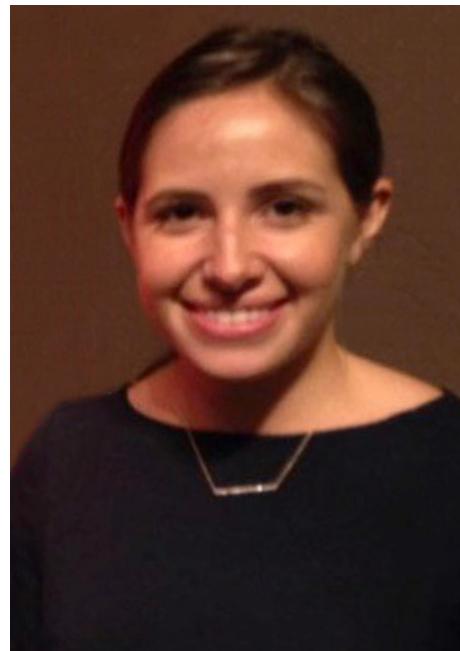
*see Misconceptions on page 22*

## Extending a Helping Hand

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.



Amanda Duva, BCaBA

When home programming begins there is typically a screening, goal-identification, and interview process with the family. During this time, the needs of the family and biggest concerns for the adult or child with disabilities is identified. Every family and person is different, and the reality sets in that the work that is done during programming sessions is only as useful as it is transferable and useful to the individual's caretaker. While maintaining



Terry Blackwell, BCBA

the goals for the individual client, but also considering and providing information to the families with questions and concerns about the care for their loved one, a wholly-inclusive model begins which highlights the mutual benefits of supporting the guardians as well.

For a family of siblings with an elderly mother, and a brother with severe self-injurious behavior: by supporting them in advocacy and attending meetings with

support 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 turns 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." 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 paperwork, 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 that melds 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

*see Helping Hand on page 23*

## 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

**E**vidence 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.



**Jamie Winter, PhD, BCBA-D**

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.



**Cynthia Martin, PsyD**

#### 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 New York-Presbyterian Hospital. The program is publicly available and uses a NDBI approach. These services are provided free of charge



**Catherine Lord, PhD**

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

**P**arents 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 (Hollroyd, Brown, Wikler, Simmons, 1975). Many of the challenges become obstacles to living a 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



**Glenn Sloman, PhD, BCBA-D, NCSP**

the “front line” positions, these parents experience a lower quality of life and elevated depressive and anxious symptoms (Poddar & Urbi, 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



**Michael C. Selbst, PhD, BCBA-D**

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

continually move toward their chosen values (Hayes & Strosahl, 2004; Hayes, et al., 2012). Values associated with raising a child with ASD may include being a caring and supportive parent, being well-educated in effective treatments for ASD, maintaining one’s own positive mental health, etc. By engendering behavioral change using this approach, we can help parents become more psychologically flexible.

### What is Psychological Flexibility?

Psychological Flexibility (PF) is the ability to be present (direct our attention, with curiosity and openness, to whatever matters in the moment), open up (fully contact our experience and make room for all our thoughts and feelings) and do what matters (act in accordance with our values) (Harris, 2013). The concept of PF stems from behavior analysis and ACT’s notion of workability. This idea answers the questions: 1. Does the behavior function effectively given the environmental conditions? and 2. Is the behavior aligned with what the parent finds meaningful? Workability links long-term behavior patterns in the service of a more meaningful (i.e., value-driven) life.

Increasing PF is critical when helping parents remain fully connected (present) throughout challenging situations they encounter themselves and when caring for

*see Flexibility on page 25*

## The Newborn and the Child with Autism: The Advice is the Same

By Kathleen G. Freeman, PhD, RNC-NIC  
Drexel Online, Integrated Nursing  
Care of Autism Spectrum Disorders  
Certificate Program

**A**s a parent with a 25 year old son with autism, I am often asked what advice I would give to parents with a newly diagnosed child. My response is the same advice I give to new mothers as a nurse on the maternity unit. Parental emotional adjustment to a new baby is analogous to the adjustment to learning that your child has autism.

One of the first maternity specialist, Reva Rubin (1961), identified three psychological phases of the adaption to motherhood: taking-in, taking-hold, and letting-go. During the taking-in phase, the new mother needs to focus on her own needs, and she is dependent on others. She is very talkative about the details of her labor and delivery experience. As she moves to the taking-hold phase, her focus shifts to the care of the baby and competent mothering. She has the desire to take charge, although she still needs some nurturing and acceptance from others. The mother is eager to learn, but she may experience some emotional ups and downs. In Rubin’s last phase, the mother focuses on moving forward as a family. During this time, the maternal and paternal roles in the newborn’s care are determined. And, eventually, the relationship with the part-



**Kathleen G. Freeman, PhD, RNC-NIC**

ner 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 inad-

equacy. 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

children or playmates helped them move through denial. They recognized “something isn’t right.” For those that are consumed 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, reassertion of relationships with their partner, and resumption of intimacy. This phase has a significant impact on the father.

*see Advice on page 23*

## Avoid Mistakes with Important Legal Forms

By Sharon Kovacs Gruer, Esq.

**M**any 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



Sharon Kovacs Gruer, Esq.

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 pursuant to IRS tables. What that means is that the ultimate beneficiaries must withdraw more

each year, and over a shorter period, than they would have had to take out if an individual had been listed as beneficiary, and this means that the ultimate beneficiaries would pay more income taxes on the distributions, and have a smaller amount grow tax deferred. Therefore, it is usually preferable to list both primary and contingent beneficiaries directly on the beneficiary designation form.

If a minor is a beneficiary of all or part of an IRA or of life insurance, it is usually best to list a trust for that minor as beneficiary of that minor's share 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.

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 for the share of your retirement accounts, life insurance and other assets that have beneficiary designation forms that you intend to leave to that beneficiary. Also, you should make sure that your will references the trust to hold that beneficiary's share of your probate estate.

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

*see Legal Forms on page 34*

  
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# What Parents of Children with Autism Should Know About Abuse

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

**I**t 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



**Nora Baladerian, PhD**

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 First Report" 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. For example, natural disasters. 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 with a disability 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. Pascrell, LCSW  
Manager of Clinical Services  
YAI Autism Center**

**O**ver 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-Zin, 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



**Laura M. Pascrell, LCSW**

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.<sup>1</sup>

### 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.<sup>2</sup> 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"<sup>3</sup> 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."<sup>4</sup>

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

**W**hen 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



**Kelly Imperial, MS**

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.

*see Job Skills on page 27*

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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  
Douglass 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., Watanabe and Sturmey, 2003).

The goal of any educational program should be to prepare individuals to function as independently in their environ-



**Robert H. LaRue, PhD, BCBA-D**

ment 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



**James C. Maraventano, EdM, BCBA**

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



**Jenna Budge, MSW**

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

*see Functional on page 26*

## *Speak 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.

*Tamara Sterling, MS, CCC-SLP, TSSLN is a Speech-Language Pathologist in Westchester County in New York. She has eight years of experience working with children and adults with articulation, stuttering, language, and autism spectrum disorders. She is an ASHA Mentor and a recent recipient of ASHA's ACE award.*

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## References

- American Speech-Language-Hearing Association. (2014). Cultural competence [Position statement]. Available from <http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935230=Overview>
- Camarota, S.A., & Ziegler, K. (2014). *One in Five U.S. Residents Speaks Foreign Language at Home, Record 61.8 million.* [PDF file]. Retrieved from: <http://cis.org/sites/cis.org/files/camarota-language.pdf>
- Christensen, D.L., Baio,J., Braun, K.V., et al. (2016). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *Morbidity and Mortality Weekly Report*, 65(No. SS-3)(No. SS-3) 1–23. Available from <http://www.cdc.gov/mmwr/volumes/65/ss-ss6503a1.htm#suggestedcitation>
- Hambly, C., & Fombonne, E., (2011). The impact of bilingual environments on language Development in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 1342-1352.
- Ijalba, E., (2016). Hispanic immigrant mothers of young children with autism spectrum disorders: How do they understand and cope with autism? *American Journal of Speech-Language Pathology*, 25, 1-14.
- Kremer-Sadlik, T., (2005). To be or not to be bilingual: Autistic children from multilingual families. *Proceedings from the Fourth International Symposium on Bilingualism* (pp. 1225-1234). Somerville, MA: Cascadilla Press.
- Ohashi, J.K., Mirenda, P., Marinova-Todd, S., Hambly, C., Fombonne, E., Szatmari, P., Thompson, A. (2012). Comparing early language development in monolingual-and bilingual-exposed young children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6, 890-897.
- Petersen, J.M., Marinova-Todd, S.H., & Mirenda, P. (2012). Brief report: An exploratory study of lexical skills in bilingual children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 42, 1499-1503.
- Reetzke, R., Zou, X., Sheng, L., & Katsos, N. (2015). Communicative development in bilingually exposed chinese children with autism spectrum disorders. *Journal of Speech, Language, and Hearing Research*, 58, 813-825.
- Valicenti-McDermott, M., Tarshis, N., Schouls, M., Galdston, M., Hottinger, K., Seijo, R., Shinnar, S. (2013). Language differences between monolingual English and bilingual English-Spanish young children with autism spectrum disorders. *Journal of Child Neurology*, 28, 945–948.
- Yu, B., (2013). Issues in bilingualism and heritage language maintenance: Perspectives of minority-language mothers of children with autism spectrum disorders. *American Journal of Speech-Language Pathology*, 22, 10-24.



# The Lighter Side of the Spectrum ~ A Mom's View

By Carrie Cariello

## 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.



Carrie with her husband Joe

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 patting 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

*see Because on page 22*



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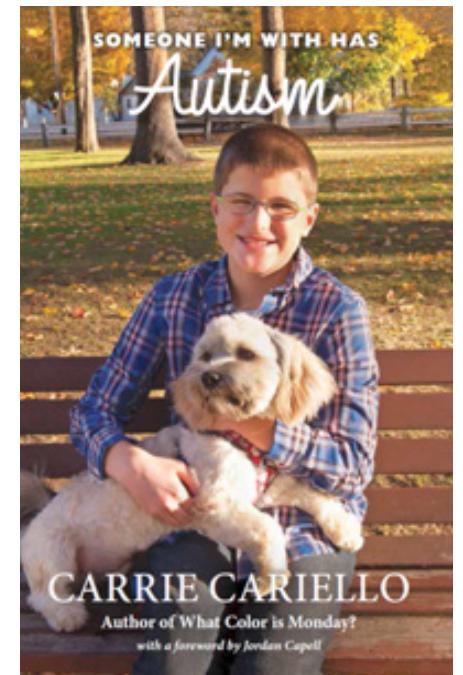


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## New Study Aims to Quantify Effects of Respite Vacation Experience on Families with Special Needs

By Alyssa SooHoo, MAT  
Doctoral Student  
Intellectual Disability/Autism  
Teachers College,  
Columbia University

**A**utism spectrum disorder (ASD) has become increasingly prevalent over the past 15 years, which has baffled researchers and frustrated parents. In mid-November 2015, The National Health Statistics Report revealed an increase of ASD prevalence, suggesting that 1 in 45 children, ages 3 through 17, have ASD (Zablotsky, 2015).

Parents of children with ASD have been known to experience higher levels of stress than parents of children with any other conditions (Phelps, 2009). The parents in Phelps' study indicated that the implications of ASD affected each area of their lives: psychological, family, social, services, spiritual benefits, economic challenges, and focus on the future of having a child diagnosed with autism. McCabe's 2007 study stated that parents with children with ASD reported extreme sacrifices they made with respect to their children. Benson (2009) found higher levels of parenting stress for ASD parents than parents of children with Down syndrome and parents with other disabilities (Benson, 2009). The



Alyssa SooHoo, MAT

severity of the child's autism symptoms and behaviors has consistently been found to be a strong predictor of parental stress. Benson (2009) defined stress proliferation as a tendency for stressors to create additional stressors. This has been an important contributor to depression among caregivers for children with ASD. These caregiv-

ers are put at greater risk for depression and other mental health problems than are parents without children with disabilities.

A study by Sawyer et al., (2010) provides strong evidence suggesting that the mothers of children with ASD have higher rates of mental health problems than other mothers in the community. Factors that have been identified with the increase risk for mental health problems among parents with children with autism include: level of childhood behavior problems, gender and age of the parents; level of parental social support and parental psychological characteristics, such as perceived self-efficacy, and locus of control and coping style (Sawyer et al., 2010). Additionally, the study found that diagnostic postponement, difficulty dealing with ASD problem behaviors, and lack of social networks and leisure activities were the factors associated with the higher stress levels of caregivers for individuals with ASD.

Phelps (2009) discusses the demanding responsibilities for caregivers, thus producing caregiver strain. This strain is associated with aggressive behaviors, extreme dependence of the child or attachment and affection not expressed in the ways parents might have anticipated. It has been shown that mothers experience greater instances of stress or strain related to daily exposure to problems when compared to fathers of

children with autism (Falk, 2014). The inability of parents to manage or alter negative behaviors may lead to increased stress and hindered psychosocial well-being (Estes, 2009). Studies have been conducted internationally and appear consistent. These findings may provide insightful information to caregivers of individuals with autism spectrum disorders and practitioners providing services to them.

Phelps' 2009 research states that the highest stress pertains to family social activities, personal social activities, and their relationship with their partner. Past research supports that families of children with developmental disabilities participate in less family interactions and recreational activities than families who do not have a member with a child with ASD.

Although new coping mechanisms for assisting with stress management for caregivers with ASD are being introduced daily, it is vital to find the key factors that impact this. The literature suggests that more empirical studies must be done to further identify individual stress factors. When individual factors are identified, more effective supports can then be affirmed and provided to caregivers in need. Providing effective stress management supports for caregivers of children with ASD may lead

*see Respite on page 26*

### Guilt from page 8

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 his 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 kind 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 quickly when he challenges her, because of all her guilt.

**Scenario #4: Guilt over child's suffering:** Samantha is a sixteen year old teenage girl with a diagnosis of ASD who has recently started acting out, challenging her parents, and spending more time in her room and on the computer. Her grades remain consistent, and she does continue

to sustain her few, but close friendships. When her older brother (neurotypical) went through a similar process during his teenage years, his parents chalked it up to adolescent development and saw his behavior through that lens. With Samantha, they tend to worry that this is somehow secondary to her ASD and worry that they are missing something related to her symptoms and her past. They start second-guessing their choices and want her to attend therapy. Samantha is resistant, claiming she is doing just fine, but her parents feel bad and worry they are not helping her get better. In their zealousness to address her difficulties, and their worries that 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 per-

sonal 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 impulsive 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 trying to help their 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 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 [shulisanderspsyd@gmail.com](mailto:shulislanderspsyd@gmail.com).*

### References

- Greenspan, S.I. & Wieder, S. 2006. *Engaging Autism*. Philadelphia, PA: Da Capo Lifelong Books.

# 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



**Vanessa Tucker, PhD, BCBA-D**

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 is 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 absolution 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. De-

grees 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 more 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.

*see Collaborate on page 33*

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## Mindfulness from page 14

force on their wellbeing.

Laura M. Pascrell is Manager of Clinical Services with the YAI Autism Center. For more information about YAI services for children and adults with autism and their parents or caregivers, please call 212-273-6182.

## References

1. Jon Kabat-Zinn, Full Catastrophe Living (Revised Edition): [Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness](#), Volume 34, Issue 1, Jan-

uary 2013, Pages 246–253

2. Mindfulness-based therapy in adults with an autism spectrum disorder: A randomized controlled trial
3. Tara Brach, Radical Acceptance: Embracing Your Life With the Heart of a Buddha
4. Mindfulness-Based Stress Reduction for Parents of Young Children with Developmental Delays: Implications for Parental Mental Health and Child Behavior Problems Cameron L. Neese Department of Psychology, Loma Linda University, Loma Linda, CA, USA Journal of Applied Research in Intellectual Disabilities 2014, 27, 174–186

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## **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



**Maggie Haag, LSW, CBIS**

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 ac-



**Mary Jane Weiss, PhD, BCBA-D**

tive 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 can 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



**Frank L. Bird, MEd, LABA, BCBA**

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 is 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



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*see Reducing Stress on page 30*

# AUTISM SPECTRUM NEWS DESK



## New CDC Funding Will Expand Knowledge About Children with ASD

By The Centers for Disease Control and Prevention (CDC)

**O**ver 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 under-



stand genetic and environmental factors related to having ASD, health conditions among children with and without ASD, and the range of developmental and behav-

ioral 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.

*see CDC Funding on page 29*

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

By Staff Writer  
Autism Spectrum News

**M**ental 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



**Linda J. Walder, Esq.**

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 ASAHI, 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.

As a spokeswoman and expert on adult autism, Linda has appeared in news media including *Dateline NBC*, *News 12 New Jersey*, *WOR News Radio* and in publications including *The New York Times*, *Parade Magazine*, *USA Today* and *The Bergen Record*. Linda has also moderated Congressional briefings on adult autism and a panel of experts at the United Nations for World Autism Day. Linda's blog entitled, *Autism for a Lifetime: Finding Joy in the Journey* offers unique perspectives on adult autism for those directly affected by autism and the community at large.

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 and 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](http://www.mhnews-autism.org/editorial_board.htm).*

### **Misconceptions from page 10**

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 generality or applicability of an ABA-based approach. ABA is perceived to be useful in 1) specialized settings, 2) with specific populations, 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 impaired individuals and cannot/should not be used with higher-functioning people with disabilities or neuro-typically-developing people.”
- “ABA is only applicable for severe problem behavior like aggression but not for bizarre behaviors like self-injury, psychotic 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 techniques 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 contrived, and so they don’t mimic the real world.”

### **Because from page 17**

always watching you to see what move you'll make next.

And like a stray cat in the dark, you are always waiting for me to give up or get tired. I will never get tired.

Well, that's not exactly true. Some days I am very, very tired. I am tired because you wake him up at the crack of dawn and told him that he *has* to make *pancakes* because he made pancakes on this exact day two years ago except this year is a Leap Year so it was different but still he should make them.

But I will never give up. I vow to be as tenacious as you are determined, as resourceful as you are wily, as steadfast as you are slippery.

Because of you, I came *this close*—thumb and forefinger close—to crashing my minivan into an oil truck, after you made 6-year old Jack shriek and scream when he saw an orange cone because he was afraid of anything that was orange that year.

Because of you, I missed the first half of my oldest son’s fourth grade play, when you whispered in 9-year old Jack’s ear that the auditorium, with its colorful stage and crowded audience, was too loud, too bright, too much.

Because of you, he feels threatened by every single thing around him—a loud noise in the kitchen, or a street light that

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 problems on the individual, organizational, and community-level. This includes, but is not limited to, [clinical/mental-health settings](#),<sup>5</sup> business and industry, clinical and applied health psychology, and [education](#).<sup>6</sup> The behavior analytic analogue of Industrial-Organizational Psychology, [Organizational Behavior Management \(OBM\)](#),<sup>7</sup> is one of the most rapidly growing subfields within ABA. Despite great differences in the setting 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 set of misconceptions reflect the need for more demonstrations of the effectiveness 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 unethical, harmful and should not be used. Proponents 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 edible reinforcers, and children don’t learn for the sake of learning.”
- “Reinforcement is bribery and is an unethical practice.”
- “ABA is like animal training and is inhumane.”

- “ABA practitioners seek to control people.”

The care and rights of the individual client are at the fore of the practice of applied behavior analysts. Prior to the field of ABA having established its own code of professional ethics, the Association for Behavior Analysis adopted the American Psychological Association [code of ethics](#)<sup>8</sup> 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.<sup>9</sup>

Unfortunately, some criticisms of human-rights violations are based on cases in which behaviorally-based interventions have been implemented without appropriate or sufficient oversight, resulting in neglectful or [abusive conditions](#).<sup>10</sup> 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](#).<sup>11</sup> Although the history of the practice of behavioral therapy includes cases of the misuse of behavioral techniques, these make up a small minority of cases that have been illustrated through decades of applied, clinical, and experimental applications resulting in meaningful 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 apply on any level greater than superficial appearance and/or for more than a small

number of cases. Moreover, it is becoming 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/applied-behavioral-analysis.cfm>.*

#### References

1. <http://www.cdc.gov/ncbdd/autism/data.html>
2. <http://www.autism-help.org/comorbid-disorders-autistic-spectrum.htm>
3. <http://bacb.com/about-behavior-analysis/>
4. <http://foa.sagepub.com/content/16/2/86.short>
5. <http://files.eric.ed.gov/fulltext/EJ801237.pdf>
6. <https://www.abainternational.org/constituents/special-interests/special-interest-groups.aspx>
7. [http://www.obmnetwork.com/what\\_is\\_obm\\_definition\\_description\\_common\\_applications](http://www.obmnetwork.com/what_is_obm_definition_description_common_applications)
8. <https://www.abainternational.org/about-us/policies-and-positions.aspx>
9. [http://bacb.com/wp-content/uploads/2015/07/BACB\\_Newsletter\\_09-14.pdf](http://bacb.com/wp-content/uploads/2015/07/BACB_Newsletter_09-14.pdf)
10. [http://samples.sainsburysebooks.co.uk/9781135608880\\_sample\\_857122.pdf](http://samples.sainsburysebooks.co.uk/9781135608880_sample_857122.pdf)
11. <http://psycnet.apa.org/journals/amp/33/2/194/>

suddenly goes out, or a different item on the lunch menu. He spends his day in a perpetual state of fight-or-flight, trying to protect himself from an invisible, nameless attack.

Because of you, 11-year old Jack has the hardest time with language, and he communicates with the world around him in his very own dialect. Sometimes it is funny, sometimes it is frustrating, but always it is fascinating.

*And how would you like your burger? Medium? NO! I want it LARGE! I want a LARGE BURGER.*

Because of you, I have to watch his inner torment over something as simple as choosing the right clothes to wear; his ceaseless longing to fit in with those around him balanced precariously against his need for order and routine.

*Everyone. All the boys. They for wear shorts. But I will be too cold. To wear shorts. I think for my turtleneck.*

For months now, you have trapped him inside of his own private blizzard—you have cloaked him in fury and tantrums, curse words and depression. He is sad one minute, mad the next.

My son is hurting and I can’t reach him and this is all because of you.

Although his diagnosis is clear, his future is as hazy as a morning in springtime. A high school diploma, a driver’s license, and an apartment of his own—they all dangle just above his head, like light bulbs

burning in a chandelier.

*Because of you.*

Because of you I had to call our local police department. I worry he will run away from me one day into the street or through the woods or out of the car, and I will need their help to find him.

I want them to know about you—about the wolf that shadows my child and clutches him tightly, even as he thrashes and squirms and begs for release.

*Because of you, I worry all the time.*

I worry about the f-word in the line at Chipotle because they ran out of guacamole and he really, really wanted guacamole and I worry about my other four kids and whether their childhood will always be overshadowed by the phrase *your brother has autism* and I worry he eats too many pancakes.

I worry he spends too much time on the computer and what will happen if I die and whether or not I should make him brush his *teeth* better.

I worry one day my marriage will buckle beneath this tremendous weight; that we are just one meltdown away from complete chaos, because parenting this boy together is so hard.

I want to hate you, autism, but like a child picking petals from a flower, I vacillate between hate and love, loathing and tenderness.

To hate you would be to hate a fundamen-

tal piece of my Jack-a-boo, and that is something I can never ever do, no matter which way the silky petals scatter in the wind.

I know you love this boy almost as much as I do. In some ethereal way, I know you chose him—you chose me, and us.

Because if you, I know the kindness of strangers and the devotion of *teachers*.

Because of you, my *children* are flexible, and tolerant, and tender, and kind.

*Mom, it's no big deal. Nothing really happened in the beginning of the play anyway.*

Because of you, this dark-haired man and I found one another again. In the midst of diapers and speech therapy, doctor’s visits and long, sleepless nights, we rediscovered our own private language.

*He said he wanted a large burger, it was so cute. He decided on a short-sleeved shirt with cargo pants. I can't believe you got him in here before the second act, headphones was a good idea.*

So today, autism, I’m going to hang up my gloves and stop chasing you. I’m going to try to understand you, and give you the room you need to help this boy blossom.

I only ask one thing. Share him with me. I miss him.

*What Color Is Monday?*” is available on [Amazon.com](http://Amazon.com) and [BarnesandNoble.com](http://BarnesandNoble.com). You can also follow Carrie on her weekly blog: [www.CarrieCariello.com](http://www.CarrieCariello.com) and [Facebook.com/WhatColorIsMonday](http://Facebook.com/WhatColorIsMonday).

# The Intermingling of Tech and Therapy

By Ladislas de Toldi  
CEO and Co-founder  
[Leka](#)

**T**he 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 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



Ladislas de Toldi

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 [dueling robots rep-](#)

resenting 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 much more 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

*see Tech on page 29*

## Helping Hand from page 10

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 she just does not have the time in the day to get to herself. She and her son now have more time avail-

able 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 the families and caretakers 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.

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## Advice from page 12

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 new-

born. 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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## References

Ellis, J. B. (1989). Grieving for the loss of the perfect child: Parents of children with handicaps. *Child and Adolescent Social*

*Work Journal*, 6(4), 259-270.

Gargiulo, R. M., & Graves, S. B. (1991). Parental feelings: The forgotten component when working with parents of handicapped preschool children. *Childhood education*, 67(3), 176-178.

Goodman, J. (2005). Becoming an involved father of an infant. *JOGNN*, 34(2), 190-200.

Hutton, A.M. & Carron, S.L. (2005). Experiences of families with autism in rural New England. *Focus on Autism and Other Developmental Disabilities*, 20(2), 180-189.

Naseef, R. A. (2013). *Autism in the family: Caring and coping together*. Paul H. Brookes Publishing Company.

Rubin, R. (1961). Basic maternal behavior. *Nursing Outlook*, 9(11), 683-686.

***Essential from page 4***

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 and Caron, 2005).

Siblings of individuals with ASD are also considerably affected by the extent 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 are intently focused on the specialized 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 ineffective parenting 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, & Bennett, 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 (Hutton & Caron, 2005). Furthermore, while the primary benefit of a respite program is to allow parents a break from fulltime caregiving responsibilities, advantages may extend beyond the effects on primary caretakers. Siblings often have increased access to their parents' time and attention when respite services are available (Hare et al., 2004). Several studies have also reported improve-

ments in children's behaviors as a result of reduced parent stress (Osbourne et al., 2008).

Research has indicated the need for more "autism-friendly" respite options to provide the type, quantity, flexibility, and level of service that families need in order to cope with daily and chronic challenges (Hare et al., 2004). Parents have also consistently reported the critical nature of training for respite personnel (Hare et al., 2004). They express significant concern about entrusting their loved one with others less familiar with the individual and the impact of his or her diagnosis. Respite offered by those who may be well-intentioned but not well-trained can negate the potential benefits of service. Specifically, parents have suggested that low-quality services were unreliable and caused "confusion and distress for themselves and for the person with ASD," in part because providers "did not recognize the importance of routine and predictability" for individuals with autism (Hare et al., 2004, p. 434). Having the provider understand the complex and unique diagnostic criteria of autism and the specific ways autism affects the individual are critical to the success of the respite time.

Families entrust respite providers with the ultimate responsibility: the sole care of their loved one. No matter the age of the individual with autism, the family's concern regarding placing this trust in someone else must be respected. Due to the unique challenges associated with autism, parents typically have certain expectations of their respite providers. Above all else, safety is the primary objective. Parents have repeatedly shared how desperately respite services are needed, but only if they feel that their child will be safe in the provider's care. Understanding the traits of autism, knowing the individual well, and appreciating potential dangers in the environment can help ensure the safest conditions. Flexibility, staying calm during stressful situations, and good problem solving skills are all essential qualities of respite providers that relate directly to keeping everyone safe. Beyond the clear focus on safety, certain professional characteristics are also important when providing respite, such as being reliable, punctual, and adhering to confidentiality. Providers should support the individual's development by learning how to engage him or her and following the plans the family has in place to increase independence. It is crucial to be as consistent as possible with the family's instructions. The role

of respite provider takes energy, enthusiasm, and creativity as well as a willingness to learn new skills.

Whether you are caring for someone in your family or doing so as your profession, caregiving is a unique job that requires a lot of patience and energy. While 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 communicating the need to take a break 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](http://www.autismnj.org/publications) or call 800.4.AUTISM to obtain a copy. It is designed to be of use whether the provider is 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**

- Abelson, A. G. (1999). Respite care needs of parents of children with developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, 14, 96-100.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51, 702-714.
- Boyd, N. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism.
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- Pisula, E., & Kossakowska, Z. (2010). Sense of coherence and coping with stress among mothers and fathers of children with autism. *Journal of Autism and Developmental Disorders*, 40, 1485-1494.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40, 167-178.
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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 audiology. 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

*Focus on Autism and Other Developmental Disabilities*, 17, 208-215.

Chan, J. B., & Sigafoos, J. (2001). Does respite care reduce parent stress in families with developmentally disabled children? *Child & Youth Care Forum*, 30, 253-263.

Hare, D. J., Pratt, C., Burton, M., Bromley, J., & Emerson, E. (2004). The health and social care needs of family carers supporting adults with autistic spectrum disorders. *Autism*, 8, 425-444.

Harris, S. L., & Glasberg, B. A. (2003). *Siblings of children with autism: A guide for families* (2nd ed.). Bethesda, MD: Woodbine House.

Hutton, A. M. & Caron, S. L. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and other Developmental Disabilities*, 20, 180-189.

Jacobson, J. W. (2000). Early intensive behavioral intervention: Emergence of a consumer-driven service model. *The Behavior Analyst*, 23, 149-171.

Lee, L., Harrington, R. A., Lewis, B. B., & Newschaffer, C. J. (2008). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders*, 38, 1147-1160.

Manning, M. M., Wainwright, L., & Bennett, J. (2011). The double ABCX model of adaptation in racially diverse families with a school-age child with autism. *Journal of Autism and Developmental Disabilities*, 41, 320-331.

Osbourne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Developmental Disorders*, 38, 1092-1103.

Pisula, E., & Kossakowska, Z. (2010). Sense of coherence and coping with stress among mothers and fathers of children with autism. *Journal of Autism and Developmental Disorders*, 40, 1485-1494.

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40, 167-178.

# Keeping It Together When Faced with an Autism Diagnosis

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

**Y**our 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 right 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



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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



**Nicole Pelliciari, MS, BCBA**

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://faces4autism.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*

## Flexibility from page 12

their child with ASD without trying to change one's thoughts, feelings, or core beliefs (Hayes, et al., 2006). For instance, when working through a functional communication training protocol and their child is becoming frustrated and starts to tantrum, the parent commits to the action of withholding the requested item until the child approximates communicating appropriately rather than giving the item to end the tantrum.

### How to Increase Psychological Flexibility?

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 discomfort may include yelling at your child, arguing with 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 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 inconsistent 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 be 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

- Blackledge, J. T., & Hayes, S. C. (2006). Using Acceptance and Commitment Training in the Support of Parents of Children Diagnosed with Autism. *Child & Family Behavior Therapy*, 28(1), 1-18.
- Coyne, L. W., & Murrell, A. R. (2009). The Joy of Parenting: An Acceptance and Commitment Therapy Guide to Effective Parenting in the Early Years. Oakland, CA: New Harbinger.
- Harris, R. (2013). Getting Unstuck in ACT: A Clinician's Guide to Overcoming Com-

mon Obstacles in Acceptance and Commitment Therapy. Oakland, CA: New Harbinger Publications.

Hayes, S. C., Luoma, J., Bond, F., Masuda, A., & Lillis, A. (2006). Acceptance and commitment therapy: Model, processes, and outcomes. *Behaviour Research and Therapy*, 44(1), 1-25.

Hayes, S. C., & Strosahl, K. D. (Eds.). (2004). A Practical Guide to Acceptance and Commitment Therapy. New York: Springer-Verlag.

Hayes, S.C., Strosahl, K.D., & Wilson, K.G. (2012). Acceptance and Commitment Therapy: The Process and Practice of Mindful Change (2nd edition). New York, NY: The Guilford Press.

Holroyd, J., Brown, N., Wikler, L., & Simmons, J. Q. (1975). Stress in families of institutionalized and noninstitutionalized autistic children. *Journal of Community Psychology*, 3(1), 26-31.

Poddar, S., Sinha, V., & Urbi, M. (2015). Acceptance and commitment therapy on parents of children and adolescents with autism spectrum disorders. *International Journal of Educational and Psychological Researches*, 1(3), 221.

Polk, K. L., & Schoendorff, B. (Eds.). (2014). The ACT Matrix: A New Approach to Building Psychological Flexibility Across Settings and Populations. Oakland, CA: New Harbinger Publications.

Polk, K.L., Schoendorff, B., Webster, M., & Olaz, F.O. (2016). The Essential Guide to the ACT Matrix: A Step-by-Step Approach to Using the ACT Matrix Model in Clinical Practice. Oakland, CA: New Harbinger Publications.

### **Functional from page 16**

referred to by a variety of names, such as self-help skills, life skills, or activities of daily life (ADLs). Functional skills, simply put, are those skills that are practical in nature and helpful for fostering independence.

All too often, practitioners implement academic goals that have little or no functional outcome. For example, an instructor may teach an adolescent to put plastic shapes into a shape sorter while they are unable to place coins in a vending machine. Students may be taught to identify the pictures of lesser-known U.S. Presidents (e.g., James K. Polk) or list the characteristics of sedimentary rock as a part of their academic programming. These kinds of goals can be a concern as they do not translate in any meaningful way to activities the individual is likely to encounter in their daily life. From this perspective, instructional time that is devoted to teaching non-functional skills is a waste of valuable educational resources and highlights the need for appropriate educational curricula with a focus on functional skills (Conderman & Katsiyannis, 2002).

#### Functional Skills Assessments

In order to evaluate an individual's current level of functioning and identify skills to target for intervention, it is important for caregivers to conduct assessments of

an individual's capacity to perform various functional skills. Specifically, functional skills assessments may be valuable in the identification of meaningful instructional targets, in determining the level and type of support that an individual may need. Some commonly used instruments for identifying functional skill targets include the Vineland Adaptive Behavior Scales II (Sparrow, Cicchetti, & Balla, 2008), the Scales of Independent Behavior-Revised (Bruininks, Woodcock, Weatherman, & Hill, 1996), and the Assessment of Functional Living Skills (Partington & Mueller, 2012). These measures can be a useful guide for parents and practitioners when selecting curricular targets and can be used to determine socially-significant short and long-term goals.

#### Types of Functional Skills

The spectrum of functional skills is quite diverse, encompassing multiple domains of performance, such as self-care, domestic, recreational, community safety, prevocational/vocational, social and behavior management skills.

*Self-Care Skills* - Self-care skills are among the most important and basic kinds of functional skills in that they contribute to the maintenance of well-being and are necessary to sustain one's health. Self-care skills include a number of important targets, such

as the ability to bathe oneself, self-grooming (e.g., teeth brushing, shaving, hair brushing, putting on deodorant), washing (e.g., hand and face washing, showering), self-toileting, and getting dressed (e.g., choosing clothes, tying shoes, dressing independently).

*Domestic Skills* - Domestic skills encompass the skills related to household affairs. These skills involve maintaining one's home as well as providing necessary daily sustenance. Domestic skills may include food preparation and safety (e.g., using a microwave or an oven to cook food), meal planning, sweeping/vacuuming the floor, doing dishes (e.g., loading a dishwasher), making a bed, and doing laundry (e.g. washing, drying, folding and sorting clothing).

*Community Skills* - Community skills include those abilities that are required to navigate and access resources within one's specific locality. Important community skill targets may include the ability to cross a street safely (e.g., using a crosswalk, observing "Walk/Don't Walk" signs), the ability to recognize stores (e.g., grocery store, pharmacy, laundromat), the use of public transit (e.g., using the bus or train), or locating and purchasing items in a store (e.g., paying for items, counting change).

*Vocational Skills* - A common goal for many individuals with intellectual disabili-

ties and their families is obtaining employment. Vocational skills include those skills that involve the production aspects of jobs, such as busing tables at a restaurant or filing paperwork at a doctor's office. Vocational targets often depend on several factors, such as opportunities in the community, individual levels of challenging behavior, individual skill level, and parent/student preference. Such instruction may begin with prevocational skills to teach the prerequisite skills (e.g., sorting tasks, discrimination tasks) that are components of more complex skills (e.g., delivering inter-office mail).

*Recreational Skills* - Recreational skills typically involve an individual's engagement with activities or items that they find 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.

**see Functional on page 34**

### **Respite from page 18**

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 experience 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.

Researchers of the Autism on the Seas Foundation hypothesize 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](http://Autismontheseas.com).*

#### References

- Amet, 2013. Holiday, What Holiday? Vacation Experiences of Children with Autism and Their Families. Retrieved from <http://omicsgroup.org/journals/holiday-what-holiday-vacation-experiences-of-children-with-autism-and-their-families-2165-7890.1000123.php?aid=21234>
- Benson, P., & Karlof, K. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism & Developmental Disorders*, 39, 350-362.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H., & Abbott, R. (2009). Parenting stress and psychological func-
- Falk, N. H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *Journal of Autism and Developmental Disorders* (12), 3185-3203. doi:10.1007/s10803-014-2189-4
- Lehto, 2009. Vacation and Family Functioning. Retrieved from <http://www.sciencedirect.com/science/article/pii/S0160738309000553>
- McCabe, H. (2007). Parent advocacy in the face of adversity: Autism and families in the People's Republic of China. *Focus on Autism and Other Developmental Disorders*, 22(1), 39-50.
- Phelps, K., Hodgson, J., McCammon, S., & Lamson, A. (2009). Caring for an individual with autism disorder: A qualitative analysis. *Journal of Intellectual & Developmental Disability*, 34(1), 27-35.
- Sawyer, M. G., Bittman, M., La Greca, A. M., Crettenden, A. D., Harchak, T. F., & Martin, J. (2010). Time demands of caring for children with autism: What are the implications for maternal mental health? *Journal of Autism and Developmental Disorders* (5), 620-628. doi:10.1007/s10803-009-0912-3
- Zablotsky, B. (2015). Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey. (2010, October 13). Retrieved from <http://www.cdc.gov/nchs/data/nhsr/nhsr087.pdf>

# Liberty Resources Announces Expansion of Service Area Through Recent Acquisitions

By Staff Writer  
Autism Spectrum News

**L**iberty 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 pediatric 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 Presi-



**John Torrens, PhD**  
**President, Liberty POST**

dent 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."



**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 continue 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.

*see Resources on page 24*

## 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 without 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 at 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 who 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 frequented 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 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.

*Kelly Imperial, MS, is the Director of Employment Training Services at the New York Institute of Technology Vocational Independence Program (VIP). She may be reached at [kimperia@nyit.edu](mailto:kimperia@nyit.edu).*

## References

- Brown, J., & DiGaldo, S. (Presenters). (2011). *Post-secondary and career issues faced by individuals with autism spectrum disorders*. Lecture presented at Annual meeting of the Connecticut Career Counseling and Development Association, Hartford, CT.
- Bureau of Labor Statistics. (2015). *Persons with a disability: Labor force characteristics summary* [Fact sheet]. Retrieved June 1, 2016, from <http://www.bls.gov/news.release/disabl.nr0.htm>
- Dipeolu, A., Storlie, C., & Johnson, C. (2014). College students with high-functioning autism spectrum disorder: Best practices for successful transition into the world of work. *Journal of College Counseling, 18*(2), 175-190.
- Lorenz, T., Frischling, C., Cuadros, R., & Heinitz, K. (2016). Autism and overcoming job barriers: Comparing job-related barriers and possible solutions in and outside of autism-specific employment. *PLoS ONE, 11*(1).
- Moyer, S. (2011). Building foundational skills now to improve employment outcomes in the future. Retrieved June 1, 2016, from Pathfinders for Autism website: <http://www.pathfindersforautism.org/articles/view/building-foundational-skills-now-to-improve-employment-outcomes-in-the-future-strategies-for-parents-of-children-with-autism-spectrum-disorder>
- Scott, M., Falkmer, M., Girdler, S., & Falkmer, T. (2015). Viewpoints on factors for successful employment for adults with autism spectrum disorder. *PLoS ONE, 10*(10).

# AUTISM SPECTRUM NEWS

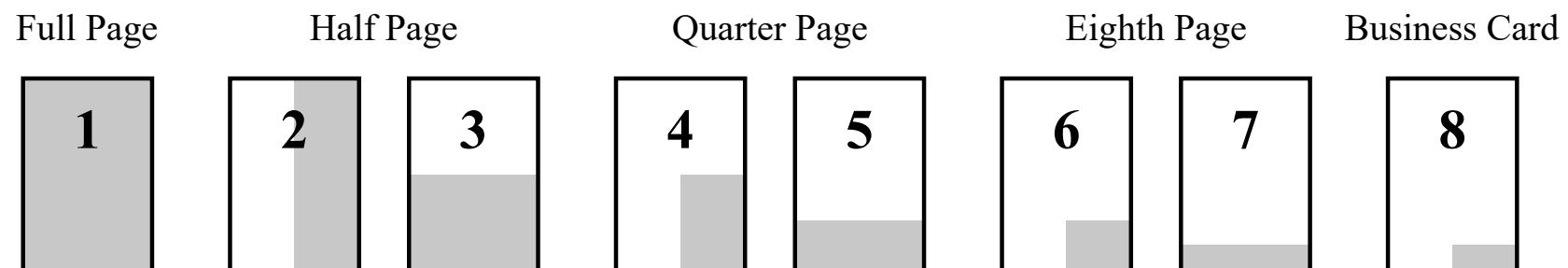
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***Supporting Parents from page 1***

of individuals supporting children with ASD (Catania, Almeida, Liu-Constant, & Reed, 2009; Digennaro-Reed, Coddington, 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 with 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

**Angela Nelson, MS, BCBA**

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.

According to Milt Ezzard, Head of Ben-

efits at Activision Blizzard, "We've found that highly specialized and targeted programs, like Rethink, are a much better fit for our employees and their families. As a result of moving away from outdated and costly clinical solutions, we're seeing increased engagement across all our programs and greater employee impact." Parents ultimately need an easy way to support their children and themselves, and technology is an answer. Going to work every day, having access to free supports, and being empowered to effectively care for their child outside of work, in turn, benefits them in the workplace as well. It just makes sense then for an employer to facilitate support for these parents. Delivery of this tailored parent training and support translates into a win-win-win for the employer, employee, and their child.

*For more information about the work Rethink is doing with employers, contact [support@rethinkbenefits.com](mailto:support@rethinkbenefits.com), (877) 988-8871, or visit [www.rethinkbenefits.com](http://www.rethinkbenefits.com).*

**References**

- Baker, D.L., Drapela, L.A., (2010). Mostly the mother: Concentration of adverse employment effects on mothers of children with autism. *The Social Science Journal*, 47, 578-592.
- Bearss, K., Johnson, C., Smith, T., et al. (2015). Effect of parent training vs parent education on behavioral problems in children with autism spectrum disorder: A randomized clinical trial. *JAMA*, 313(15), 1524-1533.
- Catania, C. N., Almeida, D., Liu-Constant, B., & Reed, F. D. D. (2009). Video modeling to train staff to implement discrete-trial instruction. *Journal of Applied Behavior Analysis*, 42(2), 387-92.
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38(7), 1278-91.
- Digennaro-Reed, F., Coddington, R., Catania, C. N., & Maguire, H. (2010). Effects of video modeling on treatment integrity of behavioral interventions. *Journal of Applied Behavior Analysis*, 43(2), 291-5.
- Drapela, L.A., & Baker, D.L. (2014). Correlates of negative experiences with health care providers and health care insurers among caregivers of children with autism spectrum disorders. *Sage Publications*, 4(3), 1-13.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, XH., Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism: The International Journal of Research and Practice*, 13(4), 375-387.
- Leblanc, M., Ricciardi, J. N., & Luiselli, J. K. (2005). Improving discrete trial instruction by paraprofessional staff through an abbreviated performance feedback intervention. *Education & Treatment of Children*, 28(1), 76-82.
- Therapies For Children With Autism Spectrum Disorder. (2012, May). Retrieved from <http://www.businessgrouphealth.org/about/evidence-deliverables.cfm>
- Training Helps Parents Reduce Challenging Autism Behaviors. (2015, April 21). Retrieved from [Kara Reagan, Ph.D., BCBA-D](http://www.kara-reagon.com).

***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](http://www.cdc.gov/autism). To learn more about SEED, please visit: [www.cdc.gov/SEED](http://www.cdc.gov/SEED).*

***Tech from page 23***

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

and there are 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 Kersstin 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**

- Dautenhahn Kerstin, & Werry Ian. (2004). *Toward interactive robots in autism therapy: Background, motivation, and challenges*. *Pragmatics & Cognition*, 12(1), 1-35. <http://doi.org/DOI: 10.1075/pc.12.1.03dau>
- Kozima H., Nakagawa C., & Yasuda Y. (2007). *Children-robot interaction: a pilot study in autism therapy*. *Prog. Brain Res.*, 385-400. [http://doi.org/10.1016/S0079-6123\(07\)64021-7](http://doi.org/10.1016/S0079-6123(07)64021-7)

**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 report lower levels of parenting stress. A multiple regression demonstrated that empowerment related to the family was most closely associated with parenting stress ( $\beta = -.69, p < .01$ ). 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, correlations demonstrated that family quality of life was positively associated with parent empowerment related to the family ( $r = .72, p < .01$ ), child services ( $r = .41, p < .01$ ), and community involvement ( $r = .46, p < .01$ ). As with parenting stress, empowerment related to the family was most closely associated with family quality of life in a multiple regression analysis ( $\beta = .71, p < .01$ ). Once again, empowerment related to child services and community involvement did not explain additional variance beyond that explained by family-related empower-

ment. This suggests that parent empowerment related to family life is most closely associated with both parenting stress and family quality of life. Parents who reported higher family-related empowerment also reported lower levels of parenting stress and higher overall quality of life.

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.

*Laura L. Corona, MA, and Stephanie A. Fox, MA, are Graduate Assistants, Center for Autism and Related Disabilities, Melissa L. Rinaldi, PhD, is a Clinical Investigator, and Kristin V. Christodulu, PhD, is Director of the Center for Autism and Related Disabilities ([www.albany.edu/autism/](http://www.albany.edu/autism/)). For more information about this research, contact Laura Corona at [lcorona@albany.edu](mailto:lcorona@albany.edu).*

**References**

- Abidin, R. R. (2012). *Parenting Stress Index* (4th ed.). Lutz, FL: PAR.
- Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups*, 33:1, 69-83.
- Karst, J. S., & Van Hecke, A. V. (2012). Par-

ent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, 15:3 247-277.

Keen, D., Couzens, D., Muspratt, S., & Roger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders*, 4:2, 229-241.

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 37:4, 305.

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6:1, 293-303.

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research*, 49:10, 777-783.

Tonge, B., Brereton, A., Kiomall, M., Mackinnon, A., King, N., & Rinehart, N. (2006). Effects on parental mental health of an education and skills training program for parents of young children with autism: A randomized controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45:5, 561-569.

Weiss, J. A., MacMullin, J. A., & Lunsky, Y. (2015). Empowerment and parent gain as mediators and moderators of distress in mothers of children with autism spectrum disorders. *Journal of Child and Family Studies*, 24:7, 2038-2045.

**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 Georgiades**, 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 has-

ten access to treatment and improve their outcomes relative to the siblings of controls, who receive a diagnosis later, Georgiades 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.

By 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 re-

search, 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.

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.org/news/psychiatric-problems-common-in-siblings-of-people-with-autism/>.*

**References**

- Jokiranta-Olkoniemi E. et al. JAMA Psychiatry 73, 622-629 (2016) PubMed

**Reducing Stress from page 20**

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

**Maggie Haag, LSW, CBIS**, is Director of Adult Campus Residential Services, Frank L. Bird, MED, LABA, BCBA, is Chief Clinical Officer, and Mary Jane Weiss, PhD, BCBA-D, is Executive Di-

rector of Research at Melmark. The mission of Melmark is to serve children, adults and their families affected by a broad range of intellectual disabilities. With service divisions in Berwyn, Pennsylvania, and Andover, Massachusetts, Melmark provides evidence-based educational, vocational, clinical, residential, healthcare and rehabilitative services,

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**References**

- Shattuck, P., et al. (2012). Services for

adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, 57, 284-291.

Smith, L. E., Greenberg, J. S., & Malick, M. (2012). Adults with autism: Outcomes, family effects, and the multi-family group psychoeducational model. *Current Psychiatry Repertoire*, 14, 732-738.

### **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, Dissanyake, Zierhut, Rogers, & Victorian ASELC 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 mealtime, 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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#### References

Rogers, S. J., & Dawson, G. (2010). Early Start Denver Model for Young Children with Autism: Promoting Language, Learning, and Engagement. New York, NY: The Guilford Press.

Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., ... Halladay, A. (2015). Naturalistic developmental behavioral interventions: Empirically validated treatments for autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 1-18. doi: 10.1007/s10803-015-2407-8

Stahmer, A. C. (2014). Effective strategies by any other name. *Autism*, 18(3), 211-212.

Vivanti, G., Dissanyake, C., Zierhut, C., Rogers, S. J., & the Victorian ASELC Team (2013). Brief report: Predictors of outcomes in the Early Start Denver Model delivered in a group setting. *Journal of Autism and Developmental Disorders*, 43(7), 1717-1724.

Vivanti, G., Paynter, J., Duncan, E., Fothergill, H., Dissanyake, C., Rogers, S. J., & the Victorian ASELC Team (2014). Effectiveness and feasibility of the Early Start Denver Model implemented in a group-based community childcare setting. *Journal of Autism and Developmental Disorders*, 44(12), 3140-3153.

Wetherby, A. M., Guthrie, W., Woods, J., Schatschneider, C., Holland, R. D., Morgan, L., & Lord, C. (2014). Parent-implemented social intervention for toddlers with autism: An RCT. *Pediatrics*, 134, 1084-1093.



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***Abuse from page 14***

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 caregiving 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 a danger of life, but with planning and creating strategies for increased safety, the reduction of risk is a worthy goal.

It must be said that most parents are not warned by their physician, case manager, school personnel, that abuse is more likely for children with disabilities than for those who do not have disabilities. I do not know why this is, but to counter this reality, I have developed a one page guide for parents, so that they are prepared. This Parents' Guide is called "Ten Tips for Parents" and is available on our website for free in English and Spanish (<http://disabilityandabuse.org/resources/index.htm>). I believe that being aware and prepared is far better than remaining blissfully unaware and unprepared.

Parents and agencies who have adopted the practices and strategies detailed in "A Risk Reduction Workbook for Parents and Service Providers to Individuals with Intellectual and Developmental Disabilities" have stated that they feel very much more prepared. The initial instruction, to treat

abuse similarly to other unwanted but likely events as discussed above, makes it easier to accept the idea of making a plan, and discussing the unwanted event with their loved one. By visiting the website of the Disability and Abuse Project at <http://disabilityandabuse.org/books/index.htm>, you can see the comments of our reviewers who contributed to the book by making their own assessments and recommendations.

The essence is that abuse is a serious problem for those with autism. Abuse cannot be prevented but the risk of it happening to your loved ones can be reduced. And, through careful planning and practice, if abuse does occur, all parties know what to do. This includes having access to therapy for both victim and parent or siblings. By planning ahead, victims more easily become survivors, and by working together families can heal more

quickly. Remember, knowledge is power.

To contact the author, send an email to [nora@disability-abuse.com](mailto:nora@disability-abuse.com) or visit [www.disabilityandabuse.org](http://www.disabilityandabuse.org).

**Useful Resources**

- Recognition of a Pattern, Call for a Response: A "Rule Out Abuse Campaign" for Physicians

<http://disabilityandabuse.org/resources/ten-point-guide-to-abuse-response.pdf>

- A Guide on Responding to Suspected Abuse of People with Developmental Disabilities

<http://www.disabilityandabuse.org/rule-out-abuse-physicians.pdf>

***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 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 conducted 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](http://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 wonder 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 significant other, and being proactive to prevent maladaptive behavior from occurring.

Parents also shared having family and friends close by can be a great resource. One parent expressed, "If you're lucky enough to have family close by, ask for help." Having a family member come over might allow you to get your household in order, run errands, or even socialize with 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 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.

**References**

Celiberti, D., Buchanan, S., Bleeker, F., Kreiss, D., & Rosenfeld, D.(2004). *The Road less traveled: Charting a Clear Course for Autism Treatment. Autism Basic Information*. COSAC, New Jersey.

Fry William, B. & Lee Williams, R. (2011). *Effective Programs for Treating Autism Spectrum Disorder: Applied Behavior Analysis Models*. Routledge, NY.

Maurice, C., Green, G., & Fox, R.M. (2001). *Making a Difference. Behavioral Intervention for Autism*. Pro-Ed, Austin, Texas.

### **Collaborate from page 19**

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 to avoid situations that erode collaboration experiences?

#### Right from the Start

Educators may become frustrated with what they perceive as negative experiences with families. It is indeed a difficult dance to get this right, and all educators experience successes and failures in their career during attempts to collaborate. As a former Special Education teacher, I recount my own experiences and frustrations with families. Sometimes I was able to create and maintain a good relationship with families while other times it seemed that no amount of effort was going to change the reality of the situation. I also recall hearing many negative statements from fellow educators regarding the parenting practices of my families, their "demands" or their child's behaviors. Now a faculty member responsible for preparing future teachers, I often hear my candidates express similar thoughts and frustrations, many of which appear to come directly from being socialized into the profession by more experienced educators. These perceptions appear to crystallize very early in the "life" of the educators we train. One possible and logical solution is that pre-service educators gain exposure to families directly in order to change their opinions *before* they become ingrained and hard to change.

#### Parent Panels: The Ultimate Experts

Practitioner-friendly information on collaboration with families is readily available in most textbooks as well as professional,

peer-reviewed articles crossing multiple disciplines (e.g. Edwards, C.C. & Da Fonte, A. 2012; Whitbread, K.M., Bruder, M.B., Fleming, G. & Park, H.J. 2007). No amount of written material can replace the power of an informant who presents the reality of life in human form. I had found that delivering information about the experiences of families as well as listing and reviewing best practices resulted in little to no development of understanding and empathy with my pre-service candidates. 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 developing.

#### 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 the 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 sto-

ry 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 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.

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#### References

Blue-Banning, M., Summers, J.A., Frankland, J.C., Nelson, L.L. & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children*, 70 (2), 167-186.

Edwards, C.C. & Da Fonte, A. (2012). The 5 point plan: Fostering successful partnerships with families of students with disabilities. *Teaching Exceptional Children*, 44 (3), 6-13.

Hess, R.S., Molina, A.M. & Kozleski, E.B. (2006). Until somebody hears me: Parent voice and advocacy in special education decision making. *British Journal of Special Education*, 33 (3), 148-157.

Wellner, L. (2012). Building parent trust in the educational setting. *Leadership*, 41 (4), 16-19.

Whitbread, K.M., Bruder, M.B., Fleming, G. & Park, H.J. (2007). Collaboration in special education: Parent-professional training. *Teaching Exceptional Children*, 39 (4), 6-14.

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### Legal Forms from page 13

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

Another common issue is that many people execute a health care proxy naming 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 wishes, and make sure that he or she is willing and able to carry them out. Sometimes a family member has a religious or other 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 children or other beneficiary who receives public benefits, but who have not coordinated their estate plan to ensure that all the assets they intend to bequeath to the beneficiary would go to the supplemental needs trust. Some may have accounts that are "payable on death" ("p/o/d") or "transfer on death" ("t/o/d") to the beneficiary, which mean that upon their death, the accounts would be distributed directly to the beneficiary, and not to the supplemental needs trust. This could adversely affect the beneficiary's public benefits. Reviewing how accounts are titled, and updating or changing that where necessary, is an important part of estate planning.

Some people have a beautifully drawn revocable trust to avoid probate, but they never fund the revocable trust. If assets are not properly transferred into

the trust and are held in your own name alone, the assets may need to go through probate. It is important to make a list of your assets and then transfer the appropriate assets (but not any retirement accounts) to the revocable trust to avoid or minimize probate.

We have also seen situations where people have had irrevocable trusts prepared for asset protection purposes, for example, to protect a co-op, but then never transferred their co-op shares into the trust. If the shares are not transferred into the trust, then the trust provisions do not govern the co-op shares. It is important to have the correct trusts prepared, but just as much care should be taken to make sure that the trusts are properly funded and that the assets are titled correctly.

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

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### Functional from page 26

**Social Skills** - An individual's ability to participate in their community is, to a large extent, dependent upon their ability to interact with others. Social skills are the skills necessary that facilitate interaction and communication with others. Under normal circumstances, social rules and relations are developed without specific teaching. However, for individuals with intellectual disabilities, specific teaching strategies may be necessary to develop appropriate social behavior, such as respecting 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 ability to be integrated into the community is often directly dependent on the absence of maladaptive behavior. Specifically, the presence of problem behavior significantly limits an individual's ability to participate in functional activities. Effective, function-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 appropriate alternative behavior, and strategies 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 communication skills (e.g., appropriate ways to ask for a break, attention, preferred items and activities), in addition to various strategies 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 variety of domains, are specific to an individual's natural environment, and are more than just what an individual needs to survive. These skills are essential to achieving 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 on their own, they will require more restrictive environments with fewer opportunities 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 functional skills affords more choices in life and lessens the need for intensive support. Functional skill development allows the individual to be more integrated with his or her community and increases opportunities for gainful employment and volunteer work. Sound functional programming can lead to the development of adaptive hobbies and leisure activities. Actively participating in the community and maintaining gainful employment can lead to a more rewarding lifestyle.

The benefit of sound functional skills programming extends beyond the individual. Benefits can be seen among friends and family members through the establishment of more meaningful relationships with others. Family members can spend less time providing intervention and more time enjoying interactions with their loved ones. In addition, the more functional and independent an individual is, the less need there is for support. In short, individuals who do not require intensive support and services require less financial support than those who are unable to function on their own, so costs may be reduced for family members and taxpayers.

These factors underscore the importance of selecting sound functional goals for individuals with intellectual disabilities. The acquisition of self-care, domestic, recreational, community safety, pre-vocational/vocational, social, and behavior management skills are of paramount importance

for improving outcomes for this population. To aid in the selection of appropriate goals, tools like the Vineland Adaptive Behavior Scales II, the Scales of Independent Behavior-Revised, and the Assessment of Functional Living Skills can provide a roadmap for practitioners to target necessary skill areas.

We should always be focused on the acquisition of skills that are immediately useful, practical, helpful, and beneficial. As parents and practitioners, we should question the need for each goal being addressed. Is this skill important? Is this skill a component of a larger, important skill? Is this goal going to make a meaningful difference 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 similar goals), which can lead to wasted time and frustration on the part of the individual. As a general rule, if a program is not promoting independence, parents and practitioners should be doing something else. Everything that we target as educators should prepare individuals with intellectual disabilities for the post-school environment that they will be living in.

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#### References

Ayres, K. M., Lowrey, K. A., Douglas, K. H., & Sievers, C. (2011). I can identify Saturn but I can't brush my teeth: What happens when the curricular focus for students with severe disabilities shifts. *Education and Training in Autism and Developmental Disabilities*, 46, 11–21.

Bannerman, D., Sheldon, J. B., Sherman, J. A. & Harchik, A. E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis*, 23, 79-89.

Bruininks, R. H., Woodcock, R. W., Weathersman, R. F., & Hill, B. K. (1996). SIB-R. *Scales of independent behavior-revised*. Itasca, IL: Riverside Publishing.

Conderman, G. & Katsiyannis, A. (2002). Instructional issues and practices in secondary special education. *Remedial and Special Education*, 23(3), 169-179.

Courtade, G., Spooner, F., Browder, D., & Jimenez, B. (2012). Seven reasons to promote standards-based instruction for students with severe disabilities: A reply to Ayres, Lowrey, Douglas, & Sievers (2011). *Education and Training in Autism and Developmental Disabilities*, 47(1), 3-13.

Favell, J. E., Favell, J. E., Riddle, J. L., & Risley, T. R. (1984). Promoting change in mental retardation facilities: Getting services from the paper to the people. W. P. Christian, G. T. Hannah, & T. J. Glahn (Eds.). *Programming Effective Human Services: Strategies for Institutional Change and Client Transition*. (pp. 15-37). New York: Plenum.

Harrison, P. L., & Oakland, T. (2003). Adaptive Behavior Assessment System (2<sup>nd</sup> ed.). San Antonio: Harcourt Assessment.

Partington, J. W. & Mueller, M. M. (2012). AFLS. The assessment of functional living skills. Marietta, GA: Stimulus Publications.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2008). Vineland adaptive behavior scales: (Vineland II), the expanded interview form. Livonia, MN: Pearson Assessments.

Watanabe, M. & Sturmey, P. (2003). The effect of choice-making opportunities during activity schedules on task engagement of adults with autism. *Journal of Autism and Developmental Disorders*, 33, 535-538.

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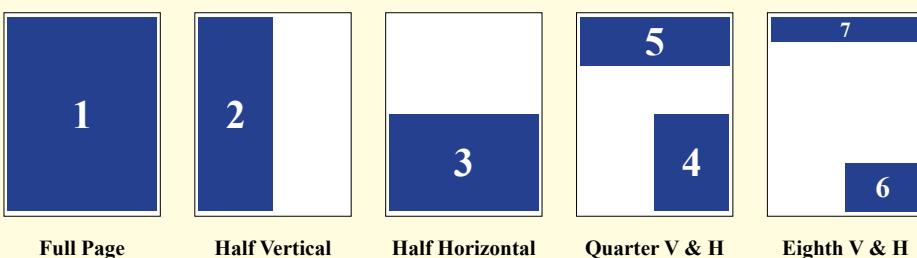
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