

The Best of *The OARacle*:
A Compilation of Articles from 2002-2007

Published by the Organization for Autism Research

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October 26, 2007

Dear Friends of OAR,

“Raise money. Fund research. Change lives.” When people ask what OAR does, that’s my simplest, clearest response. The first two tell what OAR does and are immediately understood; the last explains OAR’s fundamental and ultimate purpose and typically leads to another question, “How do you do that?”

Five years ago as OAR was taking its first steps, I would respond in the future tense, optimistically describing OAR’s near term goals and what specifically we hoped to accomplish in the coming year. Today, as OAR approaches its sixth birthday, there is an ever expanding body of work that speaks for OAR and begins to explain how OAR is changing lives.

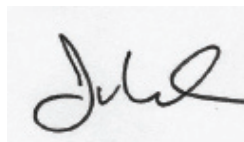
Not every one may recall who Sun Tzu was, but I’m sure most people have heard or read his patient counsel, “A journey of a thousand miles begins with a single step.” Parents of children with autism have no difficulty interpreting Sun Tzu’s meaning. Their autism journey begins with a single, unsettling step lfrom the moment their child is diagnosed with autism and lasts for life. OAR’s role is to help make the next and successive steps in between more confident and more informed.

We do that through our Web site, annual conference, and now four excellent guides in the Life Journey through Autism series. But we do it most often and most consistently through OAR’s monthly newsletter, *The OARacle*. Since the first issue in September 2002, *The OARacle* has offered news related to autism research balanced with the type of “how to” articles that provide insight and tips for dealing with the myriad, daily challenges of autism. Each useful nugget supports another single step in the journey.

Last month, *The OARacle* celebrated its fifth anniversary. As the OAR staff explored ways to create an index for the newsletter, the idea for this, *The Best of The OARacle*, emerged. For OAR, it is another significant milestone and yet another step in our journey. We offer it as another OAR resource that will better inform and guide you in yours.

Raise money. Fund research. Change lives. One step at a time. That’s what OAR does.

Sincerely,

A handwritten signature in black ink, appearing to read "James M. Sack", is centered on a light gray rectangular background.

James M. Sack
Chairman

October 26, 2007

Dear Friends,

The OARacle, the e-newsletter of the Organization for Autism Research (OAR), has been OAR's flagship publication since the first issue in September 2002. Intended to provide the autism community with news on OAR's progress as an organization, the latest developments in autism research, and practical information on intervention and simply living with autism, *The OARacle* has been a source of accurate, accessible, and useful autism-related information now for just over five years. That is a source of great pride to all of us at OAR. So proud, in fact, that we thought it time to delve into *The OARacle* archives and collect some our best articles into one, user-friendly volume that you are now holding in your hands.

The Best of The OARacle is the distillation of effort by a great many people including OAR staff, respected professionals, dedicated parents, and talented individuals on the spectrum. Compiling a "Best Of" anything, as I have learned through this process, is a difficult and somewhat arbitrary task. What makes one article "better" than another? We took a number of variables into consideration: substantive things such as the clarity of the writing, relevance of the topic, and practicality of the information (and so on) as well as practical constraints like the maximum number of pages we could print and stay within budget. As such, many excellent articles were omitted simply due to space requirements. Thankfully, they all remain available to you through the OAR Web site (www.researchautism.org).

I mentioned *The OARacle* was the product of a great many people, and that is certainly true. As such a great many people can share credit for this Best of compilation. However, the singular vision that has guided *The OARacle* since its inception has been that of OAR's Executive Director, Michael Maloney. Mike's commitment to producing a "quality product for a critical cause" can be seen in every article in every edition we have published. While Mike is quick to give credit to many others including me, the lion's share of credit for *The Best of The OARacle* belongs to him.

I trust you will find our efforts in producing this volume to have been time well spent. I offer congratulations to the authors whose articles are included here and salute all the authors who have contributed to *The OARacle* since the beginning for their support of OAR and dedication to applied autism research. To the editors past and present, I reserve special thanks for your time, talents, and expertise in helping to make *The OARacle* the quality product that it is. And to you, the reader and the person for whom OAR publishes *The OARacle*, thanks for your interest in good applied research and your belief in the need for evidence-based practice in support of learners with autism and their families.

Now it's time for you to read *The Best of The OARacle*. As it is with each monthly issue, you're the judge when it comes to determining if meets Mike's and your quality standards. I am confident you won't be disappointed.

Sincerely,



Peter F. Gerhardt, Ed.D.
President & Chair, Scientific Council

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History and Mission

The Organization for Autism Research (OAR) is a nonprofit organization formed in 2001 and led by relatives of children and adults with autism and Asperger Syndrome. OAR promotes research that helps families, educators, caregivers, and individuals with autism find much-needed answers to their immediate questions. Committed to excellence in its services to the autism community, OAR funds research that offers to make a difference in individual lives; provides information that is timely, and presents opportunities for collaboration within the autism and research communities.

OAR's mission is to apply research to the challenges of autism.

Programs and Accomplishments

- Published four resource guides in the *Life Journey through Autism* series: *A Parent's Guide to Research*, *An Educator's Guide to Autism*, *An Educator's Guide to Asperger Syndrome*, and *A Guide for Transition to Adulthood*
- Held six national research competitions that have attracted 263 research proposals since 2002, and resulted in funding more than \$1 million in new applied autism research studies: 27 grants/\$960,000 for pilot studies and \$68,000 in grants to 38 graduate student researchers
- Hosted the Applied Autism Research and Intervention Conference, a forum featuring workshops and presentations by leading autism speakers from across the United States in every year since 2003
- Developed the *RUN FOR AUTISM* into a national event through partnerships with the Marine Corps Marathon™, The LaSalle Bank Chicago Marathon®, and races in Houston and Miami
- Publishes *The OARacle*, an e-newsletter that provides research and information updates to thousands of families each month since September 2002
- Received an unqualified opinion from an independent auditor in every year since its founding in 2001 and has an overhead-to-revenues ratio under 16 percent in the most recent fiscal year
- Hosted the first Autism Research Convocation focusing on Evidence-based Interventions in Support of Adolescents and Adults with Autism Spectrum Disorders in June 2006
- Established the annual the Schwallie Family Scholarship Program in September 2007 for persons with autism spectrum disorders attending college or enrolled in post-secondary vocational training
- Published *The Best of The OARacle 2002-2007*, a collection of the articles selected as "best" based on the importance of the topic, quality of writing, and practical value to the community

Near-Term Goals

OAR maintains its focus and measures its progress against the goals and objectives set by the Board of Directors annually. OAR's goals for the next one to three years are to:

- Publish and distribute the *Proceedings* from the June 2006 Autism Research Convocation that will include papers, a literature review, and a 10-year research plan
- Fund eight to ten new research studies (\$390,000 in total grants) annually through the annual competition
- Create and publish *A Guide to Assessments* and *A Guide to Residential Supports* as the fifth and sixth guides in the *Life Journey through Autism* series of community-oriented resource guides

- Plan, organize, and host the second Autism Research Convocation with a focus on Social Skills and Adaptive Behaviors
- Continue to host the Applied Autism Research and Intervention Conference annually
- Continue to expand the *RUN FOR AUTISM* with a goal of raising \$1 million annually
- Expand the Graduate Research Grants Program to 30 grants/\$50,000 in total grants annually

Target Interests for the Next Five Years

On June 4, 2007, OAR's Board of Directors met in New York City to plan the next five years. The directors had with two immediate purposes in mind. First, they wanted to assess OAR's performance since 2001 and determine how to build on the foundation OAR had established. Then, they sought to identify key mission areas, above the level of the current programs, where OAR could make a difference in terms of quality of life for persons with autism; their parents and families; and the persons, schools, and agencies that provide support, education, and services for individuals with autism and their families between now and the year 2012.

To do that, they began by asking and discussing the following questions.

- **Who are we now, and what do we represent?**
- **What should we be doing next? How does OAR extend its reach and fulfill its stated purpose, "Research and resources that help families today"?**
- **Where does OAR go from here in the next five years?**

Before the Board moved to the discussion of OAR's future directions, its first decision was that OAR would maintain and continue to expand its proven program functions: funding applied research studies; informing the community through the monthly e-newsletter and Web site; and educating consumers through the annual conference, the Convocation Proceedings, the Speakers' Program, as well as through sponsorship, collaboration, and participation in conferences, seminars, and professional forums sponsored by other autism and disability-related organizations.

Having made maintaining excellence in its current program a fundamental marching order, OAR's Board members then turned their eyes toward the future asking themselves:

- What are the top three to five issues facing the autism community that relate to OAR's mission?
- What can OAR do to address these issues?
- What are OAR's goals in each of these issue areas?

After a wide-ranging discussion that produced a host of worthy ideas, the Board agreed on the following areas as primary targets for new, major initiatives by OAR:

Housing and residential services and supports. Housing and residential services and supports emerged as an area of urgent and largely unmet. The excellent programs that do exist are few and far between. Furthermore, they have waiting lists and thus offer little prospect for ever being able to fully accommodate all those waiting.

OAR has made housing and residential services and supports a top priority as a new program area for the next five years. In the near term, OAR plans to write and publish *A Guide to Housing and Residential Supports* as the sixth publication in the *Life Journey through Autism* series. OAR also plans to design and fund a demonstration project intended to lead the way to more broad-based housing options that offer greater access to more families contending with the challenges of finding long-term housing alternatives for their loved ones with autism.

Employment. OAR continues to explore ways to open doors into the workplace for persons with autism. Having one of the most competent and respected autism professionals in the U.S. with respect to adolescents and adults with autism on staff in the person of Dr. Peter Gerhardt, OAR is well-suited to take the initiative in this area. As in the area of housing and residential services and supports just discussed, OAR's objective is to design and fund a project in collaboration with private sector corporations that will demonstrate the capabilities and work potential of persons with autism.

Respite. This is an area of high need for parents and families across the board regardless of the age of the loved one with autism. In approaching respite, OAR defines it broadly as encompassing all those elements that combine to provide a safe, secure environment for the person with autism and a corresponding sense of security and relief for parents and caregivers. In other words, OAR is examining things that both support and provide respite for the person with autism as well as his or her parents and siblings. OAR's intent is to develop a pilot program that offers respite information, support, and services for families touched by autism within the next two years and then expand upon it as resources allow.

OAR's Vision

OAR's vision is to be the leader in using science-based research to provide practical answers, alternatives, and solutions to the autism community. This vision expresses a future in which OAR leads the way in funding applied autism research and in providing practical, evidence-based information to the autism community. It establishes our intent to see steady growth in fundraising, provide sustained support for applied autism research, and continue to seek the best ways to use scientific methods and results to inform and educate all the stakeholders in the autism community. Most of all, OAR's vision is for a future where the collaborative efforts of many good organizations including OAR leads to a global understanding of autism that emphasizes abilities and possibilities over disability.

Evidence-Based Intervention

The Organization for Autism Research is dedicated to supporting solid, applied research into effective interventions and supports for learners on the spectrum and their families. The educational, social, and behavioral strategies that arise from such research are generally referred to as evidence-based interventions or practices. A great many of the articles published in *The OARacle* over the past five years have focused on the importance of research outcomes guiding our intervention practices. The articles contained in this section of *The Best of The OARacle* highlight different aspects and areas of evidence-based practice primarily with school age learners on the spectrum.

April 2005

On Science, Pseudoscience, and the Mega-Millions Lottery

By Peter Gerhardt, Ed.D.

First, I need to disclose something... on a weekly basis I buy two or three "Mega-Millions" lottery tickets. I do this despite the fact that I fully realize my chances of winning are, effectively, none, zero, zip, nada, zilch. I understand statistics and probability theory and that the only realistic outcome of my behavior is that I will lose two or three dollars every week. Yet, I still buy tickets. Why? Because, like the ads tell me, "I gotta be in it, to win it." While my odds of winning when I buy a ticket are pretty much zero, my odds of winning when I don't buy a ticket are absolute zero. And this small perception of difference allows me to accept a statistically impossible outcome (my winning mega-millions) to explain away the fact that, on a weekly basis, I donate up to three dollars to the state of Maryland with no possible, realistic expectation of a return.

Now you know the truth. In this case, the testimonials of the winners (pseudoscience) carry more weight for me than my understanding of probability (actual science). It seems that my behavior, at times, is shaped not by the science I know, but by the outcomes I desire. For families of learners with autism spectrum disorders, the same can often hold true.

A father of a young man with autism I know once explained to me that the reason he had tried so many alternative therapies was the "what if" factor. "Maybe those other therapies didn't work," he explained, "But what if this new one does?" What if? For him, the greatest risk was in not trying something that might help his son achieve any number of desirable outcomes. Those desirable outcomes (e.g., language, independence, social competence, friends, absence of challenging behavior, diagnostic reversal, and happiness) are formidable motivators which may shape behavior away from embracing science, with its effortful and often plodding pace, and toward an acceptance of pseudoscience which promises greater results than science with, usually, significantly less effort. As noted by Tavis (2003), "Pseudoscience is particularly attractive because [it], by definition, promises certainty, whereas science gives us probability and doubt. Pseudoscience is popular because it confirms what we believe; science is unpopular because it makes us question what we believe," (p. xv-xvi). Pseudoscience, then, in behavioral terms, would appear to offer up some pretty powerful reinforcers for its acceptance.

About This OARacle Contributor

Peter Gerhardt, Ed.D., is OAR's president. He has over 25 years experience working with adolescents and adults with Autism Spectrum Disorders in educational, employment, and community-based settings. He is the author or co-author of articles and book chapters on the needs of adults with autism spectrum disorder, the school-to-work-transition process and analysis and intervention of problematic behavior. He has presented nationally and internationally on these topics. Dr. Gerhardt received his doctorate from Rutgers, the State University of New Jersey Graduate School of Education.

So if I understand this phenomenon, and even acknowledge its impact on my own behavior, why do I continue to argue in support of the slow pace of science and against the, admittedly attractive, "quick fixes" often offered by pseudoscience? The answer is simple: It is because I do understand the phenomenon and can acknowledge its impact on my own behavior that science and the scientific method, need to be championed. The competing reinforcers are powerful, yes, but to do otherwise, I am sorry to say, is a poor use of valuable, effective and, often, scarce resources.

On a weekly basis I put my three dollars to poor use. True, but the downside is pretty minimal. Diverting our attention from effective interventions however, is a regrettable use of the learner's time, a good teacher's abilities, scarce fiscal resources, the talents and training of speech pathologists, behavior analysts, and any number of related support personnel and, of course, the energy and enthusiasm that families will need to meet their children's needs across, in many

cases, a lifetime of challenges and possibilities. We should not be willing to waste any of these resources. The downside here, it seems, is pretty significant.

This brings us to the research mission of OAR: raise money, fund research, change lives. Counting this year's funding cycle, OAR will have funded \$360,000* in applied research to benefit learners with ASD and their families. That is pretty significant by any measure. But now comes a challenge: the application of research to change lives. If good research is to compete (yes, compete) with the promises and testimonials of pseudoscience, it needs to be able to be translated into practice both easily and effectively. Yes, there continues to be a need to educate consumers (family members, professionals, etc.) about how to access and assess good research, and best evaluate potential interventions. However, there is also a need for members of the research community to make every effort to ensure that their research is accessible (e.g., readable, practical, relevant, etc.) to those who are the intended beneficiaries. If we fail to meet this challenge, researchers will continue to congratulate each other on their elegant designs and important outcomes, and the reinforcers associated with adopting pseudoscience will remain a powerful force within the autism community. Good research is only part of the goal. Good research that translates into practice and has the potential to improve lives: that is the true goal.

Embracing science in autism treatment is not about accepting less. It is, in fact, about demanding more. The use of evidenced-based interventions is not about ignoring the complex diversity that is the spectrum. It is, instead, about respecting each individual as worthy of our best efforts, which means the provision of instruction, assessment, intervention, services, and supports that science has shown to be the most effective.

*With the 2007 Grant Awards, OAR will have awarded more than \$1,300,000 in applied research funding to benefit learners with ASD and their families.

References

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March 2007

Understanding Autism: From Intervention to Outcome

By Michael Alessandri, Ph.D., and Roberto Tuchman, M.D., FAAN, FAAP

Despite reports that outcome in individuals with autism spectrum disorders may be improving following early intensive interventions, we still have much to learn about the natural history of the disorders and the effects of intervention. While there may not yet be a known cure for autism, a number of viable (although not always easily accessible and affordable) treatment options are available. The primary therapeutic approaches are non-pharmacological treatments that include applications of behavior analysis (e.g., Koegel, Koegel, and Mc-Nerney, 2001; Lovaas and Smith, 1989; McEachin, Smith, and Lovaas, 1993; Schreibman, 2000; Sundberg and Michael, 2001), developmental theory (Wieder and Greenspan, 2003), structured teaching (e.g., Panerai, Ferrante and Caputo, 1997; Panerai, Ferrante, and Zingale, 2002), and various ancillary therapies. There is limited empirical support documenting that any of these approaches has an impact on the core social-communication disturbance in autism, with the possible exception of an emerging literature on joint attention as a behavioral intervention target (e.g., Jones and Carr, 2004; Whalen and Schreibman, 2003; Whalen, Schreibman, and Ingersoll, 2006).

About These OARacle Contributors

Dr. Michael Alessandri is the director of the University of Miami Center for Autism and Related Disabilities, clinical associate professor of psychology at the University of Miami, and a member of OAR's Scientific Council. He has worked with individuals with autism and their families for over 25 years. Prior to arriving in South Florida in 1996, Dr. Alessandri was an Assistant Professor of Psychology at San Jose State University (SJSU) and Associate Director of the Stanford University Pervasive Developmental Disorders Clinic.

Dr. Roberto Tuchman is the director of Autism Programs at Miami Children's Hospital Dan Marino Center and the director of Developmental and Behavioral Neurology at Miami Children's Hospital. He was the founding director of the Miami Children's Hospital Dan Marino Center for children with developmental disorders, serving as its executive medical director from its start in 1998 through 2001. Dr. Tuchman is an associate professor of neurology at Miami Children's Hospital, in association with the University of Miami's Miller School of Medicine.

The role of pharmacological interventions is best thought of as adjunctive and is typically limited to treating specific symptoms (not core social-communication symptoms) that appear to be interfering with a child's ability to learn or function within a particular environment. The question of whether or not we can cure autism needs to be discussed in terms of the need to overcome the as yet poorly understood fundamental disturbance in autism and to develop treatment protocols specifically targeting social deficits. At the present time, it is more appropriate to speak of our quest to understand autism than it is to speak of a cure.

Behavioral and Educational Interventions

Autism includes a heterogeneous group of people with behavioral deficits in social cognition, communication, and with a restricted range of interests and repetitive behaviors (Rapin and Katzman, 1998). A wide range of cognitive challenges and a variety of behaviors and medical conditions are known to be associated with the autism spectrum. Despite the complexity of this disorder, emerging data from neurobiological investigations suggest that we can identify specific networks that are crucial for social communication (Adolphs, Baron-Cohen, and Tranel, 2002; Grady and Keightley, 2002). The hope is that by identifying social deficits early we can implement behavioral and educational interventions that will address these core social challenges and also be specific enough to maximize each child's potential. In the absence of a reliable biological marker for autism, un-

Understanding the determinants of prognosis and assessing the impact of interventions is a difficult undertaking. While a high degree of parental satisfaction with treatments appears to exist, instances of “recovery” are hard to document and the majority of children with autism require continued dependence on therapy and structured educational settings (Boyd and Corley, 2001). We will address aspects of this problem not by trying to determine if a cure for autism is a reasonable or achievable goal but instead by discussing what we know and what we need to learn about outcomes and interventions in children with autism spectrum disorders.

Numerous “psycho-educational” interventions have been described for use with individuals with autism spectrum disorders over the years, but few have been well-researched and validated. Nevertheless, these non-pharmacological educational approaches continue to be the primary treatments for autism spectrum disorders (Lord et al., 2001). While an expanding literature supports the utility of well-structured, highly engaging, intensive, individualized treatments for those affected by autism (Howlin, 1998; Lord et al., 2001), much remains to be learned about intervention in autism. Perhaps most importantly, there are typically large individual differences in response to treatment, the impact on core social-communication symptoms remains unclear, and little is known about which methods are best suited to specific individuals with autism spectrum disorders. Until the etiological and underlying neurobiological factors are more clearly elucidated and we become better informed about specific clinical subgroups, these challenges will remain.

Numerous specific interventions have been proposed since Kanner first identified autism in 1943. These varied approaches represent a range of intervention philosophies (i.e., behavioral, developmental, cognitive), and while they are typically presented as distinct, one is likely to observe notable similarities in the actual clinical application of the principles in real-world therapeutic settings. In fact, Dawson and Osterling (1997) have identified several critical common programmatic elements that may ultimately prove more important than any fundamental differences in “philosophy.” Included among these critical program elements are: scope and sequence of curriculum; supportive teaching environments with strategies and opportunities for generalization of skills; predictability and routines; functional approach to problem behavior; transition planning; and family involvement.

Pharmacotherapy

The use of medications in autism is typically limited to targeting specific symptoms that, although common in autism, may not be fundamental to the disorder (Arnold et al., 2003). This focused use of pharmacotherapy in autism is important, but what it means for the long-term outcome of those affected remains unclear (Buitelaar, 2003). For example, the use of antipsychotic medications for management of difficult behaviors and the use of anti-epileptic drugs to treat seizures are common practices in the clinical management of those with autism (Aman, Van Bourgondien, Wolford, and Sarpfahre, 1995), but their primary role in autism has not been established.

Despite successful uses of medications in autism to treat symptoms such as anxiety, obsessive-compulsive behaviors, aggression, impulsivity, and hyperactivity (Aman and Langworthy, 2000; Gilman and Tuchman, 1995; Santosh and Baird, 2001; Tsai, 1999), there are no reports of significant changes in the long-term outcome of children treated with medications relative to the social deficits that primarily define the disorder (Posey and McDougle, 2001). Furthermore, psychopharmacology in autism has several other critical limitations, as reviewed by Palermo and Curatolo (2004). Some of the concerns include the small number of subjects treated under controlled conditions, few double-blind studies, the lack of consistent replication, and the short duration of medication trials. In addition, reliable instruments to measure medication effects are not readily available, and there appears to be limited cooperation between the medical and educational communities in designing appropriate studies (Arnold, Aman, Martin, Collier-Crespin, Vitiello, Tierney, et al., 2000). Finally, the magnitude of improvement reported by investigators studying the effectiveness of medications on autism is of limited overall significance for the individual child. To date, few current studies allow us to determine the efficacy of medications, and evaluating pharmacotherapy efficacy in autism is further complicated by the differences in signs and symptoms that occur in autism at different developmental stages, the variability in response to medication, and the lack of clear end-points and specificity of the medications (Aman et al., 2004).

Predictors of Outcome

The most reliable predictors of outcome are level of intelligence and ability as measured by IQ and language tests (Nordin and Gillberg, 1998). While it seems apparent that outcomes vary widely, few long-term outcome studies are available, and those that are generally indicate a trend toward relatively poor outcomes for the majority of those affected by autism (Gillberg, 1991; Howlin, Goode, Hutton, and Rutter, 2004). Even those with high-functioning autism or Asperger Syndrome are frequently described as dependent adults who require rather extensive supports from their families and society (Engstrom, Ekstrom, and Emilsson, 2003).

The idea that long-term outcome in individuals with autism may be improving secondary to early intensive behavioral interventions is not without debate and continues to lack consistent empirical support (Howlin, 2003; Shea, 2004). While it appears from a clinical or anecdotal perspective that children with autism are benefiting from early identification and intensive intervention, there is limited evidence to support the idea that children with autism who respond to treatment with improvements in language, IQ, achievement, and adaptive functioning (e.g., Harris, Handleman, Gordon, Kristoff, and Fuentes, 1991; Lovaas, 1987; McEachin, Smith, and Lovaas, 1993; Sallows and Graupner, 2005) are less symptomatic with respect to the core deficits of autism. We still have much to learn regarding the natural history of autism, the predictors of outcome, and the types of interventions that can yield a positive effect on outcomes related to the core disturbance in autism.

Summary

Successful psychoeducational intervention programs appear to share a number of common elements such as high intensity, engagement, structure, and family involvement; the philosophical approach guiding the interventions may ultimately prove less important than the presence of these common elements. Medications are best used to treat specific behaviors or a specific medical condition, such as clinical seizures, that interfere with an individual's life or with the integration of an individual within a family or community.

Although we have certainly come a long way in determining what constitutes generally effective instructional practices and rational pharmacotherapy, we have much to learn about the fundamental deficit in autism and how to target our interventions to change the social deficit that is at the core of autism. There remains significant disagreement among professionals about what constitutes "best practices"—those interventions which maximize an individual's potential and lead to successful outcome (Goldstein, 2002; Koegel, 2000; McConnell, 2002; Rogers, 2000). What research has demonstrated in terms of effective practices does not always widely translate to clinical settings; "best practice" is not necessarily "common practice." Finally, there remains a lack of specificity in autism intervention. An elucidation of autism clinical subtypes, including biological markers, is clearly warranted. The types of intervention and potential neurobiological factors that may predict successful outcome need to be further clarified (Howlin, 1997; Kasari, 2002; Wolery and Garfinkle, 2002).

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Things Parents Should Know to Access Effective Educational Services for Children with Autism

By Anita Breslin, Psy.D., BCBA

It is currently estimated that approximately one in 166 children have an autism spectrum disorder (ASD). Public schools throughout the country are faced with an increasing number of classified children who present with an ASD diagnosis and there is much debate as to whether our educational system can appropriately meet the educational needs of children with this multifaceted disability. Thus, to conclude that we are facing a crisis of epidemic proportion at state and national levels is no exaggeration.

Over the last decade, professional endeavors have provided me with opportunities to learn much about the struggles experienced by parents as they face the multitude of “interventions” currently available. Michael Shermer, publisher of Skeptic magazine and author of the book *Why People Believe Weird Things*, contributed an article which appeared in the spring 2003 quarterly newsletter of the Association for Science in Autism Treatment (ASAT). Shermer contends that belief in the “paranormal” continues to exist in the general population and is not an uncommon phenomenon among even the college-educated.

“Science is not a database of unconnected factoids but a set of methods designed to describe and interpret phenomena,” Shermer maintains. “Past or present, [science] is aimed at building a testable body of knowledge open to rejection or confirmation.”

Service providers have an obligation to provide effective evidence-based treatment services to individuals with autism. Although there continues to be a wide array of interventions for persons with autism, applied behavior analysis (ABA) is distinguished from other interventions because it has been proven effective in promoting skill development in persons with autism. Research has demonstrated that ABA promotes meaningful and lasting behavior change in persons with autism (Green 1996). Despite this fact, behavior analytic intervention programs in New Jersey, for example, both public and private, are limited in number.

The importance of early intensive behavior analytic educational services for children with autism cannot be overemphasized. Howard, Sparkman, Cohen, Green and Stanislaw (2005) compared three different intervention approaches (intensive behavior analytic intervention, eclectic intervention, and non-intensive early intervention) for preschoolers diagnosed with ASD and found that children in the intensive behavior analytic treatment (IBT) group achieved statistically significant higher mean standard scores in all assessed domains (with the exception of motor skills). Additionally, children in the IBT group demonstrated higher learning rates at follow-up than children in the two comparison groups.

It was determined that, during a treatment period of 14 months, the rate of skill acquisition in most domains for children who received intensive behavior analytic treatment “matched or exceeded the normal rate of one year of development per year of age.” In contrast, the investigators found that learning rates in children in the comparison groups fell far below the normal range. The researchers emphasize the importance of early intensive behavior analytic intervention for children with autism in order to narrow the gap that often exists between the skill sets of these children with those of their typically developing peers. If students with autism are to benefit from inclusion,

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they must be equipped, with or without support, to manage the academic and social demands of the regular education setting.

Effective networking is perhaps the most important skill a parent can acquire in accessing appropriate educational services. Developing this multifaceted skill is especially critical given the limited available resources as well as the complexities involved in interfacing with agencies, school districts, and medical professionals once the need for special education services has been identified. Determining whether a program can provide intensive, systematic, data-driven and, ultimately, meaningful intervention services for a child with autism requires a great deal of time, effort, and coordinated multi-disciplinary manpower. In many instances, parents can and do benefit greatly from the support of other parents, medical professionals, advocates, special education counsel, and experts in the field of autism who can assist in determining the extent to which a particular educational program can appropriately meet the unique educational needs of a given child.

The following steps should be considered when seeking to obtain evidence-based intervention services for children with this pervasive developmental disability.

1. Review the various intervention options available. It is recommended that parents take a very active role in researching treatment options and evaluating the extent to which a particular intervention has the backing of scientific research. The Maine Administrators of Services for Children with Disabilities' (MADSEC) Autism Task Force emphasizes the importance of peer-reviewed studies in evaluating the efficacy of interventions. MADSEC concludes that applied behavior analysis "has been objectively substantiated as effective based upon the scope and quality of science."
2. Evaluate and determine the availability of services in your community. The Behavior Analyst Certification Board (BACB) provides a Certificant Registry, listing those individuals in New Jersey (and throughout the nation) who are certified in behavior analysis at either the associate or senior-level. The board certified associate behavior analyst (BCABA) and board certified behavior analyst (BCBA) are the two certifications that the board issues for professionals who have met the minimum standards ("knowledge, skills, and abilities") deemed required for providing behavior analytic services to schools, agencies and other organizations.
3. Inform early, ask questions, and seek specific answers. When a child is diagnosed with autism, parents begin the arduous task of confronting various systems at both the county and local level. Prior to the age of three, children diagnosed with autism can receive county-based early intervention services if it is determined that a child exhibits marked delays across developmental domains. It is recommended that parents not wait until a child is three before contacting their local school district. Referral to the school district is recommended a few months prior to the child's third birthday.
4. Take the time to observe and evaluate placement options. Parents should spend time observing public and/or private schools that provide educational services to children with autism. It is advisable to observe more than one placement option thoroughly. A thorough analysis of program components is essential to ensure that the program can meet the individual educational needs of a given child.
5. Work collaboratively with your child study team. A child's educational needs are best served when all team participants (i.e., parents, child study team members, related services personnel, and other professionals) work together to make informed decisions regarding the educational needs of a given child and the program(s) that can provide effective intervention services.
6. Keep accurate and complete records. Parents should keep an educational file that contains all evaluations completed on their child, which should include but not be limited to private evaluations, early intervention evaluations, child study team assessments, written correspondence between professionals and medical information. When observing program options, parents should make every effort to take detailed notes.
7. Persist in your efforts. Although it is often a daunting task to secure appropriate educational services for a child with autism, the extent to which the parent becomes an informed advocate can be the most critical factor in the process. Parents who have sought and been successful in securing appropriate educational services for their children are those who seek information, and become and remain active participants in their child's education.

Determining the appropriateness of an educational program for a given child requires time, expertise and (often) financial expense. A multidisciplinary team approach to program planning for children with autism is

suggested to maximize the extent to which informed programming and placement decisions can be made. Most importantly, careful evaluation of all program options and program components should be conducted. Amidst all other considerations systematic decision-making should be the overriding goal.

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A Parent's Introduction to Fluency

By Michael Fabrizio, M.A., BCBA

Defining the Terms

Children with autism continue to receive great help because they learn through instructional arrangements from behavior analysis. Behavior analysis offers these children, and many others, the benefit of receiving instruction based on a long history of solid lines of research and consistent underlying theory. Those same lines of research and underlying theories recently gave rise to the addition of a "new" component to the programs of children with autism that many parents are hearing about - "fluency." I placed quotation marks around the word new in the previous sentence because I wanted to stress that the concept of fluency is not new in behavior analysis, even though it is only recently that it has received so much attention for children with autism. Before we talk about how the addition of fluency building may enhance children's programs, we should spend a bit of time talking about what the term means, because people use the term to mean different things.

As I will discuss here (and in the second article on fluency), fluency refers to a level of skill development. It is a metaphor that describes how well a child has learned a certain skill. When children learn skills to fluent levels, they can use the skills effortlessly, automatically, and "without thinking." They learn skills so solidly that they can easily go on and use those skills to learn other, more advanced skills. Fluency is a good thing! And children should learn any important skill to fluent levels, as well as any other basic skills they will need to know to go on and learn something else.

About This OARacle Contributor

Michael Fabrizio is a member of OAR's Scientific Council. A board-certified behavior analyst, he serves as the clinical services director for both Fabrizio/Moors Consulting, a behavior analytic private practice in Seattle, WA, that works with learners with autism, and Families for Effective Autism Treatment (FEAT) of Washington. He is also an adjunct professor of behavior analysis in the University of North Texas Department of Behavior Analysis, an adjunct professor in the Applied Behavior Analysis master's degree program at the Chicago School of Professional Psychology, and the current president of the Standard Celeration Society, a special interest group within the Association for Behavior Analysis. He is currently a doctoral candidate in the University of Washington's Department of Special Education where he is specializing in behavior analysis, instructional design, autism, and technical communication.

The Benefits of Skill Fluency

I mentioned that we should consider fluency as a metaphor, meaning that we have no way of looking at any given skill and determining whether the skill is or is not fluent based only on that observation. Rather than simply observing to decide whether a skill is fluent, we must measure specific aspects of the child's performance of the skill. As a metaphor, fluency describes a high level of skill mastery associated with certain outcomes. When a skill is fluent, that skill is retained, applied, stable, and endures. If we wish to determine whether a child has learned a skill to the point of fluency, we must test the skill to ensure that the child remembers it (retention), applies it (application), uses it under highly distracting conditions (stability), and uses it for long periods of time without fatigue (endurance).

Because children with autism need to learn so many basic skills (such as basic skills associated with taking care of themselves, communicating, and interacting with other people), it is especially important that we continue teaching until those skills are truly fluent. Consider what would happen if we taught children with autism to label common household items receptively during instruction, but they could not perform that skill after we stopped (a lack of skill

retention). How frustrating it would be for students to learn to answer basic informational questions about themselves, but then be unable to do so for a long enough time that they could hold a basic conversation with their friends (a lack of skill endurance). Or, how disappointing it would be for children and their families if the children could expressively label pictures of different family members during instruction, but they could not do so looking at the family photo album (a lack of skill stability). Imagine the frustration of students with autism if they learned the concept of a triangle through instruction, but could not identify a new triangle when their teacher presented one (a lack of skill application).

Measurement in Fluency-Based Instructional Programs

If we want children to remember, apply, and generalize skills (that is, use skills with different people and in different places), teaching those skills until they are truly fluent helps ensure this will happen. To help ensure that children will enjoy the benefits associated with fluency, we must pay careful attention to how we measure while we teach. In most traditional instructional programs for children with autism, teachers and clinicians measure skills by looking at how accurately the child performs a skill. Once a child learns a skill to a certain level of accuracy (usually a relatively low level of accuracy such as 80 percent), the teacher or clinician stops instruction on the skill and moves on to the next skill.

Monitoring learning using measures that only take into consideration skill accuracy, such as percentage correct, is fine if such measures predict those crucial outcomes of mastery we discussed earlier (skill retention, application, stability, and endurance). Unfortunately, accuracy measures alone do not predict those important outcomes. To increase the likelihood that we will teach children skills to fluent levels, we should not measure accuracy, but rate.

Rate refers to some amount of correct and incorrect responding per some unit of time, and best predicts skill retention, application, stability, and endurance. The fact is that to be truly fluent at a particular skill, a child must respond both accurately and quickly. High rates of accurate responding and low rates of inaccurate responding are the hallmarks of truly competent performance. In most fluency-based instructional arrangements, teachers and clinicians look at rate per minute—the number of correct and incorrect responses a child gave during a minute-long interval.

Frequency Aims as Benchmarks

When we measure rate, we also measure accuracy at the same time. We measure both without any additional effort. For example, if we timed a student for one minute as they expressively labeled pictures, we might count 20 correct answers and two incorrect answers. We could convert this to an accuracy measure of 91 percent (20 correct answers divided by 22 total answers yields an accuracy of 91 percent). Under traditional teaching approaches, we might stop instruction at this point. The high rate seems like pretty good performance! However, when we seek to teach children skills to fluent levels, we strive to keep teaching until the student performs the skill not only accurately, but also quickly.

While 20 correct answers and two incorrect answers may be very accurate, it is also a rather slow performance for this task. The student is unlikely to enjoy the benefits of fluent performance—skill retention, endurance, stability, and application—at such a low rate of correct responding. Because of the importance of both accuracy and speed, we would continue practicing this skill until the student could perform at least as accurately, and could do so quicker. With our example of expressively labeling pictures, we would continue teaching the skill until the student could give approximately 50 to 55 correct answers within a minute with no more than one error. At that point, we would systematically test to ensure the skill would be remembered, would endure, would be stable, and would be applied by the student. Only after we showed these outcomes in the student's performance data would we say the skill is fluent and move on to teach the next skill.

Ensuring that we teach skills to fluent levels helps ensure we give our students the gift of real, long-term learning. We help ensure that we will not need to restart instruction on the skill at some point in the future because the child “lost” it, and we help ensure the student can use the skill in their everyday lives.

The Components of Programs that Develop Skill Fluency

Now that we have discussed what fluency is and how we measure it, let us turn our attention to the features an instructional program would need to have for the program to teach skills to fluent levels. While teaching to fluency may be the goal in any instructional program, reaching that goal is much more likely if the program contains certain components. Though the following descriptions of the components of good fluency programs will not be extensive enough to allow you to develop a fluency-building program for your own child, they should provide you with a basic understanding that will help you guide your child's instructional program. If you wish to incorporate fluency-building procedures into your child's instructional program, I recommend that you work closely with a board certified behavior analyst (BCBA).

Component 1: Building Accuracy First

The first component of a quality fluency-based instructional program involves teaching children new skills until they can perform the skill accurately. Before we build speed, we establish accuracy. When we establish accuracy, though, we do so only on parts of an instructional program rather than the whole program at one time. For example, if we wanted to teach a child to imitate our actions (known as gross motor imitation), we might begin by identifying one set of four actions to teach the student. Once we identified the actions, we would use established and well-researched instructional procedures to teach the child to imitate accurately those four actions. For example, we might use Discrete Trial Instruction as our instructional method to teach the student to imitate the four actions accurately. Once the child could imitate those four actions accurately (at around 90 percent accuracy), we would move those four actions out of the accuracy-building phase of instruction and into the timed-practice phase. While the first four actions were in the timed-practice phase, we would identify the next set of new actions and teach the child to imitate those new actions accurately.

Component 2: Daily Practice Under Timed Conditions

Now that the child can imitate the first set of four actions accurately, we would instruct the student to practice imitating those actions at a faster rate. To arrange such a practice, we would use a digital timer and set it so that the timer would count down. As a general rule of thumb, the smaller the number of items the child practices and the younger the child, the shorter the timing interval we would select.

To continue with our example, we might only set the timer for six seconds because the child would only be practicing the four actions they could imitate accurately. After we started the timer counting down from six seconds, we would have the child imitate as many of those four actions as they could before the timer reached zero. Each day, we would practice repeatedly with the child until the student could imitate more actions than they had the previous day in the same amount of time. By asking the child to imitate more actions on subsequent days than he or she imitated on previous days, we would build the child's rate of correct responding.

When the next set of actions that we taught the child to imitate accurately was performed correctly we would add those four actions to the set the child used during timed practice each day. In this way, the actions that the student practices getting faster with always grows as we add new actions to the set.

Component 3: Charting and Decision-Making

As important as it is that we practice with children each day until they can perform more quickly than they did the previous day is that we graph the child's best performance each day. When we graph the data we collect on a child's performance, we make better decisions about how to change our teaching to meet the child's ever-changing needs; we use the child's data more frequently to make decisions; and we document the effectiveness of our teaching methods.

Fluency-based instruction grew from an area of behavior analysis called Precision Teaching. When we strive to teach children skills to a fluent level, we use a special kind of graph called the Standard Celeration Chart (SCC). The SCC is the same graph that is used in Precision Teaching and was developed by Dr. Ogden Lindsley, a renowned behavior analyst and teacher. The SCC is the only chart appropriate for use in fluency-building instructional programs. While the SCC uses procedures for graphing that are beyond the scope of this article, there are several resources you can access to learn how to correctly and easily use the SCC to chart your child's progress on any skill. I have listed some additional resources related to the SCC and Precision Teaching at the end of this article.

Component 4: Teaching until the Child Reaches Frequency Aims

By instituting timed practice each day to help children get faster at doing what we teach them, and using the SCC, we can set performance aims for students. These performance aims describe how fast (the frequency) the child should respond before he or she will likely enjoy the benefits of fluency (retention, endurance, stability,

Recommended Frequency Aim Examples

Skills	Recommended Frequency Aims
Imitations skills such as: <ul style="list-style-type: none">• Gross motor imitation• Fine motor imitation• Imitation of sounds, sound patterns, words, and sentences	30-35 corrects per minute and 0-1 errors per minute
Receptive language skills such as: <ul style="list-style-type: none">• Identifying nouns• Following directions• Identifying actions• Identifying categories, functions, and features of objects• Answering informational questions	0-35 corrects per minute and 0-1 errors per minute
Expressive language skills such as: <ul style="list-style-type: none">• Identifying nouns• Following directions• Identifying actions• Identifying categories, functions, and features of objects• Answering informational questions	50-55 corrects per minute and 0-1 errors per minute
Imitation skills such as: <ul style="list-style-type: none">• Gross motor imitation• Fine motor imitation• Imitation of sounds, sound patterns, words, and sentences	30-35 corrects per minute and 0-1 errors per minute
Receptive language skills such as: <ul style="list-style-type: none">• Identifying nouns• Following directions• Identifying actions• Identifying categories, functions, and features of objects• Answering informational questions	30-35 corrects per minute and 0-1 errors per minute
Expressive language skills such as: <ul style="list-style-type: none">• Identifying nouns• Following directions• Identifying actions• Identifying categories, functions, and features of objects• Answering informational questions	50-55 corrects per minute and 0-1 errors per minute

and application). We call these performance standards frequency aims. I have listed recommended frequency aims for many of the skills children with autism commonly need to learn in the box on page BLANK. While these frequency aims do not guarantee that children will enjoy the benefits of fluent performance, the aims are based on a solid amount of research that suggests that once children achieve the suggested frequency aims, they will remember and apply the skill as well as use the skill for long periods without tiring, and in distracting situations.

While I certainly did not list all of the skills students with autism should learn, the skills I included are among those that children in intensive in-home programs often need to learn. Through years of applied research, clinicians have also identified frequency aims for skills in other areas such as motor skill, reading skills, writing skills, and math skills.

Component 5: Testing the Outcomes of Fluent Performance

We should not only arrange for children to practice the skills they learn until they can perform the skills at the frequencies the table on page 16 suggests, we should also systematically test to ensure that the vital outcomes of fluent performance of a skill (retention, endurance, application, and stability) actually occur. When we evaluate skill retention, we stop all instruction and timed practice on the skill for one month. After one month, we have the child complete two timings with the same materials. If we see that the student matched or surpassed their previous best performance, then we can safely say that the child's performance showed skill retention.

When we evaluate skill endurance, we lengthen the timed practice for one or two timings so that we can determine whether a child can sustain his or her high rate of correct responding across significantly longer timing intervals. To test for skill endurance, we might double or triple the length of the timings. If we see that the student can indeed sustain their response across longer timing lengths, then we have demonstrated that the child's performance shows skill endurance.

We evaluate skill stability by arranging for a child to complete timings in the presence of distracting events such as people entering and leaving the area where the child is working, turning on the child's favorite movie or cartoon, or changing where we do the timings. If we see that the child performs just as quickly and accurately even when such distractions are present, then we have demonstrated that the student's performance shows skill stability.

Finally, we can evaluate skill application by determining whether a student can respond just as quickly when we present them with all new examples that the child has never before seen. If we were testing the application of a child's gross motor imitation skills, we would present the child with actions that we had never used during either accuracy-building or timed-practice. If the child could copy those new examples at the frequency aim for gross motor imitation (30-35 correct per minute with no more than one error), then we would be confident that the student's gross motor imitation showed skill application.

Parents may find more information about the certification of behavior analysts by accessing the Behavior Analyst Certification Board website. The website describes the certification process and also provides a list of certified professionals in its certificant registry.

Resources Related to Fluency-Based Instruction and Precision Teaching

Instructional CD-ROMS

- TUCCi Learning Solutions

Books

- Standard Celeration Charting (2002), by Steve Graf and Ogden Lindsley, available from Graf Implements, 7779 Lee Run Road, Poland, Ohio, 44514-2510, e-mail: zerobros@aol.com

Websites

- Precision Teaching Module: <http://psych.athabascau.ca/html/387/OpenModules/Lindsley/>
- Precision Teaching papers: <http://www.teonor.com/ptdocs/>

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Social Skills Training for Students with ASD and Their Peers

by Jed Baker, Ph.D.

All social interaction and social problems involve at least two people. Social difficulty can be defined as both a skill deficit for the student with a social disability and a problem of acceptance of that student by peers or the community. Thus, intervention must focus on teaching skills for both the student with a disability and typical peers. All too often we strive to “fix” the child with the disability and virtually overlook the “typical” peers who may be ignoring, teasing or rejecting the student. Moreover, including typical peers as a focus for intervention may yield results much sooner, as typical peers may learn to be understanding of the student with a disability more quickly than the child with a disability can learn to interact more appropriately with peers. We might begin to target peers at the age that many students enter school environments and typically begin to interact with peers, by about age 3 to 4 years old.

Consistent with this view, I believe effective social skills training for individuals with autism spectrum disorders (ASD) and their peers consists of at least the following four components:

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For more information about Jed Baker, Ph.D. and the Social Skills Training Project, please visit www.socialskillstrainingproject.com/.

For students with ASD

1. Skills training lessons to teach explicitly the social skills that do not come naturally for ASD students
2. Activities to promote generalization of skills in the situations where they are needed

For typical peers and the student's community

3. Sensitivity training lessons for others to be more accepting and engaging of students with ASD
4. Activities to promote generalization of sensitivity to ASD students

Although most of these components are relevant for all ages, the focus of this article is on students age 3 through adulthood who have developed some basic receptive language skills and show some joint attention skill, that is, the ability to, at least briefly, attend to another person or to attend to what another person is showing a student. Joint attention and language skills are important prerequisites for later learning, as you have to be able to attend to and understand others to learn from others. To address these crucial early prerequisite skills, the interested reader should look at popular Applied Behavioral Analysis (ABA) programs like discrete trial methodology (Lovaas, 2003) and verbal behavior training methods (Sundberg and Partington, 1998) or non-behavioral methods such as Greenspan's Floortime methods (Greenspan and Weider, 1998). The methods described below are appropriate for students with some capacity for joint attention and some very basic receptive language ability.

Skill Lessons

Skill lessons include a variety of strategies geared to the students' cognitive/language functioning. For those students who can understand verbal instructions, we might break down a skill into its component steps, explain it, model it, and role-play it until he or she can demonstrate the skill and understands why it is important. Let's say a student with good verbal skills always wants to do things his way and that conduct gets in the way of developing peer relations. We decide to teach him how and why to compromise. We teach him how to ask what others want, say what he wants, and to offer to do a little of both. We explain when you do a little of both (i.e., compromise), the other person will be happy and may want to play with you again or be your friend. Using this straightforward approach, we have broken down into simple steps over 70 such social skills related to play, conversation, emotion management, and empathy in a manual on social skills training for children with social-communication problems (Baker, 2003).

For the student with less ability to understand verbal explanation, we have translated a subset of those skills into picture form (Social Skills Picture Book, Baker, 2002). Instead of explaining skill steps with words, we first show a picture sequence. Thus, for a skill like "compromise," the pictures demonstrate a student asking to play a game with another student who says he wants to play another game. We show them pictures of the students compromising and playing a little of both games with both looking happy. Then we show them pictures of the same people not compromising, not playing with each other with both looking upset. Of particular benefit is making your own picture books using pictures of your students, so that they see pictures of themselves engaged in the right (or wrong) way to demonstrate a skill. After the pictures are shown, students should still role-play the skill so that they can actually go through the motions of the skill steps.

A strategy called cognitive picture rehearsal utilizes cartoon-like drawings on index cards combined with positive reinforcement principles (Grodin and Lavasseur, 1995). Cognitive picture rehearsal always includes drawings or pictures of three components: the antecedents to a problem situation, the targeted desired behavior, and a positive reinforcer. The pictures are displayed on index cards. On the top of each card (or on the back of the card) is a script describing the desired sequence of events. Children are shown the sequence of cards until they can repeat what is happening in each picture. The sequence is reviewed just before the child enters the potentially problematic situation.

For example, a cognitive picture rehearsal was created for Matt, a 7-year-old who would throw tantrums when his teacher told him to get off the computer. Cards 1 and 2 illustrated the antecedent to the problem situation: Matt is playing at the computer and then the teacher tells him it is time to get off the computer. Cards 3 and 4 showed Matt engaged in the desired target behavior: thinking that the teacher will be happy if he gets off the computer and give him a chance to use the computer later, he then says, "Okay, I'll get off the computer." Cards 5 and 6 show the positive rewards of engaging in the desired behavior: Matt receiving a point on a reward chart and the teacher letting Matt use the computer again later because he had cooperated earlier.

Social Stories™, developed by Carol Gray and colleagues (Gray et al., 1993), uses stories written in the first person to increase students' understanding of problematic situations. Beginning with the child's understanding of a situation, a story is developed describing what is happening and why, and how people feel and think in the situation. While the story contains some directive statements (i.e., what to do in the situation), the focus is on understanding what is happening in the situation.

The following situation provides an example of a situation in which Social Stories™ may help an individual with autism deal with a social problem. Peter was a 13-year-old who frequently got into fights at lunchtime because he believed that other students in the cafeteria were teasing him. He said that several other boys who sat on the other side of the cafeteria always laughed at him. He would give them "the finger" and then they would start a fight with him. When Peter was observed at lunch, it was apparent that the other boys were laughing, but not at him. They were at least 50 feet from Peter, not looking at him, and laughing with each other, presumably about some joke or discussion they were having.

We developed the following social story for Peter starting with his perspective that others might be laughing at him:

When I am in the cafeteria, I often see other boys laughing and I think they are laughing at me.

Lots of students laugh during lunchtime because they are talking about funny things they did during

the day, or funny stories they heard or saw on TV, movies, or books they read. Sometimes students laugh at other students to make fun of them. If they are making fun of other students, they usually use the student's name, or look and point at that student. If the other students are laughing, but they do not look or point at me, then they are probably not laughing at me. Most students do not get mad when others are laughing, as long as they are not laughing at them. If they do laugh at me, I can go tell a teacher rather than give them the finger.

Like cognitive picture rehearsal, Social Stories™ are read repeatedly to children until they have overlearned them, and are then read again just prior to the problematic situation.

Generalization

Generalization refers to the ability of an individual to use a new skill in situations beyond the training session, and hopefully to use the new skill spontaneously without prompting from others. To achieve this level of fluidity with a new skill, individuals must practice and repeat the skill steps a great deal. As a result, it is unrealistic to think one can generalize many new skills at once. In my experience, true generalization occurs when individuals are reminded about or rehearse no more than one to three new skills every day for several months. Although individuals can learn the concept of many more skills during skill lessons, they may only be able to generalize one to three new skills at a given time. Generalization of a skill involves three steps: priming before the situation in which the skill is needed; frequent facilitated opportunities to practice the skill; and review of the skill after it is used.

Priming involves some reminder to the individual of what the skill steps are “just prior” to needing the skill. For example, just before going on a job interview, an individual might go over how to answer anticipated questions. Or just prior to starting a frustrating task at school or at work, the individual might review options for dealing with frustrating work. Priming can be verbal and/or supplemented by a visual aide. Verbal priming involves someone verbally explaining the skill steps prior to the situation in which they will be needed. Cue cards, behavior charts, copies of skill lessons (Baker, 2003), Social Stories™, cognitive picture rehearsals, and social skill picture books can serve as visual aides that depict the skill steps.

If students want to change their behavior but can't remember the skill steps, then cue cards or copies of the skill lessons may be ideal. We might write one to three skills on an index card and laminate it. Then we might ask a parent, teacher, or employer or the student him or herself to review the skill steps prior to the situation in which it will be needed. Although it is ideal for the student to see the skill steps immediately prior to the situation in which they need to use the skill, this may not always be practical. Instead the parent, teacher, employer, or student might review the skill once in the morning prior to school or work, once at lunch and then again at the end of the day so that the student at least has to think about the skill three times per day.

If a student has not fully agreed to try a new skill and thus is lacking in “intrinsic” motivation to perform the skill, then the behavior chart can be used as a reward chart in which external rewards are contingent on demonstrating certain targeted skills.

In order to practice the new skills, students need opportunities. Facilitated opportunities involve creating daily situations in which the skills can be practiced and coached. Sometimes those opportunities are naturally built into the day. For example, a student learning to deal with frustrating work may always have his or her share of challenging work to do during the day. Other times, the practice opportunities need to be carefully planned or created. For example, a student who never initiates conversation with anyone may be asked to call someone on the phone once per day or join others for lunch and initiate conversation once during that period.

After situations have occurred in which skills were needed, the student's performance can be reviewed to increase awareness of the skill. If a student's progress is tracked through a reward chart, the reason why the student received the reward (or not) should be reviewed with him or her to enhance learning.

Peer Sensitivity

Sometimes students with ASD are ignored, yet often they are actively teased or bullied. Students with ASD may do nothing to deserve such teasing and other times they may provoke such reactions with unintentionally “irritating” behaviors like perseverating on a topic, making loud noises, or having angry meltdowns. When

students are harassed, teased, or rejected because they look or behave differently, it is crucial to explain to others the unintentional nature of their behaviors and how others can help. We often talk with peers not only about the unintentional nature of the difficult behaviors of someone with ASD, but also the person's strengths and talents as well as presenting examples of successful, famous figures who may also have had an ASD.

Generalization of Peer Kindness

We ask peers to do three things to help their ASD peers and each other: (1) include others who are left out; (2) stand up for those who are teased; and (3) offer help to those who are upset. To help these kind behaviors generalize into the daily routines of the students, we might create a lunch buddy program, where peers volunteer to eat and hang out with the ASD student on a fixed rotating schedule. We might also introduce a reward program to recognize and reward "kind" behaviors towards fellow students. We may also train peers in how to engage ASD students in play, including how to get their attention and what kinds of games to initiate (i.e., games the ASD student can play).

Motivational Problems

The explanation of skills training so far may seem pretty straightforward if not for the fact that we are teaching actual people with their own agendas, desires, and wishes that may not correspond with the well-meaning wishes of their parents or social skill therapists. For example, take the student described earlier who may be quite verbal and always wants to do things his way. We decide to teach him how and why to compromise. We explain how compromise helps others to be happy so they may want to play with him again or be his friend. And then he turns around and says, "I do not want any friends, and I do not want to play with anyone, I don't want to compromise. I just want to do what I want to do."

Clearly, one of the major challenges of skills training is motivation to socialize. For many ASD students, socializing has never been that pleasurable and so they retreat into their world of objects, facts, and routines that provide more stability and comfort.

For students with good verbal reasoning skills, generating motivation is about building a rationale for the importance of social skills training. Motivation may come from an individual's insight into his or her own pattern of strengths and weaknesses. Many students with special needs deny or otherwise resist any mention of weakness or difficulty. It takes a modicum of self-esteem to tolerate thinking about one's difficulties.

One way around such resistance is through counseling that allows them to explore and experience their talents and strengths. Targeting weaker areas that need improvement must come after first identifying strengths. For most students, it is helpful to have someone else point out two to three strengths for every weakness that is highlighted. The student can be asked directly what talents and strengths they have and then the counselor can add or refine that list of strengths before suggesting areas in need of improvement. For example, during group sessions, I will ask each member what their special talents are and corroborate these positive descriptions. Then I might say "there are some minor issues I want to address with you guys so you can continue to do as well as you are doing." Then comes the lesson on a skill topic.

There are several more ways to motivate engagement for skill lessons, including: linking skill lessons to real-life goals, using entertaining role-plays, linking skill lessons to fun group activities or projects, and creating skill lessons to teach others. This last method of reducing resistance to learning new skills is to have students participate in the teaching of skills to others. By creating picture books, videos, or live skits, students can demonstrate the skills to others. As such, they can learn a skill without having to acknowledge that they themselves needed to learn it.

For students without good verbal reasoning skills, increasing motivation cannot involve verbal reasoning. Instead, we may enhance motivation by insuring that our social activities with the student are enjoyable. That may mean we have to make sure the student is not overstimulated by too many people and complicated activities. We might decide to meet one-on-one in a quiet room with little distractions and introduce interactive activities that the student can understand. Researcher Steve Gutstein (2002) has compiled a series of activities from simple to more advanced to help students enjoy social interaction while truly interacting rather than retreating into their own self-stimulation worlds. Early activities to build joint attention might include imitation games like follow

the leader, or “follow my eyes to the prize,” where students have to look at an adult’s eyes to find where the adult hid a prize in the room (the adult is looking in the direction of where the prize is hidden). Although these activities have not yet been empirically tested, the concept is reasonable; engage students in activities that limit overstimulation and complexity while focusing on attending to others.

With some motivation to socialize, skills can be more easily taught and generalized. By an additional focus on peer training, we can enhance both sides of the social interaction and create an accepting atmosphere for individuals with ASD to attend school or an employment setting.

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Social Skills: An Elusive Target

By Mary Jane Weiss, Ph.D., BCBA

The Challenges of Learning and Teaching Social Skills

Social skills, which are centrally important to the success of individuals on the autism spectrum, are among the most elusive targets to teach. One impediment to teaching such skills is that there may not be much intrinsic interest on the part of learners with autism spectrum disorders (ASD) in learning these skills. Many learners with ASD lack social interest and fail to comprehend social nuances. Additionally, they often exhibit little social initiation, as well as reduced social responsiveness.

Furthermore, it is often difficult to conceptualize how to teach such skills. Most social skills are multi-element skills that require the individual to engage in several different and distinct tasks. And most of the skills in the social realm involve an element of judgment (i.e., is it appropriate to engage in this behavior at this time?) Such complexities make it difficult to teach such skills. How does one operationalize social judgment? How can we prepare learners for the myriad possibilities that exist in real life?

This article will review some of the ways in which such skills are commonly taught to individuals on the autism spectrum. Many of the commonly used approaches are package interventions, with several components, or are used in combination with other procedures. Weiss and Harris (2001) provide a thorough description of several strategies for teaching social skills to young children on the autism spectrum. A few of these strategies, which are also relevant for teaching older learners such skills, will be discussed in this article. One of the challenges for a behavior analyst in approaching instruction in such skills is that many of the commonly used strategies have limited empirical support to date. Alternately, some approaches have been empirically validated with other populations, but not with individuals on the autism spectrum. It is not always clear whether it is possible to extrapolate information from other populations, but the strategies may be useful in the clinical context of teaching social skills. Several commercially available social skills chapters and curricula have well-formulated and clear lessons for a variety of social skill instructional targets (e.g., Baker, 2003a; 2003b; McGinnis and Goldstein, 1990; Richardson, 1996; Taylor, 2001; Taylor and Jasper, 2001).

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In clinical application, a number of commonly used strategies fall into the descriptions above (i.e., have limited data or have been used primarily with other populations.) Nevertheless, such procedures are often used to address social deficits and to teach pro-social skills. Often, they are used in combination with other, direct behavior change procedures, such as reinforcement and prompting. Commonly used procedures that will be reviewed here include social stories, role plays, rule cards, video modeling, and problem-solving techniques.

Commonly Used Techniques

Social stories. Social Stories™, an intervention developed by Carol Gray (Gray, 1993; 1994) to provide information about social situations and about behavior that is expected in those situations, are very commonly used. Gray has suggested that one directive statement be given for every three to five informational state-

ments, to ensure that the story is largely a vehicle for conveying information about complex or hard-to-define social circumstances.

Social Stories™ can be written with pictures to accompany the text, and can be adapted for the individual (including using the names of those the individual knows and using the first person). The stories can be used to convey information and expectations for multi-element tasks (such as cleaning up or waiting in line.) They can also be used as part of a package of interventions to address challenging behaviors, offering functional alternatives to the target behavior, such as asking for help instead of throwing materials.

Some encouraging, preliminary empirical support for the efficacy of Social Stories™ in increasing social communication skills exists (e.g., Thiemann and Goldstein, 2001). A small body of research exists, and a comprehensive review article has been published (Reynhout and Carter, 2006.) However, the data is quite variable and there are many deficits in the level of our existing knowledge. Some of the problems that exist in this body of literature are: highly variable effect sizes, highly variable methodology, and a lack of reports of cognitive level.

Many clinical aspects of the use of social stories like those developed by Gray remain unclear from a research perspective. It does not appear that there is an effect for descriptive sentences. However, most other elements of story construction or clinical implementation remain unclear. For example, it is not known how frequently reviews need to be done, whether comprehension activities facilitate the acquisition of the material, or when the story should be presented to the individual to maximize effect. In general, the data is not robust, in terms of the ability of Social Stories™ to facilitate behavioral change. Furthermore, data on the maintenance and generalization of such changes do not exist. As maintenance and generalization are critical issues for this population, this is a serious limitation.

In general, however, consumers like Social Stories™ and are fairly compliant about implementing them. There is also a tremendous volume of anecdotal reports of success with their use. The question for the clinician then becomes one of whether, how, and when to use them. It may be possible to use them as part of a package of interventions, in which more direct change procedures are also in use.

Role plays. Role plays provide an opportunity for behavioral rehearsal of desired behaviors (e. g., Snell and Janney, 2000; Weiss and Harris, 2001). Students with ASD often need multiple opportunities to learn and practice desired skills. Role plays can create such additional opportunities, to supplement a low number of naturally occurring events in their natural environments. Role plays can be used to target aspects of interaction that are central to social success. These include orientation to the speaker, maintaining eye contact, and answering questions appropriately. Role plays can be done with characters and puppets or with people (including the target student). The student can take on different roles, demonstrating the initial skill or the response. Role plays are always used in combination with the provision of feedback on performance. While there is not a body of research on role-play procedures, there is some support for the broad use of behavioral rehearsal strategies.

Rule cards. Rule cards assist students in following the social rules that are associated with a particular activity (e. g., Weiss and Harris, 2001). A rule card clearly states the behavioral expectations for that activity. Rule cards can be reviewed prior to an activity and can be used in combination with other procedures (such as behavioral rehearsal.) Rule cards are very helpful for targeting skills such as sharing toys, taking turns, asking peers for desired items, and accepting a peer's answer. They can also be used for explaining expected behavior in a particular environment or activity, such as the media center or school assemblies. While there is not a body of literature on the use of rule cards, they are a common clinical intervention and are related to a variety of visual prompting strategies and behavioral rehearsal techniques (e.g., Cooper, Heron, and Heward, 2007; Snell and Brown, 2000).

Scripts. Some students with autism have a difficult time engaging in conversational exchange. They may also have difficulty in creative play. In these circumstances, they may engage in much less interaction than they might if these skill deficits were addressed. One way to address this issue is to provide scripts for prolonged conversations or creative play. Scripts can be in the form of sentences, words, or pictures, and they can be used in a variety of circumstances (e.g., Snell and Janney, 2000). Scripts can also be developed for specific games and activities. Scripts can help the learner to engage in these interactions for longer durations and stay on topic while engaged in interaction. A number of studies document the effectiveness of scripts, including facilitating social initiation and social interaction in individuals with autism (e.g., Krantz and McClannahan, 1993, 1998).

Roteness of response can be a concern, so it is important to program in and reinforce variability. It will not be functional if the learner can speak about a topic in only one way. We need to prepare learners for the wide variety of circumstances they are likely to encounter in their interactions.

Video modeling. Video modeling is an area in which more research literature does exist. Video modeling has been shown to be an effective means of imitating peers (Haring, Kennedy, Adams, and Pitts-Conway, 1987), learning sign language (Watkins, Sprafkin, and Krolikowski, 1993), developing play skills (Charlop-Christy, Le, and Freeman, 2000), and developing conversation skills (Charlop and Milstein, 1989; Sherer et al., 2001). Because so much research supports its utility in teaching skills, video modeling has been used increasingly to build a variety of skills, including functional academic skills, community-relevant skills, conversational exchanges, and play skills (e. g., Snell and Brown, 2000; Taylor, 2001; Weiss and Harris, 2001).

Many students with ASD are strong visual learners, and many enjoy watching videos. They may attend better to a model presented in a video clip than they would to a live model demonstrating a skill. Clinically, video modeling is often done with an adult demonstrating the skill first. It is easier (with an adult model) to ensure that the salient aspects of the target behavior will be highlighted. Alternately, older peer tutors or mature peers can be used as models. These choices have obvious advantages, because of their similarities to the target students.

While there is some variability in how video modeling is implemented to build play skills, it usually involves having the learners observe a video clip of play and then enact it themselves. At times, there may first be concurrent imitation of what is being watched (doing the actions along with the model on tape), followed by delayed imitation of what was observed (watching the clip and then engaging in the play). As in scripting, rotteness of response can also be a concern, so it is important to program in variability. Eventually, the learner can also be rewarded for expanding upon the modeled skills.

Another extension of video teaching is to use videotape as a source of feedback to the learners on their performance during play activities. Reinforcement and corrective feedback can be provided, and better strategies for targeted areas of weakness can be modeled and rehearsed (e.g., Taylor, 2001). This may be especially useful for circumstances in which a learner has demonstrated difficulty comprehending social nuances, such as staying on topic in a conversation.

Several guidelines for the use of video with learners have been given (Krantz, MacDuff, Wadstrom, and McClannahan, 1991). Specifically, these authors suggest: assessing learners for appropriate prerequisite skills; removing extraneous stimuli from the videotape; attending to the history of the learner with the persons presenting the video or modeling on video; and considering cognitive level as a possible variable of importance (as learners with more developed cognitive skills may respond to the approach better).

Problem solving. Solving problems is an important part of success in school. In addition, it is central to navigating the social world of friendships. Many students with other types of presenting problems, such as ADHD, have benefited substantially from problem-solving approaches. Problem-solving training usually involves helping learners to identify problems and select appropriate solutions. Children with ASD often have difficulties with the ambiguity of presenting problems, and with evaluating options for a course of action. They may be impulsive or fail to see the range of options. Problem-solving training (e. g., Shure, 2001a; 2001b; 2004) can help students with ASD to identify problems, generate alternative solutions, evaluate the effectiveness of different potential courses of action, and choose the best option. This can be done as a class-wide intervention or as an individual approach.

A variation of problem solving is the social autopsy (Bieber, 1994). This approach facilitates the identification of cause-and-effect relationships between one's behavior and the reactions or consequences from others. This clinical approach includes a discussion of the situation after the event and a plan to prevent recurrence (Dunn, 2006.)

Summary

A variety of techniques are commonly used for teaching social skills to individuals with autism spectrum disorders. Some of those techniques are not empirically validated or have been used primarily with other populations. Nevertheless, they may be useful additional components to a package of behavioral interventions.

Such package interventions may assist the clinician in teaching these multi-element skills. Additionally, they may provide more practice/learning opportunities and increase the degree to which training prepares learners for the range of possible experiences in the social world. As in the case with all interventions, direct behavior-change procedures should always be used to affect behavior. In addition, data on the effectiveness of all strategies used with individual learners should be collected.

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September 2006

On Autonomy, Generalization, and Problem-solving

By Bobby Newman, Ph.D., B.C.B.A.

Last Halloween, I helped to supervise a sleepover party for the children at the Unitarian-Universalist church my family attends. I had been wrapped in toilet paper by the kids during the “make a mummy” contest, guided numerous kids through the dark to the hallway where the bathroom was lit up, and finally watched the movie end and the kids settle into their sleeping bags for the night.

Now, I thought to myself, it was time to get some program writing done on my laptop. A good five minutes of concentration time in, a small voice asked me what I was doing. I looked up from the screen and saw one of the precocious six-year-olds who had attended the party. I always got the vague feeling that I would be working for some of these kids one day. I also had the strange feeling of being the Grinch and looking at little Cindy Lu Hoo, even if I wasn’t stealing Christmas stuff. You just weren’t supposed to have deep conversations with such young children this late at night.

I explained that I was designing some plans for a project at work. We had created a “snack cart” business at the agency where I consulted, a project that I hoped would settle into a self-sustaining enterprise that would employ some of the people diagnosed with autism who wanted to work in the business. I was helping to design programs to teach some of the people who were going to work there how to do their jobs.

“Why?” came the inevitable question. It was a question that would be repeated many times during our conversation that night.

I said something to the effect of: “Well, some of the grown-up people who are being served by the agency really

weren’t taught the skills that they need to hold a job when they were in school. They never learned how to ask for help if they didn’t know what to do, or how to follow the schedules, or how to perform some of the job skills, or things like that.”

“Why not?”

I told her I wished I had an answer to that question.

“But if they never learned how to have a job, how did the people at their schools expect them to be able to live on their own like other grown-ups?”

I did my best Shrek imitation: “A fair question.” I internally debated discussing what kind of life faces those who don’t develop independent skills. It’s a life where other people make all your life’s decisions for you. Where will you live? What will be your (limited) choices of food? What will be your (limited) choices of recreation activities? When will you go to bed? With whom you will share your living space? How will you spend your days? As usual, the kid was way ahead of me and pointed out many of these facts to me. I nodded in agreement. The Unitarian-Universalist poster on the wall about respecting the worth and dignity of every individual provided additional silent assent.

Stimulus Generalization

Whenever anyone asks me what the point of behavioral and educational programming is, my

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answer is always a quick “to build autonomy.” When someone has skills, they have choices. When someone lacks skills, they lack choices. In such a case, life’s decisions are inevitably made for the individual, and even if other people have the individual’s best interests at heart, there is just no substitute for being able to make one’s own decisions and living an independent life.

Now firmly hooked and thoughts of sleep gone, the little girl asked for more detail about what I was doing. I was writing about generalization, I said. Making up a pseudonym to protect privacy, I told her about one of the employees of the snack cart business who was able to perform many of the skills related to conducting the business but only while at the training site. When he moved from there into the “real world,” it became more difficult. I was working on what we would call “stimulus generalization,” the ability to perform a skill that has been taught under one set of circumstances in a new situation.

“Like being able to kick the kick-ball on the playground the same way that you do in the gym.” I agreed that she had provided a terrific example. Those of you who like more academic material can check out Harding, et al. (2004) for an excellent and equally fun example. Of course, you should go back to Stokes and Baer (1977) to see the defining paper on generalization and begin working your way from there, tracing the literature as it has developed and matured.

As is often pointed out, generalization of skills can neither be assumed, nor hoped or prayed for. Failure to generalize is often reported in the applied literature. You must explicitly program for generalization by teaching under the wide variety of circumstances and situations the person will face. Learning how to make change or sell the product in our training situation is one thing. Learning how to do it in real time in the hallway of the office building with a stranger is quite another. We cannot hope for or assume the generalization of the skill; we must program for it by teaching under a variety of teaching situations and stimuli.

Response Generalization

“So will the person always do the same job? Or do that job the same way all the time? That sounds boring!”

Again my miniature, future behavior analyst was ahead of me.

“No, we try to help people to learn how to do all the jobs, and to mix up how they do the jobs so that they don’t get bored.”

In truth, this issue of response generalization is every bit as important as stimulus generalization. Think of George Carlin’s routine about saying good-bye to 20 people at a party. As you move down the line saying, “Okay, hey, take it easy....okay, hey, take it easy....okay, hey, take it easy,” you may seem a little uncreative (at best). If I remember the routine correctly, George announced that every month, whether he needed to or not, he would change the way he would say good-bye. People would then ask, “Didn’t you used to say “ok, hey, take it easy?” George would reply with something to the effect of, “Yes, I did, but not anymore. Now I say “FAREWELL! Farewell until we meet again! May the forces of evil become confused on the way to your house!” He finished the routine by noting that “people will remember you if you talk like that!”

While such flowery speech may not be necessary, or even always desirable, the comedy makes a good point. Boredom issues aside, it is true that some variety in behavioral responses is expected by the population at large. Perhaps even more importantly, someone who cannot vary what he or she is doing may have a great deal of difficulty adapting to changing situations. Our workplaces are in constant change. New technologies make old jobs obsolete or require new ways of performing old skills.

To think of this in concrete terms, what do you do when a transit strike makes getting to work in the old way impossible? What do you do when a computer that has never been used before is introduced to track inventory? How do you change over to a bar code system? How do you go about seeking out information that will allow you to adapt your behavior to new situations? What happens when a new supervisor wants to change the way things are done? Again, for those of you who insist on academic references, check out an interesting example from Ludwig and Geller (1997).

Please note, of course, that these twin issues of stimulus and response generalization are ones that we all face, more or less successfully. If I may be allowed one of my characteristic “House, M.D.” moments, I often find myself discussing with staff members just how well they are generalizing their own skills. I remember one psychologist I was helping to train who would frequently ask questions regarding how to proceed with a given issue

(a functional behavioral assessment or a curriculum modification, for example). After answering his questions appropriately several times, I eventually found myself responding to questions by saying “OK, now what did we do when we were in this exact same situation all those other times?”

My sleep-avoidant charge and I did not solve the problems of the world that night. We did agree, however, that people have to learn how to perform their old skills even when situations change and have to be able to change what they have been doing in order to suit new situations. Not bad for a guy who had been wrapped in toilet paper two hours before and a six-year-old who was three hours past her bedtime.

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Individuals on the spectrum do, despite the sometimes secret wishes of those around them, grow into teenagers and then into adults. And with that transition to adulthood comes a new set of challenges relevant to life in the community. The two articles in this section address different, yet wholly compatible, areas of transition intervention: sexuality and community safety. Both of these areas are complex and potentially challenging to address but both are central to the development of a life of quality and competence as an adult on the spectrum.

February 2006

Bringing the Birds and Bees Down to Earth: Social Skills, Sexuality, and Autism Spectrum Disorders

by Lisa Mitchell, LCSW-R

Over the past 10 years, much has been written about facilitating social skill development in persons with Autism Spectrum Disorders (ASD). Intensive efforts to teach social skills from very young ages have made the newest generation of young people with ASD more socially aware and skilled than the previous generation. However, the onset of adolescence and the transition into young adulthood bring new challenges, making many young people on the spectrum who adapted relatively well in social settings flounder. Parents and professionals often are at a loss with how to best support their young people through this turbulent period in their lives.

Tips and Interventions

Most individuals with ASD can benefit from some form of socio-sexual education. Such education is best if personalized to the individual's age and level of functioning. Efforts should be made to make training visual, concrete and repetitive, but also engaging. Interventions may include: social stories and comic strip conversations (Gray, 2000 and 1994); pictorial mix-and-match activity books or boards (Wrobel, 2005); role-plays; anatomically correct dolls (Teach-A-Bodies); body charts; graphic organizers; lists; scripts; schedules; instructional cards; visual checklists; and video self-monitoring (Dowrick, 1999).

About This OARacle Contributor

Lisa Mitchell is licensed clinical social worker and has worked with individuals with developmental disabilities for 15 years. Her specialties in the field include psychotherapy, social skills training, and human sexuality education and training. She is currently the coordinator of the Sexuality Education and Reproductive Health Program at The Cody Center for Autism and Developmental Disabilities in Port Jefferson Station, New York. Over the past three years, Mitchell has provided numerous seminars on human sexuality and developmental disabilities, which have been offered to parents, care providers, school and agency administrators, educational staff, clinicians, and persons with developmental disabilities. She has also published articles on sexuality and developmental disabilities in the *Cody Center for Autism and Developmental Disabilities Newsletter*, *Long Island Parents and Children*, and *Social Work Today* magazine.

Key Concepts

Preparation for Puberty: Education about puberty and body changes is best done prior to changes occurring. While some adolescents on the spectrum have difficulty with their ever-changing bodies, with advance preparation, most accept the changes in a matter-of-fact manner. Looking up-to-date and clean is important if one wants to be socially successful. Young people with ASD may need to be taught to pay greater attention to their personal hygiene and appearance. The necessity for more frequent bathing can sometimes be met with resistance. Should this occur, additional bathing days can be gradually added to the young person's schedule. Girls with ASD may benefit from practice with sanitary products prior to their first menstrual period.

Abuse Prevention: The social naivety of persons with ASD can leave them vulnerable to exploitation. Basic abuse prevention education may include: differentiating types of touches (e.g. good, bad, and sexual touches); rules for sexual touching; and what to do in abusive situations (e.g. No, Go, Tell; Krents and Atkins, 1991). Older or higher functioning individuals may benefit from being told that sex is not necessary to get others to like them, nor should it be used as a means to compensate for social skill deficits. Teaching the following may also be helpful: ways to turn down unwelcome advances; identifying exits when entering new locations;

and looking for cues for predatory behavior (e.g. people who do not take “no” for an answer, are overly controlling, denigrate, or attempt to isolate the individual).

Interpersonal Skill Training: Most individuals with ASD acquire interpersonal skills gradually and not by intuition, but by intellect and repetitive training. Basic skills needed for social success are maintaining eye contact, listening, taking turns, identifying appropriate topics of conversation, greetings, and conversing through one or two exchanges. Eventually, more advanced skills can be added to training. Such skills include: differentiating between public and private (body parts, locations, behavior, and subject matter); perspective taking; inside and outside thoughts (inside thoughts stay unsaid in the head, outside thoughts are verbalized); dealing with rejection; conflict resolution; and reading body language.

The concept of adjusting one’s social behavior to the level of familiarity with others can be made more concrete by creating a personalized Circles chart (Champagne and Walker-Hirsch, 1993). Using this bull’s-eye-like chart, pictures of the young person, family, friends, community helpers, and strangers, along with appropriate behaviors to use with each category are placed in ever-widening circles of color. Rules for healthy relationships should be provided (e.g. they are mutual, non-abusive, and fun (Melberg-Schwier and Hingsburger, 2000). Reciprocity can be made understandable by explaining that healthy relationships are like two-way streets. Caregivers can use small cars on a diagram of a two-way street to demonstrate the back-and-forth or give-and-take in positive relationships. Staircases and thermometers offer visual illustrations for issues that exist upon a continuum, such as of the gradual progression of intimacy in relationships, self-rating scales for feelings, rating perceived levels of attraction or interest, and even safe and unsafe sexual behaviors.

For the most part, individuals with ASD have similar levels of social interest and sexual feelings as their neurotypical peers (Henault and Attwood, 2002). Caregivers can best support young people by helping them to find adaptive ways to channel sexual thoughts, feelings, and impulses. Loved ones can offer this type of support by: validating the desire to masturbate and providing opportunities for such “private time;” role-playing ways to converse with prospective friends or romantic interests (both face-to-face and on the phone); assisting in writing socially appropriate letters or e-mails; or going on mock dates with the young person in preparation for an upcoming outing with a peer (Newport and Newport, 2000).

Teenagers and young adults may need guidance in how to maintain a healthy balance between new relationships and older interests or responsibilities such as those to family, work, social activities, and preexisting friends. While empathy, perspective taking and reciprocity may not come automatically to many persons with spectrum disorders, they can be taught how to care, show concern, and give comfort if made aware that is what is required of them in relationships (Ashton, 2001). Emotional and physical intimacy may initially seem daunting to individuals with ASD. However, if taught to seek intimacy through a series of small steps, they can be rewarded with satisfying relationships within their comfort zone (Bee, 2003).

Adolescence and young adulthood are difficult times for anyone, particularly so if the young person has an ASD. While there is no definite socio-sexual roadmap available for young people on the spectrum, information can still be accurately relayed and valuable skills can be taught. Through initiative, time, patience, and a bit of creativity, caregivers can help to make abstract concepts such as growing up, staying safe, interpersonal skills, reciprocity, and relationships more tangible or down to earth for their loved ones with ASD.

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Teach-A-Bodies. P.O. Box 416, Grapevine, TX, 76099-0416; 888-228-1314 or 817-416-9138; www.teach-a-bodies.com

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Social Safety Issues on the Spectrum: Why Social Skills Training Alone Isn't Enough

By Zosia Zaks

We all know this rule: Don't go anywhere with a stranger.

But let's say you meet a cute guy at the movies. The two of you chat for a few minutes while you're waiting to buy popcorn. Then he asks you if you want to walk around before the movie starts. How would you react?

Most adults recognize the potential danger and generalize from the macro rule to the micro situation: Don't talk to strangers also includes this unique situation because even though you've talked for a few minutes, you still don't know this guy. But for those of us on the spectrum, this protective cognitive process is neither easy nor automatic. After all, if you've talked to someone, then he's no longer a stranger, right?

A group of researchers based at the University of Indiana just published a meta-analysis of research studies on the efficacy rates of social skills classes. The data indicate that social skills training programs are fairly ineffective. Why?

While the study suggests that intensity and implementation of the classes plus identification of deficits are factors, the answer is also at least partially because autism is neurological. We can usually remember the lessons, rules, facts, and values we are taught. But the cognitive, social, and linguistic challenges just do not go away, making it difficult to distill social information, manage and complete social decisions, make social judgments, and protect ourselves during the myriad moment-by-moment fluctuations that are an inherent aspect of human interaction.

Specifically, it is hard for us to generalize rules to situations that in our mind are unique or specific. We also have a strong tendency to miss nonverbal clues like tone of voice or body posture that could forewarn of trouble.

We understand language so concretely that the subtle meaning of social information may escape us. One young woman on the spectrum told me she didn't need to use birth control because her sexual education teacher, her mother, and her priest all had told her, "You can't have children until you're married."

Additionally, social situations are fairly open-ended. If we can't see specific reasons for picking one course of action over another, we may lack the ability to make adept choices. In the social world, it is impossible to predict outcomes, come to sure conclusions, or chart a fixed course. Many of us have trouble enough picking what to eat from a menu.

Furthermore, we often have only a vague idea of how we feel. We do not know how to use this self-knowledge in decision making. A lack of emotional facility results in slow or out-of-proportion responses and inadvertent advertising of our vulnerabilities.

Lastly, many of us experience face blindness. We can't recognize someone who teased, bullied, or attacked us in the past.

Professionals, parents, and teachers need to keep in mind that while it is not impossible for those of us on the spectrum to improve our social skills over time, each social moment is still new, singular, and met with our unique autistic profile. This point is paramount when designing and delivering social, sexual, and relationship education for those on the spectrum. Besides providing a standard curriculum, I always tell professionals, advocates, and loved ones to add another lesson: getting help.

No matter how many social skills we have practiced, no matter how confident we are in factual knowledge, and no matter how many discussions we

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have had about what is socially healthy and appropriate, we must learn to identify at least one trustworthy person and then learn how to turn to this designated person for guidance each and every time we are at a social crossroad.

When I conduct workshops on dating, relationships, and sexuality at autism conferences, I ask attendees, “What is the first thing you do if you like someone romantically?” They inevitably supply me with decent answers: start a conversation, find out his name, ask him to do an activity together, see if a friend or sibling knows her. These answers are not wrong per se. But I teach them that actually the very first thing we must do is go talk to someone trustworthy, not because we are stupid or immature, but because we have autistic challenges that make it difficult for us to pick up social nuances, contextual details, and hidden innuendo.

We must teach everyone on the spectrum that consulting with a trustworthy confidant is always the first step in any social move. This is just a fact of autistic life and nothing to be ashamed about. Lisa Lieberman, author of *A “Stranger” Among Us: Hiring In-Home Support for a Child with Autism Spectrum Disorders or Other Neurological Differences* (AAPC 2005) and mother of an autistic son, emphasizes the need for our community to shift our focus from independence to interdependence. “All of us, whether neurotypical or ASD, have been erroneously taught to value and strive for independence...Learning to reach out for help is just as essential a life skill to master.” Accepting the fact that even neurotypicals do not get through life alone is part of making interdependence a vital and expected aspect living in the world.

I also teach specific safety strategies that can be used to reduce the risk of social danger. No single strategy can prevent all danger, but we must be proactive. My most popular strategy is the Safe Activities List, a list of activities predetermined to be totally safe. Youth and adults are taught to steer social invitations away from the unknown possibilities and subtle peculiarities of the moment toward those on the list.

Next, I teach strategies to increase emotional facility. Many of us on the autism spectrum do not intrinsically recognize our emotions or know how to use our feelings to make wise social discriminations. This may seem unusual to neurotypicals (those not on the spectrum) because non-autistic people appear born wired to understand their feelings and how to skillfully use emotional indicators to steer themselves through life.

But those of us on the spectrum must learn step-by-step that if your heart is racing and your stomach “drops” when somebody you just met asks you to walk around the movie theater, these are nervous signals and this feeling is a useful clue or tool for picking a course of appropriate and potentially life-saving action. If you are nervous, it may be time to leave the situation, use your Safe Activities List, or in a worst-case scenario, summon emergency assistance. When we do learn through effort and practice how to notice our emotional signals, how to identify our feelings, and how to accurately scale the “amount” of emotion we are experiencing, we can more confidently know what to do.

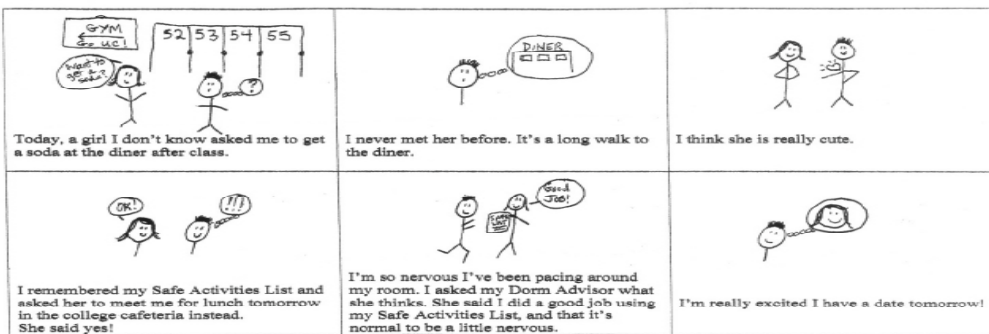
In her book *Asperger Syndrome and Adolescence: Helping Preteens and Teens Get Ready for the Real World*, Dr. Teresa Bolick explains how to make and use a feelings chart, an important visual aid and tool. Though some of her books are geared toward children, all of Kari Dunn-Buron’s books are useful for teaching autistic adults how to scale emotions and tailor reactions adeptly, thereby improving communication and engagement success.

Is my emphasis on safety strategies and help systems overbearing? After all, we are talking about adults. Shouldn’t autistic adults be free to do whatever they want, with whomever they choose? Shouldn’t adults make their own decisions without interference?

We do not have to violate the rights of adults to make their own way in life, disabled or not, but we must

Chapter 10: Using Comic Strips to Understand Safe Social Behavior

Example 2: Safe Activities List in Action



face the truth: Even articulate and educated autistic adults can experience difficulty protecting ourselves and making appropriate social choices. What we are realizing is that straight social skills training just isn't enough.

We have a responsibility as a community to provide autistic teens and adults with the tools and cognitive flexibility to navigate social life with less danger and more confidence. Needing rules about asking for help, visual aids, and safety strategies is a simple fact of autistic reality. We can't just say, "You are adults. Do whatever you want." We must endeavor to teach ways of dealing with autistic challenges and augmenting autistic strengths. Autism organizations have a particular responsibility to make judgments about what is safe, what is healthy, and what choices and activities are in line with "best practices" for those loving, feeling, thinking, and living with an autistic brain.

In summary, when preparing our sons and daughters, loved ones, students, and clients for the social world, we must consider how autistic people hear and process information, deal with emotion and choice, and struggle to communicate and socialize. We must take issues of social safety and social health seriously. It is imperative that we provide support and direct guidance, beyond basic skills training and factual knowledge, in order to promote the healthiest and least risky paths to friendship, outreach, and love.

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Challenging Behavior

A percentage of individuals with ASD may display challenging or problematic behavior which, often times, may result in more restrictive educational or adult program settings than might otherwise be necessary. This section of *The Best of The OARacle* focuses on the area of challenging behavior with a particular emphasis on skill development (for the individual learner, the family and support staff) so that the individual is better able to manage his own behavior across a variety of settings.

October 2004

Community-Based Behavioral Programming for Individuals with Autism: The Drive Toward Inclusion and the Challenge of Making It Work

By Russell Korman, Ph.D.

“Inclusion.” Just mention this one word in the field of autism and developmental disabilities (DD) and battle lines are almost immediately drawn in both the educational and community service arenas. When discussing the development of programming for children and adults with autism and other developmental disabilities who coincidentally present with serious behavioral and/or psychological challenges, ideology and practical reality often collide. The Olmstead decision (Olmstead v. L.C., 1999) in community services and the initiation and reauthorization of the Individuals with Disability Education Act in educational circles (IDEA: Congress, 2002; IDEA, PL 105-17; Turnbull, Wilcox, Stowe, and Turnbull, 2001) were not only landmark in both their mandate and scope, but also furthered an ongoing crisis experienced by service providers across the country.

Individuals with autism/DD who present with medical, psychiatric and/or behavioral challenges have been entering our classrooms and communities at an ever-increasing rate for years. The federal government has made the message clear: “Provide services for all individuals with special needs that are natural setting based and least restrictive in nature, and do it quickly.” The community has heard the message and responded with an unprecedented emphasis on community integrated housing and inclusive educational programming over the

past seven to 10 years (Sailor and Paul, 2004; Kormann and Petronko, 2002a; Daniel and King, 1997). Critical questions, however, remain unanswered: Has the practical reality of inclusion developed as smoothly as the philosophical underpinnings? Has the inclusion-based infrastructure developed sufficiently to ensure that a full range of appropriate services is available to this extremely challenged population? What clinical services are needed to best ensure that students and residents with autism/DD and behavioral challenges are supported in the most effective way possible?

The Dilemma That is Inclusion

Individuals that present with a combination of autism/DD and severe behavioral and/or psychiatric disorders have been labeled as dually diagnosed (Reiss, 1982) and make up a significant portion of the DD population (Reiss, 1985). When considered with medically frail individuals, this population has historically represented a group that requires more intensive, and sometimes segregated care in specialized residential (i.e. developmental centers) or academic (special education/self contained) programs. Treatment protocols are often complex, behaviors may be severe and the physical and emotional toll exacted on staff and families may be extraordinary. Maintaining the treatment environment as separate from the “typical” community may have been misguided but was nonetheless multi-functional: centralization of expertise and “protection”

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of the community from disruptive or dangerous behaviors often represented the philosophies that drove treatment decisions.

While the philosophy regarding the support of individuals with dual diagnosis has clearly changed, the debate regarding the impact of inclusion has not. The literature is mixed regarding the impact on academic progress for students with and without disabilities in traditional versus inclusive classrooms (Wallace, Doney, Mintz-Resudek, and Tarbox, 2004; Cole, Waldron, and Majd, 2004; Daniel and King, 1997; Kauffman, 1995) as well as on the effects of community acceptance, socialization, and attitudes (Kormann and Petronko, 2002b; Hieneman and Dunlap 2000; Luiselli, Wolongevicz, Egan, Amirault, Sciaraffa, and Trembl, 1999; Koegel, Koegel and Dunlap, 1996). Therefore, as we begin to ponder clinical intervention, the question of “point of entry” seems to be critical in attempting to identify “who the client really is” and where exactly the burden of clinical intervention really lies.

Supporting Individuals in Community Settings

Developing an ongoing training and intervention mechanism for direct support staff (i.e. classroom teachers and aides; residential staff) faced with the frequent occurrences of challenging behaviors is critical. Such support must address the idiosyncratic needs of the individual, the staff, the environment, and the socio-political system in which the behaviors are displayed (Petronko, Harris and Kormann, 1994; Colond and Weisler, 1995; Kormann and Petronko, 2002). These variables must be reflected in any intervention approach as they represent the “natural setting” in which the identified individual exists. These needs can best be met by an on-site behavioral training model, which does not necessarily view the referred person as the “target client” and therefore does not direct its only attention to that individual. A service that focuses on the natural setting and earmarks the parent/staff as the designated consumer of training and the initial vehicle for change seems to be the most appropriate option (Petronko, Anesko, Nezu and Pos, 1988; Petronko, et al. 1994; Felce deKock and Repp, 1986; Carr, Horner, Turnbull, Marquis, McLaughlin, McAtee, Smith, Ryan, Ruef, and Doolabh 1999; Feldman, Condillac, Tough, Hunt, and Griffiths 2002; Kormann and Petronko, 2002).

A critical goal that must be achieved in any naturally based support system, however, is that of behavioral competence. If the level of competence that a parent/staff member possesses can be increased through training, he/she can function as a natural support for the individual’s behavior without necessarily contaminating the environment with an observing behavioral consultant. Natural supports are frequently discussed as very attractive when building service plans that are “person centered” (Holburn, 2001; Mount, 1994). It seems clear that a service system that provides for the delivery of behavioral support from the people that are already a part of an individual’s life epitomizes the concept of “person centeredness.”

There are several obstacles, however, that must be overcome when attempting to implement a treatment model that utilizes parents/direct service professionals as the agents of change. The stress associated with providing services to individuals with autism/DD and behavioral challenges in both community residences and classroom environments is well documented (Bersani and Heifitz, 1985; Blumenthal, Lavender and Hewson, 1998; Hagopian et al., 2002; Hastings and Brown, 2002; Mitchell and Hastings, 2001). Low pay, long hours, inadequate training in behavior management, and the potential for personal injury are all obstacles that the disability community must overcome in its attempt to provide effective and consistent behavioral support to individuals with dual diagnoses. A consultation model that views parents/staff members as “the experts” who are a required component to any effective treatment approach seems to address several challenges at once.

First, burnout is often linked to a reduction of “self efficacy” (Bandura, 1977; 1986), which is defined as the perception of one’s skills and abilities to have a positive impact on life’s outcomes. The effect of stress on a parent’s sense of efficacy is described in reviews by Coleman and Karraker (1998), Dyson (1997), and Taylor (1983) and identifies one of the goals of behavioral consultation as the development of coping skills. The improvement in such skills is hypothesized to improve one’s perception of effectiveness and therefore one’s sense of self-efficacy. Moreover, burnout has been linked to the presence of chronic challenging behaviors, ineffective behavior management skills and negative emotional reactions generated in staff because of the targeted behavior (Mitchell and Hastings, 2002; Hastings and Brown, 2002). A behavioral consultation model that promotes self efficacy through the development of management skills and an intervention plan specifically tailored to the needs of the

individual, caregiver(s), and environment, would engender a sense of control in not only the caregiver, but also in the identified consumer.

Second, behavioral competence increases the likelihood of mutually rewarding interpersonal experiences between caregivers and the referred individual. The easier it is for an individual with a dual diagnosis to obtain valued reinforcers through his/her behavior, the more likely it is that the parent will be in a position to deliver those rewards. It is quite likely that a relationship in which parents are frequently delivering reinforcers would be viewed as pleasant and ones in which consumers would like to engage more often. As the frequency of such instances increases, it stands to reason that quality of life variables for all involved would be enhanced. Standliffe, Abery, and Smith, (2000), Campo, Sharpton, Thompson, and Sexton (1997) and Schalock (1994) agree that a clinical model that simultaneously promotes personal control and independence in the referred individual as well as self efficacy and the reduction in burnout in caregivers is critical for the enhancement of quality of life.

Finally, the improvement in behavioral challenges increases the likelihood that the referred individual can be maintained in more inclusive settings. Inclusion implies not only a presence, but an active participation in naturally occurring environments (residential or academic) for individuals regardless of developmental, psychiatric, or behavioral challenges (Holburn, 2001). Bridging the gap between the philosophy and reality of inclusion therefore, seems to rest with the dilemma of developing appropriate accommodations and naturally based supports. Our challenge as we continue into the new millennium is clearly to develop clinical protocols that can simultaneously support individuals with autism/DD in their natural settings while not forgetting the critical role that parents, teachers, and residential staff play in the future of our most fragile population.

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Taking It Easy: Behavioral Relaxation Training (BRT) for Persons with Autism

By Theodosia Paclawskyj, Ph.D., BCBA

Everyone encounters frustrating, frightening, or irritating situations on a daily basis. For most of us, the initial feelings of anger or stress come quickly but subside as we “talk ourselves down” or get support from another person in managing the situation. In some cases, however, the intensity of the anger or anxiety can become too much to handle. At this point, some people choose to seek help from a therapist (or perhaps even a self-help book) to manage their emotions and learn a form of relaxation training.

What about for persons with autism? Intense anxiety, rapid mood changes, or a low frustration tolerance are far more common than in the typically functioning population. In addition, intense emotions often precede problem behaviors such as self-injury or aggression.

Over 30 years of research in applied behavior analysis have resulted in a well-established conceptual framework of operant behavior that currently allows us to successfully decrease problem behaviors and increase adaptive skills in people with and without disabilities. Interventions for respondent behaviors, however, are under-researched. Common respondent behaviors include:

- Screaming
- Crying
- Sweaty palms
- Fist clenching
- Trembling
- Knee jerking
- Rapid heartbeat
- Gagging
- Tensing
- Flushing (turning red)
- Rapid breathing
- Nail-biting
- Jaw-clenching
- Grabbing onto others
- Lip-biting
- Flinging hands up (for protection)

About This OARacle Contributor

Dr. Paclawskyj is a research scientist at the Kennedy Krieger Institute. She is also an Assistant Professor in the Department of Psychiatry and Behavioral Sciences at the Johns Hopkins School of Medicine. She joined the Hopkins/KKI faculty in 2001. Dr. Paclawskyj is a Case Manager in the Neurobehavioral Unit Outpatient Clinic at Kennedy Krieger Institute, an Assistant Professor in the Department of Psychiatry and Behavioral Sciences at the Johns Hopkins University School of Medicine, as well as a Faculty Associate in the Department of Special Education at the Johns Hopkins University School of Professional and Business Education. Dr. Paclawskyj is an associate editor of the journal, *Research in Developmental Disabilities*.

One of the challenges to effective relaxation training is that the effects are gradual. However, the effort can still be worth it as it teaches a person how to independently cope with distressing emotions. Additionally, a person’s cognitive functioning is not a factor: researchers have found that knowing what an intervention was intended to do was not necessary for that intervention to work effectively in managing a person’s anxiety (Obler and Terwillinger, 1970).

This finding offers some potentially significant treatment opportunities for addressing stress, fear, and anger in people with autism. Some forms of relaxation training have already been modified for those with developmental disabilities. The most researched relaxation procedure has been a modified form of Progressive Relaxation (PR) (Lindsay and Baty, 1989; Luiselli, 1980). With PR, it is assumed that through a series of tense-release muscle exercises, an individual will become aware of the physical and emotional sensations that their body experiences in tensed and relaxed states (Bernstein and Borkovec, 1973). Thus, when the

person is anxious, he or she can employ PR techniques to help alleviate the feeling of tension through the relaxation response.

However, a limitation of this procedure is that it requires the person to report back to the trainer on how they feel, which may be difficult for individuals with communication impairments (Lindsay, Baty, Michie, and Richardson, 1989; Michulka, Poppen, and Blanchard, 1988; Poppen, 1998). Other challenges can occur if the person who could benefit from relaxation training cannot necessarily tolerate demands, or has difficulty with motor imitation. A potential alternative is a method known as Behavioral Relaxation Training (BRT; Poppen, 1998; Schilling and Poppen, 1983).

BRT focuses on the training of visible behaviors that allow an observer to independently determine whether or not the trainee is relaxed. The procedures of BRT involve modeling very specifically defined positions/behaviors in 10 areas/actions of the body listed in the accompanying chart. The person is taught to imitate the appropriate behaviors and sit in an overall position that will bring on the relaxation response. The observer can score whether or not the person is relaxed by using the Behavioral Relaxation Scale (BRS), a reliable and valid checklist for recording the presence of relaxed behaviors (Poppen and Maurer, 1982; Schilling and Poppen, 1983).

Over the past five years, we have trained 19 patients referred either for clinic-based services, inpatient treatment, or outpatient consultation. Anecdotal observation indicated that training the 10 behaviors specified in the BRT procedure appeared more difficult when taught in an unspecified order, especially when behaviors involving fine motor skills (e.g., keeping eyes lightly closed) were interspersed with gross motor behaviors (e.g., keeping torso in contact with the back of a cushioned chair). Consequently, clinicians were instructed to train the 10 behaviors in a structured order from large-to-small muscle groups: body, head, shoulders, feet, hands, throat, mouth, eyes, and finally breathing and quiet.

BRT: 10 Behaviors

- **Head**
- **Feet**
- **Quiet**
- **Shoulders**
- **Hands**
- **Body**
- **Eyes**
- **Breathing**
- **Throat**
- **Mouth**

To date, 12 studies have been conducted to evaluate the teaching and treatment applicability of BRT with individuals with mental retardation. These studies demonstrated that the participants could acquire BRT more rapidly and more effectively than other forms of relaxation training. Additionally, participants demonstrated improvement in short-term memory and attention (Lindsay, Baty, Michie, and Richardson, 1989; Lindsay, Fee, Michie, and Heap, 1994; Lindsay and Morrison, 1996; Morrison and Lindsay, 1997).

In the neurobehavioral unit in-patient and out-patient programs at the Kennedy Krieger Institute, we have begun investigating the potential of BRT as an addition to the comprehensive behavioral treatment interventions we use for children with developmental disabilities and severe behavior problems (Paclawskyj, 2002, 2004, 2005).

Our data demonstrate significant benefits when the structured training sequence was utilized. For the group as a whole:

1. Patients were taught to engage in BRT for an average of seven minutes and required an average of two hours to achieve mastery.
2. Those patients trained using the structured sequence displayed more improvements across untrained behaviors ($m=4$) than those trained in a random order ($m=1$). That is, training in the structured order on average required teaching only 6/10 responses, as opposed to having to teach 9 or all 10 responses when a random order was used.

The Relaxation Response

Warmth or tingling in the muscles from decreased muscle tension, a decrease in blood pressure, decreased oxygen consumption, improved digestion, slower breathing, and improved circulation that all result in a feeling of well-being and calm.

We now use the structured teaching sequence only, and have seen shortened training times as a result. For the patients for whom BRT was added as a standard intervention, we saw greater than expected improvements for target behaviors such as tantrums in response to noise, compulsive skin picking, and self-injury and aggression co-occurring with agitation and screaming. We hope to continue our work in treatment evaluation to identify which persons are the best candidates for such treatment and in which problem areas is it most useful.

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The Cycle of Tantrums, Rage, and Meltdowns

By Brenda Smith Myles, Ph.D.

Many students with Asperger Syndrome and other autism spectrum disorders (ASD) view school as a stressful environment, presenting several stressors that are ongoing and of great magnitude. Stressors include difficulty predicting events because of changing schedules; tuning in to and understanding teacher directions; interacting with peers; and anticipating differences in environments such as classroom lighting, sounds/noises, odors, etc. Students with this exceptionality rarely indicate in any meaningful way that they are under stress or experiencing difficulty coping. In fact, they may not always know that they are near a stage of crisis. Even though the individuals themselves often do not recognize that they are upset, meltdowns do not occur without some observable warning. Rather, students with ASD exhibit a pattern of behaviors that are precursors to a behavioral outburst. Sometimes these behaviors are subtle. Without a clear understanding of rage and the cycle in which it occurs, it may indeed appear as if rage occurs without warning. Tantrums, rage, and meltdowns (terms that are used interchangeably) typically occur in three stages that can be of variable length. They are (a) the “rumbling” stage, (b) the “rage” stage, and (c) the “recovery” stage (Myles and Southwick, 1999).

The Rumbling Stage

The rumbling stage is the initial stage of a tantrum, rage, or meltdown. During this stage, children and youth with ASD exhibit specific behavioral changes that may not appear to be directly related to a meltdown. The behaviors may appear to be minor such as nail biting, tensing muscles, or otherwise indicating discomfort. It is easy at this stage to ignore these seemingly minor behaviors; yet, these behaviors often indicate an impending crisis. Students may also engage in behaviors that are more pronounced, including withdrawing from others or threatening others verbally or physically.

During this stage, it is imperative that an adult intervene without becoming part of a struggle. Effective interventions during this stage include: “antiseptic bouncing,” “proximity control,” “support from routine,” and “home base.” All of these strategies can be effective in stopping the cycle of tantrums, rage, and meltdowns and they are invaluable in that they can help the child regain control with minimal adult support (Myles and Southwick, 1999).

About This OARacle Contributor

Brenda Smith Myles, Ph.D. is the chief of programs and development for the Ohio Center for Autism and Low Incidence and an associate professor in the Department of Special Education at the University of Kansas where she co-directs a graduate program in Asperger Syndrome and autism. The recipient of the 2004 Autism Society of America’s Outstanding Professional Award and the 2006 Princeton Fellowship Award, she has written numerous articles and books on Asperger Syndrome and autism including *Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns* and *Asperger Syndrome and Adolescence: Practical Solutions for School Success*.

Antiseptic Bouncing

Antiseptic bouncing involves removing a student, in a nonpunitive fashion, from the environment in which the difficulty is occurring. At school, the child may be sent on an errand. At home, the child may be asked to retrieve an object for a parent. During this time, the student has an opportunity to regain a sense of calm. Upon returning, the problem has typically diminished in magnitude and the adult is on hand for support, if needed.

Proximity Control

Rather than calling attention to the behavior, this strategy allows the teacher or parent to move near the student who is engaged in the target behavior. Often something as simple as standing next to a child is calming. This can easily be accomplished without interrupting an ongoing activity.

Support From Routine

Displaying a chart or visual schedule of expectations and events can provide security to children and youth with ASD who typically need predictability. This technique can also be used as advance preparation for a change in routine. Informing students of schedule changes can prevent anxiety and reduce the likelihood of tantrums, rage, and meltdowns. For example, the student who is signaling frustration by tapping his foot may be directed to his schedule to make him aware that after he completes two more problems he gets to work on a topic of special interest with a peer. While running errands, parents can use support from routine by alerting the child in the rumbling stage that their next stop will be at a store the child enjoys.

Home Base

A home base is a place in the school where an individual can escape stress. The home base should be quiet with few visual or activity distractions and activities should be selected carefully to ensure that they are calming rather than alerting. In school, a resource room or counselor's office can serve as a home base. The structure of the room supersedes its location. At home, the home base may be the child's room or an isolated area in the house. Regardless of its location, it is essential that the home base is viewed as a positive environment. Home base is not timeout or an escape from classroom tasks or chores. The student takes class work to home base, and at home chores are completed after a brief respite in the home base. Home base may be used at other times than during the rumbling stage. At the beginning of the day, a home base can serve to preview the day's schedule, introduce changes in the typical routine, ensure that the student's materials are organized, or prime for specific subjects. At other times, it can be used to help the student gain control after a meltdown.

When selecting an intervention during the rumbling stage, it is important to know the student, as the wrong technique can escalate rather than de-escalate a behavior problem. It is important to understand that interventions at this stage are merely band-aids. They do not teach students to recognize their own frustration or handle it. These strategies must be taught in a preventative manner so that the cycle does not begin.

Rage Stage

If behavior is not diffused during the rumbling stage, the child or adolescent may move to the rage stage. At this point, the student is disinhibited and acts impulsively, emotionally, and sometimes explosively. These behaviors may be externalized (i.e., screaming, biting, hitting, kicking, destroying property, or self-injury) or internalized (i.e., withdrawal). Meltdowns are not purposeful, and once the rage stage begins, it most often must run its course. During this stage, emphasis should be placed on child, peer, and adult safety as well as protection of school, home, or personal property. The best way to cope with a tantrum, rage, or meltdown is to get the child to home base. As mentioned, this room is not viewed as a reward or disciplinary room, but is seen as a place where the student can regain self-control. Of importance here is helping the individual with ASD regain control and preserve dignity. To that end, adults should have developed plans for (a) obtaining assistance from educators such as a crisis teacher or principal, (b) removing other students from the area, or (c) providing therapeutic restraint, if necessary.

Recovery Stage

Following a meltdown, the child with ASD often cannot fully remember what occurred during the rage stage. Some may become sullen, withdraw, or deny that inappropriate behavior occurred, others are so physically exhausted that they need to sleep. It is imperative that interventions are implemented at a time when the student can accept them and in a manner the student can understand and accept them. Otherwise, the intervention may simply resume the cycle in a more accelerated pattern leading more quickly to the rage stage. During the recovery stage, children are often not ready to learn. Thus, it is important that adults work with them to help them to once again become a part of the routine. This is often best accomplished by directing the youth to a highly motivating task that can be easily accomplished such as an activity related to a special interest.

Summary

Students with ASD experiencing stress may react by having a tantrum, rage, or meltdown. Behaviors do not

occur in isolation or randomly; they are most often associated with a reason or cause. The student who engages in an inappropriate behavior is attempting to communicate. Before selecting an intervention to be used during the rage cycle or to prevent the cycle from occurring, it is important to understand the function or role the target behavior plays. This is a first step in developing effective interventions. Indeed, without determining reasons, causes, or conditions under which a behavior occurs, it is unlikely that an intervention will be effective.

Children and youth with ASD generally do not want to engage in tantrums, rage, and meltdown. Rather, the rage cycle is the only way they know of expressing stress, coping problems, and a host of other emotions to which they see no other solution. Most want to learn methods to manage their behavior, including calming themselves in the face of problems and increasing self-awareness of their emotions. The best intervention for tantrums, rage, and meltdowns is prevention. Prevention occurs best as a multifaceted approach consisting of instruction in (a) strategies that increase social understanding and problem solving, (b) techniques that facilitate self-understanding and (c) methods of self-calming.

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Related Issues

This final section of *The Best of The OARacle* highlights two significant contributions that simply did not fit neatly into any of the other sections. The first selection provides an overview of some of the mental health challenges individuals with ASD may experience and offers information as to how families and individual support staff can help identify these challenges and, subsequently, get the necessary intervention. The second selection addresses the critical issue of how best to ensure that interactions between learners on the spectrum and the law enforcement community are positive and, ideally, even productive.

August 2004

Mental Health for Individuals with ASDs

By Valerie Gaus, Ph.D.

In recent years, mental health issues have gained more attention with an estimated 54 million people in the nation suffering from mental disorders. According to a 2001 study by the World Health Organization, mental health ranks first in terms of causing disability in the United States, Canada, and Western Europe (WHO, 2001). The study also found that mental illness – including depression, bipolar disorder, and schizophrenia – accounts for 25 percent of all disability across major industrialized countries. For individuals with autism spectrum disorders (ASDs), the risk of developing mental illness is no less than it is for the general population. For their parents and caregivers, mental illness presents yet another challenge to add to the list of social, educational, and behavioral issues they have to contend with. The intent of this article is to address some of the most common questions parents and caregivers pose about mental illnesses in individuals with ASDs, as well as to offer strategies that will allow them to successfully advocate for quality treatment.

About This OARacle Contributor

Valerie L. Gaus, PhD, has been a practicing cognitive-behavioral therapist serving adults and adolescents with dual diagnosis (intellectual disability with comorbid psychiatric disorder), autism spectrum disorders, mood disorders, and anxiety disorders since she received her doctorate in clinical psychology from Stony Brook University in 1992. Since then she has maintained a private practice on Long Island, New York, and serves as the staff psychologist for the Vincent Smith School in Port Washington, New York. Dr. Gaus is on the advisory board of the Asperger Syndrome and High Functioning Autism Association, the grant review committee of the Organization for Autism Research, and the adjunct faculty at Long Island University/C. W. Post. She was also a founding board member of the New York Metro chapter of the National Association for the Dually Diagnosed. Dr. Gaus has written numerous articles and book chapters on mental health issues in developmental disabilities and has lectured extensively on these topics across the United States and abroad. Her most recent work, *Cognitive-Behavioral Therapy for Adult Asperger Syndrome*, was just published by Guilford Press.

1. What is mental health and how is defined for people with ASDs?

Can a person with an autism spectrum disorder be “mentally healthy”? Before that question can be answered, we must define “mental health” and what it means for any person, whether neurotypical or on the autism spectrum. There are endless debates in the psychological literature about this question, but for the purposes of this article, I will offer Dosen’s (1993) idea. Mental health is achieved when one has:

- Limited stress in daily living
- A place of one’s own and a role in his/her surroundings
- Achieved functioning in accordance with one’s own abilities

A person with ASD may need help in tackling obstacles that can potentially interfere with the attainment of the above criteria. However, with the necessary help, persons with ASD can achieve and/or maintain mental health.

2. Can a person with an ASD have a mental health problem too?

Throughout the lifespan, there are many things that can lead any person to develop a mental health problem. These issues do not necessarily cause mental illness, but simply increase a person’s vulnerability. Some risk factors for the neurotypical population are:

- Poor social support
- Presence of central nervous system damage
- Low expectations for success
- Sense of helplessness

- Limited economic resources
- High levels of stress in family
- Presence of physical disability
- A chronic medical problem
- A family history of mental illness

Unfortunately, there have not been any thorough studies on the prevalence of mental health disorders in the ASD population. Most studies on “comorbidity,” or the co-existence of a psychiatric condition with ASD, have been based only on case reports (Gillberg and Ehlers, 1998). Preliminary studies have suggested that for some disorders, the incidence is higher for people with ASD than would be found in the general population. For example, Klin and Volkmar (1997) found in a sample of 99 individuals with ASD that 28 percent also met criteria for ADHD, 19 percent showed obsessive-compulsive disorder and 15 percent had depression. DeLong and Nohria (1994) reported a higher incidence of bipolar mood disorder in persons with ASD and within their families than found in the general population. Conversely, psychotic disorders (e.g., schizophrenia) do not appear to be more prevalent in people with ASD (Tantam, 2000), and may even be over-diagnosed in higher-functioning ASD because the individual’s willingness to inappropriately verbalize thoughts can be mistaken as psychosis (Martin, Patzer and Volkmar, 2000).

All of these data must be interpreted cautiously because, as Martin, Patzer and Volkmar (2000) point out, it is difficult at this stage to determine whether symptoms are really part of a separate disorder, or are part of the ASD itself. Also, there is still so much controversy over the precise way in which to define ASD that clear prevalence studies will not be possible until there is more agreement among scientists and practitioners over definitions.

Without accurate statistics, however, we can at least assume that the prevalence of mental disorders would be no less than the general population. In other words, there is no reason to believe that a person with ASD would be less likely than neurotypicals to develop, for example, problems with depression or anxiety. When one examines the above risk-factors, it is easy to imagine how the presence of ASD may actually increase the stress and strain on an individual and his/her family, making mental health needs all the more important for early detection and state-of-art treatment.

3. Do people with ASD have access to the same quality of mental health services that neurotypical people do?

Despite the increased risk mentioned above, individuals with ASD and other developmental disabilities (DD), including mental retardation, cerebral palsy, epilepsy and traumatic brain injury have received inadequate mental health treatment throughout most of the 20th century (see Butz, Bowling, and Bliss, 2000; Dosen, 1993, 2002; MacLean, 1993; Nezu, Nezu and Gill-Weiss, 1992 for more comprehensive reviews). There are many reasons the mental health needs of people with DD were neglected. From the 1950s to the early 1970s, the majority of people in the United States with multiple disabilities lived in institutional settings where all treatment and educational needs were inadequately addressed.

As people with DD were moved out of institutions and into the community during the 1970's and early 1980's, medical and educational/rehabilitative services improved, but mental health needs continued to be ignored. This is largely due to the fact that mental health professionals were not trained to deal holistically with people with DD and therefore had a very narrow focus on treatment. Clear symptoms of mental health problems were wrongly seen as part of the DD. This type of error is now called "diagnostic overshadowing" (Levitan and Reiss, 1983; Reiss, 1993), which happens when the primary diagnosis of a developmental disorder actually overshadows or masks the presence of a secondary problem. Symptoms that were expressed overtly (e.g., through physical aggression) were labeled as "behavior problems." Symptoms expressed in subtler ways (e.g., withdrawal, changes in sleep habits, gradual skill regression) often went unnoticed.

Treatment for "behavior problems" relied heavily on pharmacological approaches aimed at reducing problem behavior (e.g., "chemical restraint"). They were applied without a comprehensive assessment of the individual’s psychiatric status. Therefore, significant mental health diagnoses and more appropriate drug options were overlooked. Non-pharmacological approaches were limited to "behavior modification" (Alford and Locke, 1984), systems of rewards and punishments designed to reduce problem behavior. Unfortunately, these approaches

were sometimes designed by professionals who were not properly trained in Applied Behavior Analysis (ABA) and learning principles. The resulting contingency systems in these cases were not addressing the true function of an individual's behavior. In addition, the types of treatments that were known to help non-disabled people with various mental health problems, especially "talk" therapies, were not being offered to people with DD. For various reasons, people with DD were not viewed as candidates for counseling or psychotherapy.

Thankfully, within the past 10 years, there is a greater emphasis on using multi-modal, multi-disciplinary approaches to treatment planning, which includes consideration of the subjective experiences and information-processing styles of individuals (Dosen, 2002; Gardner and Sovner, 1994), as well as the neurobiology and medical factors behind problem behavior. Also, the old view that psychotherapy is not a viable treatment option for people with ASD and other DD has been strongly refuted by several authors (Butz, Bowling and Bliss, 2000; Lynch, 2000; Prout and Strohmer, 1994). For higher-functioning people with ASD, psychotherapy is more naturally considered with these newer attitudes toward people with disabilities (Gaus, 2000, 2002.)

4. How can a caregiver tell when it is time to get a consultation with a psychiatrist?

There can be any number of signs that a person needs a psychiatric assessment. Below are the most common examples.

- There is a dramatic decrease in functioning level compared to the individual's previous level of ability; a loss of skills.
- Ongoing maladaptive behavior disrupts his/her functioning. It persists even after there has been a thorough assessment and multiple assessment-based interventions designed by a qualified applied behavior analyst.
- The individual is functioning poorly despite being on multiple psychiatric medications without a clear rationale or diagnosis.
- The individual is verbalizing increased distress (e.g., reporting feelings of loneliness, anger, suicidal thoughts).

5. Doesn't it create problems when people have too many labels? Isn't the ASD diagnosis enough?

Unfortunately, it is still true in our society that having a mental health diagnosis can be stigmatizing in some situations. There continues to be fear and negative attitudes toward disability and mental illness that is largely based on ignorance. In addition, being incorrectly diagnosed can have devastating affects when inappropriate treatment is applied.

In the face of this, it is all the more important to correctly identify a mental health problem when there is one present. Ignoring psychiatric symptoms in an age when psychiatry and neuroscience are making so many advances can be equally devastating if it means a good treatment is withheld from someone who needs it.

The true purpose of diagnosis is not to label people; rather it is to label the behavior pattern that is problematic for the individual. Why is that important? If behavior can be classified, then it can be linked to similar behavior patterns that have been documented by other mental health professionals. If the behavior is similar enough to one of these well-documented behavioral phenomena, then the caregivers and professionals are given important shortcuts to viable treatment options that have already been shown to be helpful for other people with the same problem. Without this, doctors would have to start from scratch and provide "shot in the dark" treatments with every single new patient.

If you are a caregiver involved in the process of diagnosing a mental health problem in a person with ASD, here are some things to keep in mind to avoid stigma.

- You are helping to classify behavior, not the individual.
- Labeling the behavior helps the individual access treatment that has been supported by research.
- Accurately naming the behavior improves the quality of the ongoing assessment process by enhancing communication between professionals on the treatment team.

6. What can a caregiver do to ensure a person with ASD is getting appropriate mental health treatment from psychiatrists and therapists?

Many times caregivers ask how they can tell if their doctor is prescribing the right type of treatment. Though they can't tell the doctor what to do, parents want to properly advocate when they go to mental health appointments. There are two important principles for success in advocating for good quality treatment:

Knowing What Questions To Ask

Here are some good quality assurance questions that all caregivers should ask regularly when visiting psychiatrists and psychotherapists (adapted from Sovner and Hurley, 1985).

- Has there been a thorough assessment, including a medical exam to rule out possible medical causes for the problem behavior?
- What is the theory on what is causing the problem behavior?
- What is the psychiatric diagnosis as listed in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)?
- What evidence was used to arrive at the diagnosis?
- What are the goals of treatment?
- How will the treatment be carried out?
- Is the treatment plan based on the theory of what is causing the problem?
- Is the treatment based on the research literature; is it similar to the treatment that would be offered to non-disabled individuals who have the same mental health diagnosis?
- How are the effects of treatment going to be monitored?
- What signs and symptoms should the caregiver be documenting at home?
- Are there too many pharmacological agents involved?
- Is the individual being over-medicated?
- Is the individual being under-medicated?
- Is drug therapy being changed too rapidly?
- Are doses given on an emergency basis or given as on as-needed basis being used excessively?
- What are the criteria for discharge from treatment?

Practicing Good Communication

You don't have to be a doctor to seek and share information, which is a large part of what caregivers do on mental health visits. Good communication is a 50/50 process. Both you and the doctor need to be open to an ongoing collaboration in order to help the individual being treated. Because of a mental health professional's obligation to keep treatment confidential, your involvement as a caregiver will vary according to the functioning level and age of your child. Listed below are good communication practices for each party:

Psychiatrist or Therapist

- Educate patient and caregiver about target signs and symptoms.
- Ask patient and caregiver to keep track of changes and report back.
- Offer and explain treatment options and discuss supporting research.
- Use language that is understandable to a layperson.
- Be open to questions and answer them respectfully.
- Direct patient and caregiver to resources that will enhance treatment.
- Coordinate treatment with all other providers in patient's life by communicating with them on a regular basis (e.g., other therapists, teachers, case managers, other physicians).

Patient and Caregiver

- Ask the quality assurance questions listed above on a regular basis.
- Make requests of the doctor to ensure he/she is practicing the above.
- Ask for clarification if you do not understand a term used by the doctor.
- Initiate discussions about changes you have observed at home, don't wait for the doctor to ask you and be prepared to report something at each visit.
- When reporting to the doctor, try to be concise and objective. Keep it short and to the point, using descriptive terms about what you saw or heard; avoid using vague terms that you can't back up with evidence.

Conclusion

It can be a very confusing and intimidating process to interface with the mental health service delivery

system. By practicing the guidelines listed above, you can be more confident that you are advocating for the best treatment for your child's problem. Remember, you don't have to be a doctor to ask lots of questions!

For more information and resources on this topic, contact the National Association for Dual Diagnosis (NADD), an organization for persons with developmental disabilities and mental health needs at www.thenadd.org.

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May 2006

Autism Spectrum and Law Enforcement Training

By Dennis Debbaudt

For many of us, autism spectrum risk and safety management is a daily concern. We now know that with the increase in autism diagnoses, there is also a corresponding increase of autism-related contacts with law enforcement, community safety and juvenile and criminal justice organizations and professionals. Across the nation, autism advocacy organizations are increasingly addressing the educational needs of police and law enforcement professionals; first and initial responders such as fire rescue, paramedics, 911 dispatch operators, and hospital personnel; criminal justice professionals, including prosecutors, defense attorney, judges and magistrates, correctional, probation, and parole professionals. Consequently, the U.S. Department of Homeland Security and many other U.S. law enforcement agencies are currently providing autism training and educational materials for their work forces. While there is much, much more to be done, the strides the autism community has made in developing national, regional, and local partnerships with law enforcement, emergency response, and criminal justice agencies are a step in the right direction. The following excerpts are from the Autism and Law Enforcement Roll Call Briefing Video Script and Appendix (Debbaudt and Legacy, 2004).

Some Common Reasons for Autism Related Contacts or 911 Calls

A child or adult has wandered away from parent or caregiver, home or school. The person may also wander into traffic, railways or attempt to enter nearby homes or dwellings. Parent or caregiver actions are misinterpreted or appear as assault. When a person displays

unusual behavior in a community setting where they are not known, these behaviors may be interpreted by others as suspicious, threatening, criminal in nature, or as someone high on drugs or other substances. Rearranging or making order out of store displays or products may appear as shoplifting. When a person displays escalated behavior in the community, at school, or at home, unaware of the person's autism, citizens will call 911.

Officer should understand that an individual with autism:

- May inappropriately approach or run towards officers.
- In emergencies, may flail against medical procedures; may attempt to re-enter dangerous environment (i.e., a burning home, flee into traffic, or touch a downed power line).
- May be non-verbal.
- Can become upset with changes in routine for apparently trivial reasons.
- May not recognize your uniform or marked vehicle, or understand what is expected of them if they do.
- May not understand your verbal commands or use of slang expressions.
- May not understand your command pres-

About This OARacle Contributor

A professional investigator and journalist for 28 years, Dennis Debbaudt turned his attention to autism spectrum disorders in 1987 after his son was diagnosed with autism. He's authored numerous articles and books including *Autism, Advocates and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders* and "Contact with Individuals with Autism: Effective Resolutions" with Darla Rothman for the *FBI Law Enforcement Bulletin* and reprinted in *Sheriff Magazine*. Debbaudt's "Autism and Law Enforcement Roll Call Briefing" video was released in 2004. Over the past 11 years, Debbaudt, a member of the American Society for Law Enforcement Training (ASLET), has trained law enforcement, criminal justice, and education professionals throughout the United States, Canada, and United Kingdom.

ence, body language, and non-verbal communications, such as rolling of eyes, raising of eyebrows, shrugs, or hand signals.

- May be attracted to shiny objects and actually reach for your badge, radio, keys, belt buckle, or weapon.
- May display repetitive, self-stimulation behaviors, such as twirling an object or themselves, finger or hand flicking, body rocking, pacing, or talking to themselves.
- May run or move away when approached by officer or any stranger; sensory overload.
- May flee from lights, sirens, canine partners, aromas or even a light, comforting touch.

Be alert to sensory overload. Your sirens and lights may cause further anxiety and increase a negative reaction from the child or adult who has autism. Be aware that your attempts to stop these behaviors may result in the person's escalated, self-protective actions, such as a "fight or flight" reaction.

De-escalation

You may be called to respond to a situation where the person with autism is displaying escalated behavior that has alarmed a citizen or is apparently beyond the control of the parent or caregiver. These calls will challenge the training and instincts of even the most experienced veteran.

You may learn the person has autism from your dispatcher, someone at the scene, or the person himself or herself. Here are some tips for responding officers.

- Make sure the person is unarmed and maintain a safe distance because they may suddenly invade your personal space.
- Talk calmly and softly.
- Speak in direct, short phrases such as: "Stand up now." "Get in the car."
- Avoid slang expressions, such as: "What's up your sleeve?" "Are you pulling my leg?"
- Allow for delayed responses to your questions or commands.
- Repeat or rephrase.
- Consider use of pictures, written phrases and commands, and sign language.
- Use low gestures for attention; avoid rapid pointing or waving.
- Examine for presence of medical alert jewelry or tags, or an autism handout card.
- Model calming body language (such as slow breathing and keeping hands low).
- Model the behavior you want the person to display.
- A person with autism may not react well to changes in routine or the presence of strangers, even a uniformed stranger.
- Officers should not interpret the person's failure to respond to orders or questions as a lack of cooperation or a reason for increased force.
- Seek information and assistance from parent or others at the scene about how to communicate with and de-escalate person's behavior.
- Avoid stopping repetitive behaviors unless there is risk of injury to yourself or others. If the individual is holding and appears to be fascinated with an inanimate object, consider allowing subject to hold the item for the calming effect (if officer safety is not jeopardized by doing so).
- Evaluate for injury: person may not ask for help or show any indications of pain, even though injury seems apparent.
- Be aware that the person may be having a seizure.
- Be aware of person's self-protective responses and sensitivities to even usual lights, sounds, touches, orders, and animals.
- If possible, turn off sirens and flashing lights and remove canine partners, crowds, or other sensory stimulation from the scene.
- If person's behavior escalates, use geographic containment and maintain a safe distance until any inappropriate behaviors lessen.
- Remain alert to the possibility of outbursts or impulsive acts.

- Use your discretion. If you have determined that the person is unarmed and established geographic containment, use all available time to allow the person to de-escalate themselves without your intervention.

Interview

The person with autism will have difficulty processing your questions. They may be unable to give name, address, phone number, or be unable to present ID when asked. Expect your interview to take longer. The person may have the information you need. However, they may be difficult to understand.

It is common for people with autism to repeat your words and phrases. This is known as echolalia. For example, the officer says, "What's your name?" Person replies, "What's your name?" Officer says, "Are you trying to be a smart aleck?" Person replies, "Are you trying to be a smart aleck?" Officer says, "How about if I run you in?" Person replies, "How about if I run you in?" Be aware that a person with autism may also model your body language and emotional state.

Here are some tips for interviewing a person with autism.

- Do not take a lack of eye contact, the changing of subjects, or answers that are vague, evasive or blunt as evidence of guilt knowledge. These are common characteristics of people with autism.
- The person may truly not understand Miranda warnings even when they say they do.
- The verbal, higher functioning person may have autism or Asperger Syndrome. They may be overly influenced by standard interrogation techniques and produce a misleading statement or false confession.
- To avoid confusion, ask questions that rely on narrative responses.
- Consider asking a series of unrelated "yes" or "no" questions to determine the style and dependability of the response.
- If you have learned that the person has autism or Asperger Syndrome, prior to questioning, consider contacting a specialist familiar with these conditions.

With their unusual responses to your questions, the person with autism may challenge all of your training. Follow procedure, but also follow your gut instincts if you feel something isn't quite right with the subject of your investigation. As in the old adage: if the statement or confession is "too good to be true," it probably is.

Victims

People with autism are oftentimes victims of crime, such as: sexual, verbal, or physical assault. This can occur anywhere. Investigators can overcome the communication barriers of interviewing the person with autism when they seek assistance from the autism community. Become familiar with the person's communication style and background by reviewing fresh records and interviewing others who know the person well. Ask parents, caregivers, and people who know the victim for tips about how the person gives and receives information. If not verbal, how do they communicate?

Further Tips

- Seek permission to and consider videotaping the interview.
- Consider having a person the victim trusts present at the interview.
- Avoid uniforms or authority clothing.
- Get to know the person's communication style through casual conversation before any attempt to get recollection of event.
- Plan questioning based on person's ability level.
- Develop good rapport; use person's first name.
- Use simple, direct language and deal with one issue at a time.
- Encourage the witness to recreate the context in his or her own words. Ask questions that require a narrative answer.
- Make sure your words and their words have meanings that you both understand to be the same.
- Make sure that you and the victim-witness understand whom is being referred to when using pronouns.
- Be alert to non-verbal cues that suggest the witness does not understand, is confused, or does not agree

with the question you asked or the statements you have made (i.e., restlessness, frowning, and extremely long pauses).

- The victim may not want to answer questions more than once (explain first that you may have to ask questions more than once).
- Let victim know it is okay to say “no” to your questions.
- Become convinced the person understands or is known to tell the truth.
- Avoid leading questions.
- Carefully establish timelines.
- Learn person’s schedule and determine events through this context, rather than asking, “What time did it happen?”
- Person may have short attention span. Consider several short interviews.
- Be alert to a spontaneous disclosure of evidence (Farrar, 1998).

U.S. research indicates that persons with developmental disabilities, including autism, will have up to seven times more contacts with law enforcement than a member of the general population (Curry et al., 1993). These contacts can be public safety emergencies or criminal justice situations. High on the list of risks are children and adults who bolt and flee from our homes, parents and care providers. As with Alzheimer's families, autism families face constant pressure to secure their home's doors and windows. We erect fences, consult with security companies, sleep in shifts, and fear the scrutiny of neighbors, law enforcement and social service professionals all the while looking for answers from professionals about our children's wandering. Persons with autism often lack a fear of real danger. When mixed with a propensity to wander, the two are a deadly combination. Autism wanderers commonly drown, are found in road ways, on train tracks, attempt to enter homes and dwellings, have been frozen to death, have disappeared, and have been sexually abused and murdered. The autism community worldwide is keenly aware of life-threatening, autism-based wandering and is taking steps to address it.

Preparing for a wandering incident may seem extreme for some families. After all, their child or adult hasn't wandered or bolted. Yet, for many other families addressing wandering the first time is the worst time. These preparations will also be invaluable in a natural or man-made emergency situation. For example, when a parent or care provider has their own medical emergency and becomes quickly incapacitated.

Modifications in the Home

For many families, securing their home against chronic and dangerous wandering is the first order of preparedness. They may consult with professional security and burglar alarm, locksmiths, and home improvement companies that are familiar with 21st century technology that can help secure a home. Always keep a record of your anti-wandering efforts. You may need to prove to authorities that you are not neglectful parents or care providers. Anyone interested in the Environmental Modifications for the Home report by Jason Hoffroge can visit www.autismriskmanagement.com and download it.

The Autism Society of America's Safe and Sound initiative features autism alert stickers for homes and vehicles—and an example of what information can be developed, photocopied, carried by parents, care providers, or persons on the spectrum to produce or be found during an emergency—and shared proactively with law enforcement, emergency response agencies, and persons that should be contacted during an emergency. Visit www.autism-society.org for more information.

An Autism Emergency Contact Handout Model should include the following information:

- Name of child or adult
- Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- Sensory, medical, or dietary issues and requirements, if any
- Inclination for elopement and any atypical behaviors or characteristics that may attract attention
- Favorite attractions and locations where person may be found

- Likes, dislikes—approach and de-escalation techniques
- Method of communication, if non-verbal → sign language, picture boards, written word
- ID wear → jewelry, tags on clothes, printed handout card
- Map and address guide to nearby properties with water sources and dangerous locations highlighted
- Blueprint or drawing of home, with bedrooms of individual highlighted
- Obtain and maintain fingerprints (Debbaudt, 2002)

In the United States, some law enforcement, fire rescue, and emergency 911 call centers are willing and able to proactively place this information into their data base. When a call comes in for response to Alzheimer's, autism, or medically fragile families who participate—911 dispatchers can alert the first responder before they arrive with key information that was provided. Although not every system or agency is able to provide this service, it is certainly worthy of inquiry.

Alert Your Neighbors

The behaviors and characteristics of autism have the potential to attract attention from the public. Law enforcement professionals suggest that families of individuals with autism reach out and get to know their neighbors. Knowing your neighbors can lead to better social interactions for your loved ones with autism. (Debbaudt, 2004) The best way to approach this is to take the following measures.

Decide what information to present to neighbors.

Plan a brief visit to your neighbors.

Introduce your child or adult or a photograph.

Give your neighbor a simple handout with your name, address, and phone number.

Ask them to call you immediately if they see your son or daughter outside the home.

This approach may be a good way to avoid problems down the road and will let your neighbors.

Know the reason for unusual behaviors.

Know that you are approachable.

Have the opportunity to call you before they call 911.

School-Based Awareness

Sharing autism recognition, risk and safety information with all district employees is crucial. It is essential to include transportation, maintenance, cafeteria, and secretarial staff in briefings and training on issues such as school safety, threat assessment, information gathering, and crisis intervention procedures.

There are many reasons why it is important to include transportation, maintenance, cafeteria, and other non-teaching staff in autism risk and safety sessions. For one thing, when these individuals learn to use basic spectrum communication and response techniques, they can become valuable assets for school authorities. For another, there are added benefits for the students, since these staff members may come to be viewed as teachers or administrators, and as such, the student may seek assistance from them. In addition, these employees can assist school security by providing extra sets of eyes and ears, especially when it comes to monitoring episodes of bullying, teasing and taunting. Most importantly, the relationships developed with non-teaching staff can pay off in early recognition of school-place bullying.

It is predictable that the behaviors and characteristics that students on the spectrum inherently display will draw the attention of other students. Unaware that their behaviors, physical posture, vocal tone, apparent aloofness, and social gaffes are attracting unwanted attention, students with ASD can make perfect targets for bullies (Debbaudt, 2003). Bullies typically become adept at selecting their victims. Their actions often take place quickly, and out of the sight and hearing space of teachers. Since bullying often occurs on the school bus, school security can and should observe the interactions between the student on the spectrum, and his or her peers on the school bus. Likewise, they should exercise vigilance with respect to observing students entering and leaving schools; navigating the hallways between classes;

and using the restrooms, cafeteria, and playground, since these are also target areas for bullies. Finally, it is important to be mindful that older, more independent students on the spectrum may be at greater risk than those who require, and hence receive, more adult supervision.

It is well understood that early intervention and education are the keys to helping students with ASD to develop critical life skills. Helping students on the spectrum navigate the tough and confusing unstructured social spaces in school, and in life, is one of those critical life skills. Addressing this issue will take some forethought; however, parents and educators can learn valuable information through his/her contacts with drivers and aides, maintenance and cafeteria employees that can enable him or her to discover the seeds of bullying and to deal with it early and effectively. (Excerpt from the Autism Spectrum Quarterly, Summer 2004, The Role of the Family-School Liaison Counselor: Safety and Risk Support for Students with ASD by Walter Coles and Dennis Debbaudt)

Safety and Risk Life Skills Education for Students on the Spectrum

Safety and risk management becomes part of all of our everyday lives. We may not be involved in auto accidents on a daily basis, but we still buckle our seat belts before we drive off. We make safety and risk preparation part of our everyday routines by preparing for the worst and hoping for the best.

Children and adults on the spectrum will benefit greatly throughout their lives from safety and risk life skills education at home, school and in the community. This education should begin early, often and be suited to the person's age and ability level.

For example, some lessons may be to learn to expect and respond well to a sudden interaction with police, emergency responders, and other authorities. In addition, how to safely carry and produce personal ID and autism information card, to stay with, not run from a safe "go to" uniformed officer and to avoid sudden movements could also be useful information for someone with autism.

Planning contacts with police and other authorities can help demystify those in uniform and allow first responders to see for themselves the dilemmas of communication and behavior the person with autism may present. These cross-educational opportunities can help educate persons on the spectrum, parents, care providers, educators, and law enforcers about each other's needs and expectations. The knowledge obtained through these safe, structured, and controlled contacts will allow both person with autism and good law enforcers to make accommodations during a future sudden yet predictable field interaction.

Developing Partnerships with Law Enforcement

We can assist and encourage our advocacy organizations in their outreach to law enforcement and emergency agencies when we help identify autism contacts who work in these professions.

Almost every good autism and law enforcement partnership that I'm aware of has identified autism moms and dads, brothers and sisters, grandparents, aunts, uncles, friends and neighbors who are police officers, investigators, fire rescue or emergency medical technicians, 911/999 dispatchers, hospital emergency room professionals, prosecutors, defense attorneys, judges and magistrates, correctional and private sector criminal justice professionals who are more than willing to help with these efforts. Some are able to take a public position and some are not. All, however, can provide advice, contacts, technical assistance with an eye toward opening doors and minds to issues of autism safety and risk. Ask yourself whom you know in these professions. Then ask them to help.

Families and persons with new diagnoses need to be alerted immediately about wandering and safety and risk issues. Our advocacy organizations are now moving to make these issues permanent agenda items. Our advocacy organizations-national, regional and local-are us, need to hear from us and, more importantly, need our assistance and support.

Working together we can make our communities safer for us as well as our sons and daughters.

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Applied Behavior Analysis (ABA) ~ ABA is the science of behavior and represents a field of inquiry dedicated to investigating and modifying behavior in a systematic way.

Board Certified Behavior Analyst (BCBA) – A board certified behavior analyst has been credentialed by the Behavior Analysis Certification Board and must possess at least a master’s degree, have 225 classroom hours of specific graduate-level coursework, meet experience requirements, and pass the Behavior Analyst Certification Examination. The BCBA conducts descriptive and systematic (e.g., analogue) behavioral assessments, including functional analyses, and provides behavior analytic interpretations of the results. The BCBA designs and supervises behavior analytic interventions.

Discrete Trial Instruction (DTI) – A common educational intervention based on the principles of Applied Behavior Analysis. DTI involves a three-part process: a presentation by a teacher (the antecedent); the child’s response (the behavior); and a consequence (reinforcement). Each trial is a separate attempt to teach a new behavior or reinforce an existing behavior.

Early Intensive Behavioral Intervention (EIBI) – A program of early intervention for young children with autism based upon the principles of Applied Behavior Analysis. EIBI (sometimes referred to as “Lovaas Therapy”) involves the intensive presentation of discrete-trial teaching, task analysis, shaping, chaining, and positive reinforcement for a minimum of 40 hours/week.

Meta-analysis ~ A statistical procedure used to combine a number of existing research studies into (in the ideal case) the equivalent of a single study with the combined size of all original studies.

Operant Behavior – A class of behavior controlled by its consequence. For example, if crying at night brings parental attention, then crying is an operant behavior controlled by the reemergence of sleepy parents.

Pharmacological – The characteristics, properties, or use of medication.

Pharmacotherapy – Treatment involving the use of medications.

Pseudoscience – Any body of knowledge, methodology, belief, or practice that claims to be scientific but does not adhere to the basic requirements of the scientific method.

Psychopharmacology – The use of medications designed to affect thinking, feeling, and behavior.

Social Stories™ – Simple stories that describe social events and situations that are difficult for a child with autism to understand. Carol Gray developed Social Stories™.