



Science in Autism Treatment

Newsletter of the Association for Science in Autism Treatment

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Letter from ASAT's Executive Director

On behalf of ASAT, I hope 2016 brings you good things. I also hope that this year will bring to all a deeper appreciation for the relevance of science in both grounding and guiding autism treatment, greater expectations of accountability from all treatment providers, more accuracy within media portrayals, and heightened awareness of the pitfalls, costs, and distractions of pseudoscience, for there are, sadly, quite many.

In contrast to most other disorders, parents of children with autism have to work harder to find effective interventions supported by scientific research. This is against a backdrop of often irresponsible journalism and an Internet replete with misinformation and marketing ploys. At ASAT, we truly believe that parents deserve access to a community that values science over profit, expects accountability from all treatment providers, and gravitates towards methods already proven to be effective.

As you may recall, my Co-Editor, Dr. Daniela Fazzio, shared some of last year's accomplishments in the Fall 2015 issue of *Science in Autism Treatment* (SIAT). As we move into the new year, we are anticipating an even more promising 2016. Therefore, it is with great pride and optimism that I outline an array of goals and initiatives for this year:

- ◆ Create additional content for our newly launched, comprehensive website as well as a cross listing of articles throughout the site.
- ◆ Continue to expand our website's pages for parents with a newly-diagnosed child, medical professionals, and members of the media.
- ◆ Increase our Facebook "fans" to 10,000, Twitter followers to 1,250, and ASAT's presence on quality autism community blogs and websites.
- ◆ Increase our reach to the medical community, particularly pediatricians and family practice doctors, making information about ASAT and science-based treatment available to them.

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- ◆ Increase the number of grant proposals to support our important work.
- ◆ Provide information regarding ASAT and autism to faculty in special education, psychology, and speech pathology university programs nationwide.
- ◆ Increase *Science in Autism Treatment (SIAT)* subscriber base from 12,000 to 13,000 with representation from over 105 countries.
- ◆ Publish more synopses of recently published research to keep up with the growing number of studies on interventions for autism.
- ◆ More extensively tap into the wealth of experience and expertise of our Advisory Board members.
- ◆ Recruit new writers and increase the number of Media Watch responses to accurate and inaccurate portrayals of autism treatment, increasing our focus on international stories, biomedical advances, and lifespan considerations.
- ◆ Advance an aggressive 2016 strategic plan and conduct our annual, in-person board meeting in November to finalize this plan.

Please indulge me in ending this letter with a heartfelt appeal. We cannot carry out our important work without your financial support. The ongoing success of ASAT is predicated on the financial support of generous donors.

If you support our mission, believe in the promotion of science, and recognize the need for accurate information about autism treatment, and we hope you do, please make a donation at www.asatonline.org/donate or by mail to: ASAT PO Box 1447 Hoboken, NJ 07030. Any amount would be deeply appreciated. We acknowledge our 2015 donors on page 37. We do not typically list our board members but are pleased to report that 100% of our board donates each year. If you were a donor last year and we inadvertently omitted your name, please contact me at dceliberti@asaonline.org.

In addition, if you are affiliated with an organization that shares ASAT's commitment to science in the treatment of autism, please consider becoming a 2016 Real Science Real Hope Sponsor. We are pleased to report over 40 organizations participated last year. Please see page 31 for more information about our 2016 Sponsorship Campaign, our list of last year's sponsors on page 32, and brief program descriptions of our four Champion level sponsors on pages 33-36.

We wish you all a happy and healthy new year.

Best,



David Celiberti, PhD., BCBA-D
Executive Director and Co-Editor of *Science in Autism Treatment*

CLINICAL CORNER

What is the Relationship Between Autism Spectrum Disorders and Intellectual Disability?

Leanne Tull, M.ADS, BCBA
Bobby Newman, PhD, BCBA-D

"While autism diagnoses have become increasingly common, they have also become increasingly complex. This can leave parents of newly diagnosed children in the dark and unclear about what their child's diagnosis actually means. In this edition of Clinical Corner, Dr. Bobby Newman and Leanne Tull shed some light on the recent diagnostic changes outlined in the DSM-5 and discuss the relationship between autism and intellectual disability."

Nicole Pearson, PsyD, BCBA-D
Clinical Corner Coordinator

My four-year-old child is diagnosed with autism spectrum disorder (ASD). His evaluator said that my son was "intellectually disabled in addition to having autism." What is the relationship between autism spectrum disorders and intellectual disability? Is my son also intellectually disabled?

Answered by:

Leanne Tull, M.ADS, BCBA
ASAT Secretary

Bobby Newman, PhD, BCBA-D
Room to Grow
ASAT Past-President and Advisory Board Member

This can be a very sensitive subject, and the response you get can vary depending on the professional you ask. Before answering your question, it is important to highlight diagnostic labels that have changed since the debut of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Two notable name changes, specific to the diagnoses you mention in your question, are:

1. Intellectual Disability: previous editions of the DSM used the term *mental retardation*. The shift to Intellectual Disability marked a major milestone of efforts to solidify the use of a term that has been commonly used by behavioral, medical, and educational professionals, including advocacy groups, for the past two decades. Mental retardation replaced obsolete terms such as feeble-minded-

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ness, moron, and imbecile; now, over fifty years later, the term 'mental retardation' is being eliminated for similar reasons (Harris, 2013).

2. *Autism spectrum disorders (ASD)*: previous editions of the DSM referred to ASDs as Pervasive Developmental Disorder, a “diagnostic umbrella,” with five subtypes: 1) Autistic Disorder; 2) Asperger’s Disorder; 3) Rett’s Disorder; 4) Childhood Disintegrative Disorder; and 5) Pervasive Developmental Disorder-NOS (“Not-Otherwise-Specified”). ASD is a label that now reflects a scientific consensus that the five previously separate disorders are actually a single condition with different levels of symptom severity. However, it is important to note that a previous diagnosis of any of the five ASD subtypes was grandfathered into the DSM-5 ASD diagnosis. Individuals with any of these diagnoses do not lose them and at this time do not need to be re-evaluated under the new criteria (APA, 2013a; 2013b).

Your child may have some degree of intellectual disability; some areas of ability may be normal, while others (i.e., cognitive functioning and language abilities) may be weak. To expand on this further, consider the criteria for the diagnosis of intellectual disability. According to the DSM-5, there are three criteria for intellectual disability:

1. Deficits in intellectual functioning, confirmed by both clinical assessment and individualized, standardized testing;
2. Significant adaptive living skill deficits; and
3. Onset of intellectual and adaptive deficits during the developmental period (APA 2013a; 2013c).

Furthermore, adaptive living skill deficits involve three domains, or areas. These domains determine how well an individual copes with everyday tasks:

1. The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory;
2. The social domain refers to empathy, social judgment, interpersonal communication, the ability to make and retain friendships, and
3. The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks (APA, 2013a; 2013c).

Does your child meet these three criteria *including* demonstrated impairments in the adaptive functioning domains? Many individuals diagnosed with ASD, showing symptoms during the developmental period, are also diagnosed with an intellectual disability. A central question, however, is whether your child’s measured intellectual deficit is a reflection of deficits in all adaptive functioning domains. For example, a child with ASD may do well on tasks related to visual-perceptual skills (such as completing a jigsaw puzzle) but may not do as well on social problem-solving tasks (such as

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empathy or perspective taking). Some children with ASD (such as those formerly diagnosed with Asperger's syndrome) often have average or above-average language skills and do not show delays in cognitive ability or speech.

Limitations in intellectual functioning are generally thought to be present if an individual has an IQ (intellectual quotient) test score of 70 or below, approximately two standard deviations below their expected IQ compared to same-age-peers (APA, 2013c). If you consider the requirements of standardized intelligence tests, the general focus is on how the individual is required to interact with the tester, answer questions, follow directions, imitate, and receptively or expressively identify requested items. Many individuals diagnosed with ASD have simply not learned these skills at the time of testing and may demonstrate challenging behavior in contexts in which demands are being placed upon them. Following effective programming, IQ may increase by dozens of points (e.g., Lovaas, 1987). However, increased IQ scores do raise some concern. For instance, did intervention increase the individual's intelligence, or help the individual to develop the skills that allowed them to successfully participate in the test? To account for this gap in testing validity, the new diagnostic criteria for intellectual disability place emphasis on both clinical judgment and standardized intelligence testing; and less emphasis is placed on the IQ score, there is no longer a "cut-off" score or threshold.

To illustrate the rationale for this change, consider the following personal anecdote: A colleague of Bobby Newman was reading a story to Newman from a magazine about a celebrity actor. At one point, the colleague realized Newman was looking at her blankly and said, "you have no idea who I'm talking about, do you?" Newman did not; he couldn't identify 98% of the celebrities currently in the limelight - it's just not his area of interest.

Why mention this anecdote? Consider that many students diagnosed with ASD are not exposed to various life experiences that provide the knowledge necessary to answer questions on IQ tests. Scaled IQ scores represent approximations of conceptual functioning; however, they may be insufficient to assess reasoning in real-life situations and mastery of practical tasks within conceptual, social, and practical domains.

To consider the question with respect to your son, more information is needed. What type of testing was administered? Did the test have verbal and nonverbal components? Was there a large spread among the subtests' scores? Was it a test appropriate for someone of his age? Was the test ever standardized with people with disabilities? Was the test conducted properly? Was the test conducted by someone with whom your son was familiar with, and in a familiar setting, was the test done in such a way that he was comfortable or motivated?

Was there a measure of adaptive behavior collected? Adaptive behavior measures are often assessments that do not directly test the individual, but rather interview significant others to compare the behavior to age-standardized norms. If so, was there a spread among subscales' scores? A large spread, particularly with some subscales in or around the normal range, would argue against an intellectual disability label. Finally, was adaptive behavior testing completed properly? Tests should not

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be conducted by mailing the questionnaire to parents; this is a completely inappropriate use of such measures.

The best course of action at present is to understand the diagnostic criteria improvements in the DSM-5. Mental retardation had long been divided into mild, moderate, severe, or profound levels of severity. The DSM-5 highlights the need to use both clinical assessment and standardized testing of intelligence when diagnosing intellectual disability. The severity of impairment is now based on adaptive functioning rather than IQ test scores alone; specifiers, instead of subtypes, are used to designate the extent of adaptive dysfunction in academic, social, and practical domains (Harris, 2013). Consider your child's intellectual disability diagnostic label as an artifact of continuing language, interactive, or other skill deficits, as opposed to some inherent and global intellectual delay.

Approach the "high-functioning" and "low functioning" ASD labels with caution; given the specific and scattered nature of skills and deficits displayed by individuals diagnosed with ASD, it often makes little sense. Higher and lower functioning in what areas? Criteria that surround these labels do not speak to the specific challenges of each child, and may actually undermine the effort that many individuals on the spectrum put forth each day.

The late, great Stephen Jay Gould once published a book entitled *The Mismeasure of Man*. The book describes some of the historical problems with IQ tests and measures of intelligence in general. This publication may provide useful background when further considering your question.

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CONSUMER CORNER

Caveat Lector: Let the Reader Beware

David Celiberti, PhD, BCBA-D
Renee Wozniak, PhD, BCBA-D

The decisions of many consumers are influenced by what they read in the newspaper or on the Internet and hear about on television or on the radio. It is our belief that access to effective treatment for the autism community is enhanced by accurate representations of autism treatment in the media. Unfortunately, many media representations are fraught with inaccuracies. Additionally, effective treatments typically receive less press because their providers are often focusing on maximizing outcomes in an accountable manner rather than on soliciting media attention.

Many of you are familiar with the Latin phrase, “Caveat Emptor” which means that “the buyer alone is responsible for checking the quality and suitability of goods before a purchase is made.” With scores of “miracle cures” and “breakthroughs” for autism receiving widespread media attention well before they have been shown to be beneficial through credible, peer-reviewed research, “Caveat Lector: Let the Reader Beware” seems to be a very suitable guiding principle across all media platforms (e.g., print, radio, television, Internet). In other words, the reader is put in the position of being responsible for evaluating the quality and suitability of information being presented to him or her.

As a consumer, you bear a responsibility to scrutinize sensational claims related to various autism treatments and to be knowledgeable enough to consider such stories through a skeptical lens. We wish you did not need to work so hard to differentiate good and bad information, but that is the sad reality of autism treatment today, with 500+ treatments being touted. With that in mind, when reading or hearing an autism treatment story in the media, please consider the following questions:

About the Intervention

- ⇒ Does the article or story actually describe how the intervention helps individuals with autism? In what ways? Are those ways observable and measureable? Substantial? Meaningful?
- ⇒ Does the article or story report the costs of the intervention? Are these costs reasonable both in monetary and human resources terms?
- ⇒ Is there any report of harm imposed by this intervention? What are the risks? What are the side effects? Does the article or story appear balanced between these?
- ⇒ Who can carry out this intervention? What kind of education, training and supervision do individuals need to have before implementing the intervention?



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About the Experts

- ⇒ Whom did the author interview for this story and what are his/her qualifications? Is this person presented as an expert?
- ⇒ Is the interviewee making claims of efficacy/effectiveness that are supported by scientific data? What does he or she stand to gain by this story? *Who* may benefit financially from this particular media exposure? How would they benefit?

About the Underlying Scientific Support

- ⇒ Did the article or story mention the existence of published research articles in peer-reviewed journals documenting the efficacy of the intervention method discussed? If not, could it mean that no such research exists?
- ⇒ If so, did the author comment on whether these studies were well designed? Are they presented as an extension of existing work, or rather sensationalized as a breakthrough, keeping in mind that often interventions are pitched as a “breakthrough,” when indeed they are not?

Some Final Questions to Consider

- ⇒ Are other media outlets reporting this article (or a similar story)? Were they favorable or unfavorable? Did they consider data in their opinions?
- ⇒ Has ASAT responded to this article? See <http://www.asatonline.org/media-watch/> for our library of archived media watch letters.
- ⇒ Has the author consulted with an unbiased and knowledgeable individual for his/her input about the intervention described (e.g., someone who is not personally benefitting from the story or someone with a strong grasp of research)?

Inaccurate portrayals of autism treatments in the media often fall within the following themes:

- ⇒ Exaggerating the research support for an intervention for which no research exists;
- ⇒ Ignoring the research basis that may already exist for the treatment in focus;
- ⇒ Disregarding the relevance of science;
- ⇒ Disregarding position statements from various professional organizations that warn against or discourage the use of a particular treatment; and
- ⇒ Failing to acknowledge research that does NOT support a particular intervention.

Being mindful of these themes will enable you to truly embody “Caveat Lector.”

BOOK REVIEW

Freeman, S. K. (2011). *The complete guide to autism treatments. A parent's handbook: Make sure your child gets what works!* (2nd edition) Bellingham, WA: SKF Books, Inc.¹

**David Celiberti, PhD, BCBA-D
Carolyn J. Sniezyk, MS, BCBA**

Just when we think we have seen everything, we are reminded that with autism treatments anything and everything is possible, particularly given that many individuals have recognized that autism treatment can be a very lucrative business. The array of treatments for autism is indeed quite diverse and includes treatments that are downright dangerous and can be absolutely overwhelming when taken together. Thankfully, there is a book available to help parents and other consumers with this laborious task while also helping them to develop the skills needed to differentiate science from pseudoscience and viable options from nonsense.

The Complete Guide to Autism Treatments Second Edition is comprehensive, thoroughly researched, and well organized. Throughout, Dr. Freeman communicates a critically important message: individuals with autism deserve access to science-based treatment - their time, their potential, and the overall resources of their families should not be wasted. As will be detailed below, Dr. Freeman shares her perspectives as a mother, which further contributes to the authenticity of this book, and may appeal to parents who may be more receptive to the cautionary words of one who walks in their shoes.

The second edition of *The Complete Guide to Autism Treatments* begins with a forward by Dr. Richard M. Foxx which details the importance and quality of the book in addition to a well-written summary of the content. Following the forward, the reader will find that the book is divided into two primary sections. Section I is organized around topics related to the various treatments for autism. Section II highlights basic concepts about science, hypothesis testing, and research methodology. Each of these will be discussed below.

Section I begins with a review of behavior-analytic treatments for autism across home and school settings, as well as within the area of early intervention. The various offshoots of applied behavior analysis are also summarized and evaluated (e.g., intensive behavioral treatments, pivotal response training, positive behavior supports, verbal behavior therapy, and fluency training). Then there is a fairly comprehensive subsection related to the myriad of non-behavioral treatments, including those that occur in school, as well as those that are child-initiated or parent-facilitated. These subsections are followed by biomedical therapies, speech and language therapies, and ultimately, a final section for miscellaneous therapies not better categorized in the above subsections. Each of these subsections is divided, and in some cases divided further, in an effort to capture the more frequently-touted treatments for autism. Each of these treatment subsections is organized around responses to a series of 8-9 questions.

¹Please note this is an updated version of a review of the 1st edition of this book.

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- These questions are applied to each treatment discussed (see table at end of the review).
- Section II, titled “How do we know what works and what doesn’t?” focuses on the scientific method, hypothesis testing, and research methodology. At times, the content may seem somewhat dense, but that speaks more to the complex nature of scientific inquiry than to Dr. Freeman’s writing style. These more technical sections are preceded by a number of caveats empowering parents to question the “experts” whom they will undoubtedly encounter over the course of their child’s treatment. There is considerable attention paid to the components of research, data interpretation, and analysis of a study, as well as descriptions of many all-too-common red flags in autism treatment.
- Section II also includes an afterword which provides information regarding how the literature review was conducted for the second edition, some conclusions regarding the more recent research that was used to update this publication, and a review of new therapies that have gained popularity since the first edition. Section II ends with 54 pages of references!

This book has many notable strengths.

1. The format of nine recurring questions within Section I provides a predictable framework for the reader. In fact, Dr. Freeman’s careful analysis of the state of the research underlying specific applied behavior analysis (ABA) treatments is offered in the same spirit and with the same diligence as the non-behavior analytic treatments.

2. Proponents of the various treatments would benefit from careful consideration of the suggestions offered in the “What kind of study would I like researchers to do?” section. Far too often, a single study is put forth as validation of an entire treatment and all of its theoretical and conceptual underpinnings. The reader will find that Dr. Freeman has individualized her recommendations based on each treatment’s existing research history. Execution of these research agendas may enable a number of treatments to live up to their promises.

3. Perhaps of greatest significance is that the author is writing from the dual perspectives of professional and parent. When speaking as a parent, her commitment to science is unwavering, and appropriately so; she is unapologetic in sharing her perspective as an informed mother. This is greatly needed at a time when many individuals fear being perceived as close-minded or unwilling to recognize the contributions of other disciplines. Her professional perspective only adds further credence to her stance regarding treatment options. There are wonderful insights throughout the book which will make this resource useful to those who will tend to read this book a few parts at a time. For instance, there is a very interesting discussion at the beginning of the book about participation in research with the caveat that precious time and resources should never be wasted on low-quality research, for not all research is created equally.

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In summary, we believe *The Complete Guide to Autism Treatments* is a much needed contribution to the field of autism. The diligence and comprehensiveness of the various treatment reviews make this book an important “go-to” resource for parents and professionals alike. Undoubtedly this is a resource that the reader can expect to pick up time and time again.

For more information about *The Complete Guide to Autism Treatments*, as well as other books written by Dr. Freeman, please visit www.skfbooks.com.

Questions applied to the treatments highlighted in Dr. Freeman’s book:

<p>“What is _____?”</p>	<p>Dr. Freeman defines the treatment, highlights its purpose or intent with respect to autism, and describes its rationale and theoretical underpinnings. The proponent’s more significant hypotheses about autism’s etiology and treatment are often described as well.</p>
<p>“What evidence do the practitioners have that this really works?”</p>	<p>Dr. Freeman summarizes and evaluates peer-reviewed research and other possible sources of support (e.g., anecdotal evidence). She reports the results of database searches and is often quite explicit about numbers of articles that fall into categories (e.g., non-published studies, pamphlets, published in peer-reviewed journals, published in non peer-reviewed journals).</p>
<p>“What does this therapy actually look like?”</p>	<p>Dr. Freeman describes, often in great detail, the actual procedures associated with the treatment. This information is essential, as many consumers know little about the therapies to which they are subjecting their children. These descriptions are written in an objective, non-partial manner which, when read in isolation, would not necessarily reveal the author’s stance on a particular treatment. Information about side effects and/or</p>
<p>“Would I try it on my child?”</p>	<p>In contrast to the objective and factual tone of her responses to the questions above, here Dr. Freeman offers a more personal take on the treatment: a take that is honest and at times, blunt. Clearly, every child with autism is different, and thus, treatment decisions need to be made in consideration of those differences. Even if readers disagree with Dr. Freeman’s position, they will appreciate the candor and thoughtfulness of her position as a</p>



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FROM THE ARCHIVES

Interview With Jane Asher, Actress, Advocate, and Entrepreneur

David Celiberti, PhD, BCBA-D
ASAT Executive Director

In this installment of *From the Archives*, we are featuring my interview with Jane Asher, a member of our Professional Advisory Board from a few years ago. If you have not already done so, please view the three Public Service Announcements narrated by Ms. Asher (links are provided below).

In the first [Public Service Announcement](#), Jane Asher describes the many challenges facing parents of newly diagnosed children with autism. In the second [Public Service Announcement](#), Jane Asher highlights the many resources that ASAT has to offer the autism community. In the final [Public Service Announcement](#), Jane Asher offers several important considerations to guide any and all decisions about autism treatment. Please share amongst your networks.

David Celiberti, PhD, BCBA-D
ASAT Executive Director

I recently had the wonderful opportunity to interview Jane Asher. Aside from her busy life as an actress and entrepreneur, Jane Asher is an advocate, author, and businesswoman. She has been working professionally in film, theatre and radio since she was 5 years old, and has run her own business, Jane Asher Cakes, based in Chelsea, London, since 1990, selling bespoke celebration cakes and a wide range of home baking equipment.

She has also written more than a dozen books, including three best-selling novels. Jane's work in the charity sector is well respected. She is President of Parkinson's UK, President of the National Autistic Society and President of Arthritis Care, Vice President of Autistica, Ambassador for the Prince's Trust, Friend for Life, Terrence Higgins Trust. She is a Patron of many other voluntary organizations.

David: Can you share with our readers how you were first introduced to autism?

Jane Asher: I first became involved with autism when I went to a children's tea party in 1985. Children representing various charities had been invited, and I remember the room being full of the noise and excited laughter that one would expect. One table, though, was oddly different. At first I couldn't think quite why it stood out from the other three – the children had no obvious disability and looked quite 'normal' – but after a few seconds of watching I could clearly see that not only were the children unusually quiet, but that there was no interaction between them: no shouting or joking – no squabbling or arguing. They didn't even look at each other – indeed they seemed completely unaware of each others' presence. The difference from the behaviour of the other children was so marked that I asked one

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Jane Asher

of their helpers where they were from. (This ‘carer’ was Lorna Wing, whom, as I’m sure you know, was one of the great pioneers in the autism world and first described the ‘triad of impairments’. So I had my first lesson from the top!). The children were, of course, autistic, and that was when my

association – and, in some ways, fascination – with autism began.

David: Your work within the autism community has grown substantially since that initial encounter. What has led up to your heightened level of involvement?

Jane Asher: Soon after that day, I was asked by the National Autistic Society (NAS) to open a new playgroup they were going to run in a room at their head office for some local children with autism, and I was only too happy to do so. While I was there I learned even more about the condition, and spent quite some time with the children.

Clearly, although autism can be extremely distressing, even devastating, for those affected and their families, it also entails a way of seeing and interacting with the world that is extremely interesting and makes one consider just what we neurotypicals take for granted and consider “normal.” I have huge sympathy with the view of much of the Asperger community that the autistic way of looking at things is just as, or in some ways more than, valid as that of the rest of us.

The way neurotypicals talk nonsense in ‘social communication’ for instance (whether it’s talking about the weather or casually lying without thinking twice). I found myself becoming more and more intrigued and interested – and, gradually, more knowledgeable and engaged.

Eventually I found I could be useful to the NAS by not only visiting schools and residential units and hopefully gaining a little publicity and spreading awareness, but also by speaking about autism to people who might know nothing about it or who could provide us with valuable funding. Once drawn into the world of autism, few of us ever leave it!

David: You are very knowledgeable about the fact that there are so many unsubstantiated treatments for autism, many of which are dangerous. Most lay people have no idea that this is a huge challenge for the autism community as a whole, particularly for parents of newly-diagnosed children who are looking for clear answers and expert guidance. What is the experience like for parents of newly-diagnosed children in the UK?

Jane Asher: You are so right about the many unsubstantiated ‘treatments’ – even ‘cures’ – that are suggested for autism (as, indeed, they are for so many other conditions). It’s so hard for any parent or caregiver to have their child diagnosed with an incurable condition that it’s unsurprising that many turn to alternative or complementary therapies. There are large numbers of these therapies which can be divided into several rough categories; from manipulation of various parts of the body to the channeling of ‘energy fields,’ from the removal of mercury from the body to changes in diet. Few of these therapies are supported by any clinical research, but you can easily see how a desperate parent might leap at the idea of some ‘miracle cure’ highlighted in one of the tabloids – something that sadly happens only too often. Some of these interventions are

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positively harmful; but with autism being such an individual and variable condition it can be very difficult to construct standardised, double-blind clinical trials.

In the UK, particularly in the current economic climate, it can be hard enough – still – to access a diagnosis of autism, and even harder to access the correct educational and social support that is the statutory right of every child with a disability. You can well understand why people turn to unconventional theories and implausible interventions. As a doctor's daughter, naturally I fear for those who make such uninformed choices and only wish that everyone had access to someone with genuine understanding and knowledge of this condition and its possible interventions. It's vital that a fully informed choice is made. Parents and medical practitioners should be aware of the extent to which a particular intervention has been shown to be safe and effective in peer-reviewed scientific studies. So much is anecdotal (even the very popular gluten-free diet has not yet been shown to be effective in scientific studies, and it may even be that such restricted diets are potentially harmful).

At the NAS we work very hard in lobbying government and local authorities to do more for those with autism (the Autism Act was a recent triumph in at least putting the case for adults with autism clearly on the agenda), but there is a long way to go. Not enough doctors, psychologists, nurses or educationalists understand the complexities surrounding autism, let alone know just what it may take to offer the best possible hope of an improvement in symptoms and a maximisation of the potential of the individual. Every person with autism will show the effects of their condition differently and there will never be one solution that will work for all.

David: Here in the United States, families are bombarded by information on the Internet

much of which is grossly inaccurate. Where can UK families turn for accurate information?

Jane Asher: In the UK there is excellent information available nowadays, firstly via the National Autistic Society (particularly on our website, www.autism.org.uk), which is easily



Jane with Dr. Lorna Wing

accessible and puts across a balanced view of just what the parents of newly-diagnosed children should be trying to access in order to help give their child the best possible outcome (also for newly diagnosed adults of course). There is also the other organisation that I support, Research Autism, www.researchautism.net, that specifically researches interventions in autism and gives balanced and scientifically-based information on just what appears to help, and – maybe more importantly – what has no basis for claiming to do so. So the information is there, but naturally again, as with cancers, degenerative diseases and other serious conditions, you will never stop people from searching for an answer; especially for that elusive ‘cure’; and we can all become irrational when confronted with

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something so potentially devastating and for which there is no easy or obvious way forward.

David: As an actress, there must be so many different organizations lining up to ask for your help. We are so grateful that you have chosen to use your celebrity status to support the development and testing of science-based treatments. The concept that science is crucial in terms of treatment for people with autism is much more complex than simply supporting any organization that helps children with autism swim with dolphins or access some other specific treatment.

Do you have a background in science? How did you become so involved in this particular issue (advocating for science-based treatment)?

Jane Asher: That's an interesting question! I suspect it is largely due to the influence of my father, Dr. Richard Asher, a consultant endocrinologist who was renowned for his rational and well-informed approach to the complex field of medicine (and for his witty and inspirational lecturing and writing: his ex-students include Oliver Sacks and the British doctor/theatre director Jonathan Miller). I've grown up fascinated and enthralled by science, and get very depressed when its wonders are ignored and pushed aside by pseudo-science or fantasy. For many years I was a patron of another organisation of which I was very proud – SIMR, which campaigned for public understanding of the need for animal research. This organization was started by a young man with Friedrich's Ataxia, who was deeply frustrated by the actions of the anti-vivisectionists. He sadly died a few

years ago after many years of excruciating pain and other problems. So I guess the subject of promoting the understanding of science is a subject generally very close to my heart.

David: Due to your knowledge in this area, do you have a vision about how we need to go about educating professionals, paraprofessionals and laypersons about the importance of following the science before subjecting a person with autism to a treatment?

Jane Asher: No specific vision I fear... it's all part of the major problem that I've touched on in the previous paragraph. How do we combat the



Jane with one of the children at the National Autistic Society's Sybil Elgar School

rather fascinating, but ultimately extremely damaging, instinct and tendency of the human species to believe in things for which there is absolutely no evidence— whether it be the supernatural, rituals, luck, magic or other paranormal areas, or 'miracle cures' and their like – rather than trusting science and modern medicine? And, as I mentioned before, it's particularly difficult to target the strong instinct of a

parent to try almost anything, no matter how expensive and/or unproven, in the desperate search for something to help their child. We all know how easy it is to make completely erroneous deductions from what appears to be clear evidence, and I'm sure if I had had a child with autism who had been speaking and behaving in a neurotypical way up to the time of an MMR jab and who had soon thereafter developed autism, it would have been only too easy to have come to a totally misguided conclusion. We just need more people spreading the word about the only approaches to autism that appear to make a

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difference, and even that is not really researched enough to give unequivocal results. As with so many important causes, money comes into this, and also the teaching of science in schools, which has not been as good as it should be in the UK for some years. For anyone keen to learn more, I highly recommend an Open University course that I took a couple of years ago – ‘Autism in the 21st Century’ – which is a beautifully constructed, scientifically-based module that really brought my information up to date.

David: Finally, do you have any advice for parents of newly-diagnosed children?

Jane Asher: Naturally it can be very distressing for any parents to have their child diagnosed with autism, but I think it’s really important to see that as the first achievement in making the best possible life for him or her. Without a diagnosis it’s impossible to access whatever support and education may be the best way forward. It’s important, too, to understand exactly what the diagnosis means – the word autism now covers such a very broad spectrum of conditions. It’s vital to know exactly which one the child has and whereabouts on the range of ability the condition falls. Early intervention can make a real difference and if parents are not automatically put in touch with them, then it’s a good first step to contact the local social and educational services – they’ll be the key contacts for providing what may be needed. But I’m not going to say it’s easy – even if the best possible school is found, for example, it can be a legal and emotional nightmare getting the funding put in place to access it. And this is why it can be so tempting to try an unsubstantiated intervention that may be easily available, but I’d definitely recommend that before trying anything, a call is made to the NAS helpline. They can put parents in touch with the right person to help them. There’s also a very helpful leaflet on the website ‘After Diagnosis’ to download. For sure I’d say don’t try anything that

hasn’t been recommended by a medical professional before checking for certain that it will do no harm and that it won’t interfere with accessing something that can really make a difference. Above all, with the knowledge that we now possess, I think it’s worth saying that, although children with autism will grow up to be adults with autism, there is much to be done to ensure that they can live lives of dignity and fulfillment. Families in the UK can contact the National Autistic Society Helpline: 0808 800 4104 (Monday-Friday 10am – 4pm).

On behalf of the Association for Science in Autism Treatment, I want to thank you, Ms. Asher, for taking time from your very busy schedule to participate in this interview. The autism community in the UK is very fortunate to benefit from your time and talent, particularly given your strong adherence to the notion that science matters and that research should guide decision-making. We certainly hope our paths cross again!

ASAT’s Guiding Values

ASAT is committed to science as the most **objective**, time-tested and reliable approach to discerning between safe, effective autism treatments and those that are harmful or ineffective. ASAT supports **all** scientifically-sound research on the prevention, treatment and cure of autism, as well as **all** treatments for autism that are shown to be effective through solid scientific research, **regardless of discipline or domain.**

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In addition to our Advisory Board, a number of Coordinators, Externs, and other Volunteers lend their time and talents to support ASAT's mission and initiatives. These are our helping hands.

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For more information about
our Externship, please see:

[www.asatonline.org/
description-application-
process/#externship](http://www.asatonline.org/description-application-process/#externship)

THANK YOU!

FUNDRAISING INITIATIVES

Science, snacks, but not dress slacks: The three ways one organization raises money for science.

Melissa Taylor, BCaBA
ASAT Extern

We are continually impressed by the unique ways our supporters raise money for ASAT and wanted to take this opportunity to share one example. Monarch House, a Canadian-based organization, has developed a fundraising program using staff and client incentives. They host three ongoing ASAT fundraising initiatives.

1. The first one allows staff to dress down on Fridays in return for a \$2.00 donation to ASAT.
2. On a daily basis, the organization offers baked goods, treats, and snacks to staff for a donation.
3. Clients of Monarch House are also encouraged to participate in fundraising by making a contribution to ASAT as the “charity of choice.” Monarch House provides public recognition in their lobby for any clients making a donation to support the dissemination of science in autism treatment.

Monarch House is a state-of-the-art facility that is family-centered and offers an interdisciplinary approach to the assessment and treatment of individuals with autism spectrum disorder (ASD) and other developmental disabilities. According to Tracie Lindblad, Clinical Director at Monarch House, the organization is passionate about ASAT because "ASAT provides valuable resources that have proven helpful to our staff in their continuing education about scientifically-proven beneficial treatments, but more importantly, these resources are critical for our families and clients in assisting them in making sound treatment decisions. In addition, the resources available through ASAT are presented in a way that can be easily understood and accessed by a diverse range of individuals, including those who may be new to the world of ASD. This is very important to us at Monarch House because our families are our first priority and we are constantly striving to make things as easy as possible for them. In fact, we have so much appreciation for ASAT that we have been actively working to give back to this amazing association."

ASAT is grateful to Monarch House for their continued support and partnership in the distribution of information about science in the treatment of autism.

If you are part of an organization that may want to follow in the footsteps of Monarch House, please write us at donate@asatonline.org.



The Monarch team during Dress Down Friday



ASAT's Media Watch monitors mainstream media to identify published information about autism and autism treatments. Understanding that each and every media contribution has the potential to reach thousands of consumers and colleagues, we support accurate media depictions of empirically-sound interventions, and also respond to inaccurate information or proposed treatments described or even promulgated by news outlets.

**Barbara Jamison, BA, Parent Board Member
Media Watch Coordinator**

ASAT RESPONDS TO NEWSWEEK.COM'S "ANDREW WAKEFIELD, FATHER OF THE ANTI-VACCINE MOVEMENT, RESPONDS TO THE CURRENT MEASLES OUTBREAK FOR THE FIRST TIME" (July 15, 2015) - We commend Newsweek.com's Stav Ziv's informative, accurate, and evidence-based reporting on the recent measles outbreak, Andrew Wakefield's response, and the research that has negated a link between the MMR vaccine and autism.

<http://www.asatonline.org/media-watch/asat-responds-to-newsweek-coms-andrew-wakefield-father-of-the-anti-vaccine-movement-responds-to-the-current-measles-outbreak-for-the-first-time/>

ASAT RESPONDS TO AU.TV.YAHOO.COM'S "CLASSROOM CAGES" (August 7, 2015) - When educators are not taught how to work effectively with individuals with autism, we should not be surprised when they may resort to ineffective or harmful practices in their attempts to respond to behavioral crises. <http://www.asatonline.org/media-watch/asat-responds-to-au-tv-yahoo-coms-classroom-cages/>

ASAT RESPONDS TO AUTISMDAILYNEWSCAST.COM'S "AUTISM COST ESTIMATED TO REACH NEARLY \$500 BILLION" (September 9, 2015) - ABA information and services are not always easily accessed when families must sift through myriad advertised treatments on the Internet and in the media, and navigate through insurance companies, medical doctors and therapists. <http://www.asatonline.org/media-watch/asat-responds-to-autismdailynewscast-coms-autism-cost-estimated-to-reach-nearly-500-billion/>

ASAT RESPONDS TO JSPACE.NEWS.COM'S "ISRAELI INSTITUTES OPEN FIRST-OF-ITS-KIND AUTISM CENTER IN MIDDLE EAST" (September 23, 2015) - It is our firm belief that to protect individuals with ASD and their families from wasting valuable time and resources on unsubstantiated claims, only treatments and related developments founded on the tenets of scientific research should be promoted in the field. <http://www.asatonline.org/media-watch/asat-responds-to-jspace-news-coms-israeli-institutes-open-first-of-its-kind-autism-center-in-middle-east/>

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ASAT RESPONDS TO BSCI21.ORG'S "U.S. DEPT OF ED: ABA NOT ENOUGH FOR AUTISM TREATMENT" (November 3, 2015) - The Director of the Office of Special Education Programs (OSEP) recently stated her concern that treatments for children with autism spectrum disorders (ASD) are overly focused on applied behavior analysis (ABA) therapy. <http://www.asatonline.org/media-watch/asat-responds-to-bsci21-orgs-u-s-dept-of-education-aba-not-enough-for-autism-treatment/>

ASAT RESPONDS TO NYTIMES.COM'S "PARENTING EXPERT PANEL WITHHOLDS SUPPORT FOR EARLY AUTISM SCREENING" (November 8, 2015) - The NY Times reports that "an influential panel of experts has concluded there is not enough evidence to recommend universal autism screening of young children." <http://www.asatonline.org/media-watch/asat-responds-to-nytimes-coms-parenting-expert-panel-withholds-support-for-early-autism-screening/>

ASAT RESPONDS TO NBC NEWS DATELINE'S "ON THE BRINK" (December 7, 2015) - Our country is currently facing a critical point in providing services for an increasing number of individuals with ASD who have reached adulthood. <http://www.asatonline.org/media-watch/asat-responds-to-datelines-on-the-brink/>

ASAT RESPONDS TO GLOBEANDMAIL.COM'S "EMBRACING AUTISM: OWNERS OF VANCOUVER CANUCKS WANT FAMILIES OF AUTISTIC KIDS TO RECEIVE SUPPORT" (December 9, 2015) <http://www.asatonline.org/media-watch/asat-responds-to-globeandmail-coms-embracing-autism-owners-of-vancouver-canucks-want-families-of-autistic-kids-to-receive-support/>

ASAT RESPONDS TO FORBES.COM'S "SESAME STREET' INTRODUCES AUTISTIC GIRL INTO THE NEIGHBORHOOD" (December 16, 2015) - Sesame Street introduces Julia, a character with autism, into their cast. <http://www.asatonline.org/media-watch/asat-responds-to-forbes-coms-sesame-street-introduces-autistic-girl-into-the-neighborhood/>

ASAT RESPONDS TO CBC.CA'S "MOM SAYS SHE WAS DUPED BY STRANGER AFTER POSTING 'AMAZING' VIDEO OF SON WITH AUTISM" (December 17, 2015) - It's saddening when parents spend precious time and resources on bogus treatments by unscrupulous providers. <http://www.asatonline.org/media-watch/asat-responds-to-cbc-cas-mom-says-she-was-duped-by-stranger-after-posting-amazing-video-of-son-with-autism/>

ASAT RESPONDS TO PSYCHOLOGYTODAY.COM'S "MAKING SEVERE AUTISM VISIBLE" (December 29, 2015) - The media tends to highlight "success stories" about some of the most capable individuals diagnosed with autism, which may inadvertently minimize the daily struggles many other families face when impacted by behaviors such as elopement, pica, self-injury, aggression, and property destruction. <http://www.asatonline.org/media-watch/asat-responds-to-psychologytoday-coms-making-severe-autism-visible/>

ASAT RESPONDS TO EXAMINER.COM'S "RESHAPING PUBLIC MISCONCEPTIONS OF PARENTING A CHILD WITH AUTISM" (December 30, 2015) - When writing an autism story, media professionals

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should keep in mind that symptomatology varies from individual to individual, and mention to readers that anyone highlighted in such a story is representative only of him or herself. <http://www.asatonline.org/media-watch/asat-responds-to-examiner-coms-reshaping-public-misconceptions-of-parenting-a-child-with-autism/>

ASAT RESPONDS TO [ABCNEWS.GO.COM](http://www.abcnews.com)'S "MOM PRAISES MALL SANTA CLAUS FOR KINDNESS TOWARD SON WITH AUTISM" (December 31, 2015) - It's a bit of Christmas cheer when kindness is shown to a child with autism. <http://www.asatonline.org/media-watch/asat-responds-to-abcnews-go-coms-mom-praises-mall-santa-claus-for-kindness-toward-son-with-autism/>

You can review our 100+ published letters at <http://www.asatonline.org/media-watch/> and see models of professionals interacting with members of the journalism community.

Additionally, guidelines are provided for journalists to tackle their next autism story from a science-minded and careful perspective at <http://www.asatonline.org/for-media-professionals/top-10-questions-to-ask>.

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RESEARCH REVIEW

Generalization of PECS & Randomized-Control Trial Intervention for Sensory Difficulties with Children with Autism

The article summaries in this issue of SIAT address the generalization of the Picture Exchange Communication System with children with autism and an intervention targeting sensory difficulties. We hope you enjoy reading these summaries!

Karen Fried, PsyD, BCBA-D
Research Corner Co-Coordinator

1.

TITLE: ASSESSING GENERALIZATION OF THE PICTURE EXCHANGE COMMUNICATION SYSTEM IN CHILDREN WITH AUTISM

Greenberg, A., Tomaino, M., & Charlop, M. (2012). Assessing Generalization of the Picture Exchange Communication System in Children with Autism. *Journal of Developmental and Physical Disabilities, 24*, 539-558.

Reviewed by:

Melissa Taylor, BCaBA, ASAT Extern
Karen Fried, PsyD, BCBA-D, ASAT Board Member

Why research this topic?

The Picture Exchange Communication System (PECS) is a popular approach to teaching children with autism to communicate by selecting pictures and handing them to a communication partner. For PECS to be an effective communication system, the learner must be able to use it in a variety of situations and with a variety of people. When this variety is achieved, PECS use is considered “generalized.” Adults with developmental disabilities have been shown to achieve generalized use of PECS as a communication system in different settings and with novel people. In contrast, research remains limited on PECS generalization in children with autism. The goal of this study was to contribute to our knowledge of PECS generalization in children with autism and to explore a “train and probe” technique of assessing generalization in this population.

What did the researchers do?

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Four nonverbal boys with severe autism between the ages of four and eight years old participated in the study. The boys received individual training to use PECS. The design used for this study, a “multiple baseline design across participants,” is an experimental method for evaluating the effects of an intervention on each participant. The researchers provided PECS training in a small room at the children’s after-school behavioral treatment program one afternoon a week for two hours. The researchers also tested the children in specific environments before and during training to probe whether the children used their PECS to request items without direct training in that environment. The researchers also tested whether the children used their PECS across people, including their therapist, their parent, and an unfamiliar store clerk.

What did the researchers find?

After the initial training, three of the four children used PECS much more frequently in the four different types of situations that the researchers tested. One of the four participants required additional training to reach this outcome. At follow-ups conducted 1-18 months after the intervention ended, the children continued to use PECS in all locations. The findings indicate that when learning PECS in one setting with one instructor, children with autism can generalize PECS across settings and people. The findings also support the use of a “train and probe” technique to assess generalization after each phase of PECS training.

What are the strengths and limitations of the study?

At the start of this study, the researchers documented that all four boys showed signs of severe autism (as measured by a widely used rating scale), were nonverbal and lacked PECS skills. To ensure the data were valid, the researchers had a second observer take data on a segment of the sessions to compare coding of the children’s responses and to assess procedural accuracy. One limitation of this study was that generalization probes all occurred with the same people (therapist, parent, store clerk) and in the same environments (treatment center, home, local store). For a child to use PECS fully functionally, assessment of generalization should span a larger variety of people and locations. Also, as with most other studies that use a single-subject design, the small number of participants is a limitation; conclusions are accepted with caution until results are replicated with other participants.

What do the results mean?

This study replicated previous studies demonstrating that children with autism can learn to use PECS as a functional communication system. The researchers showed that PECS skills generalized across settings and people by the end of training. The study highlighted the importance of assessing generalization after each phase of PECS training rather than waiting until the end. When PECS training is limited to specific settings, it is even more important to test for PECS generalization so that booster trainings can be delivered as needed to individual children. Frost and Bondy, the creators of the PECS approach, recommend that adults create communication opportunities throughout a child’s day by restricting access to preferred items. The current study supported this

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recommendation by designing the free-play environment to include restricted access to highly preferred items and frequent temptations with these items. More research should be conducted looking at generalization across other environments and communication partners (at school, with peers). Future research might also compare the commenting skills of PECS users to users of other modes of communication.

2.

TITLE: AN INTERVENTION FOR SENSORY DIFFICULTIES IN CHILDREN WITH AUTISM: A RANDOMIZED TRIAL.

Schaaf, R., Benevides, T., Mailloux, Z., Faller, P., Hunt, J., van Hooydonk, E., Kelly, D. (2014). An intervention for sensory difficulties in children with autism: A randomized trial. *Journal of Autism and Developmental Disorders*, 44 (7), 1493-1506. doi: 10.1007/s10803-013-1983-8.

Reviewed by:

Sunita Chhatwani, MSc, MEd, ABA, ASAT Extern
Karen Fried, PsyD, BCBA-D, ASAT Board Member

Why research this topic?

Occupational therapy using sensory integration (OT/SI) is an intervention based on the premise that children with autism spectrum disorder (ASD) have trouble processing information received from the senses. OT/SI aims to overcome sensory dysfunction in children with ASD through activities that provide sensory input to the brain about the body's movement through space or about movement of muscles and joints. Examples of OT/SI activities include swinging, riding a scooter board, or brushing the child's body.

Though OT/SI has been used for quite some time with children with ASD, there is not yet a body of evidence supporting its effectiveness for this population. The research to date has had methodological limitations. The current study set out to examine OT/SI using a more rigorous design.

What did the researchers do?

Researchers randomly assigned 32 children with ASD, ages four to eight years, to one of two groups, the control and experimental group. Over 10 weeks, the control group received only "usual care" which was defined as the non-study related services the children were already receiving, including school-based occupational therapy, school- or home-based behavioral intervention, and/or pharmacological treatment. The experimental group received the same "usual care" plus three hours per week of an OT/SI intervention that followed procedures in a manual and measured the degree to

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which providers were sticking to those procedures. The experimental OT/SI intervention also used a systematic method for defining each child's goal priorities and attainment, using assessment data and parent input. Before and after the 10-week study period, all children were assessed by independent evaluators who were unaware of the group assignments. The children's individual goal attainment, sensory behaviors, functional and adaptive behaviors were evaluated. The two groups were compared to see if there were any differences.

What did the researchers find?

At the end of treatment, compared to the control group, the experimental group obtained significantly higher scores on the parent-reported measures of individual goal attainment and functional behaviors, as well as marginally significantly better scores on a parent-reported measure of sensory behaviors. However, there was no significant group difference on a parent-reported measure of adaptive behaviors.

What are the strengths and limitations of the study?

A strength of the study is that the OT/SI intervention followed a manualized protocol and measured the therapists' adherence to that protocol. A manualized protocol can be replicated by other therapists and researchers. Measuring adherence helps establish that therapists are consistently providing the intended service, rather than drifting. Another strength is that the experimental OT/SI intervention used a systematic method for defining each child's goal priorities, emphasizing assessment data, parent input and measurable objectives.

The researchers identified some of the main limitations of their study. To judge the children's progress, they relied on parent interview and parent-report measures rather than on direct observation. While parent-report measures have value, they are prone to bias and are best used in combination with direct observational measures. The parents in the current study were not blind to the intervention, and so parent report measures need to be interpreted with caution.

The researchers noted that the OT/SI intervention is not meant to be a comprehensive treatment for ASD but rather part of a comprehensive program. With that in mind, it might be valuable for a future investigation to compare the current manualized OT/SI intervention (with measurable objectives and adherence checks), when combined with another well-specified treatment, to the other treatment alone.

What do the results mean?

Because of the exclusive reliance on reports from parents who were aware of whether or not their children were receiving OT/SI, results of this study are inconclusive regarding the effects of OT/SI on individual goal attainment, sensory behaviors, and functional and adaptive behaviors in children with ASD. Nevertheless, this study illustrates greater rigor in examining OT/SI by using a manualized protocol for the OT/SI intervention, measuring therapist adherence to the protocol, and using a systematic method for defining each child's goal priorities and attainment, including measurable objectives. OT/SI needs more research to be termed an evidence-based intervention.



ALCANZANDO

Alcanzando es una organización sin fines de lucro que provee servicios educativos basados en el análisis aplicado del comportamiento a niños con autismo y a sus familias, brinda servicios en distintos países de Latinoamérica. Esto incluye instrucción individualizada, grupos de socialización, apoyo para la inclusión educativa, talleres, cursos y entrenamiento para padres profesionales.



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Contamos con la acreditación otorgada por el BACB® para dictar el curso de certificación para BCaBA y BCBA en Lima-Perú.



MISIÓN

Nuestra misión está basada en la premisa de que cada individuo con autismo debe tener la oportunidad de alcanzar su potencial máximo. Trabajamos en alcanzar esta meta un niño a la vez, individualizando cada programa para satisfacer cada una de sus necesidades.



DRA. MAPY CHAVEZ

Nuestra fundadora y directora la Dra. Mapy Chávez Cueto, cuenta con un doctorado en Educación de Niños dentro del Espectro del Autismo otorgado por Columbia University (Nueva York), Analista Conductual Certificada al nivel de Doctorado (BCBA-D) por el Behavior Analyst Certification Board desde el 2005.



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PERSPECTIVES

Malcom's Tiles

Franca Pastro, BA
ASAT Parent Board Member

In this issue, Perspectives is showcasing Malcolm, Dr. Corley's son, and his very original and interesting tile painting business. Through the interview with Dr. Corley, we follow Malcolm's steps that led him to a place where he developed the skill sets necessary to create and successfully operate such a unique business that represents one of his passions.

Franca Pastro, BA
Perspectives Coordinator

Franca: Dr. Maria Thompson Corley describes Malcolm, her 16-year-old son who was diagnosed with autism, as a sweet, funny, friendly, loving young man. She is also quick to add that, "although his challenges are great, his gifts far outnumber them."

Dr. Corley: Thirteen years ago, at the age of three, Malcolm received the diagnosis of PDD-NOS. His particular individual aspects of this condition dictate that expressive language is difficult, although receptive is very good. Malcolm reads fluently, but answers questions best in multiple choice format. He is given to self-talk, typically reciting passages from his favorite videos. He often stims with his hands, or through happy, high-pitched squeals. He demonstrates some proficiency at self-care tasks, but almost always needs a prompt.

Franca: How much involvement did you personally have in Malcolm's development and his love for the arts?

Dr. Corley: I have always exposed my children to music, even in utero, because of my love of music as a classical pianist. I taught Malcolm piano for a while, took him to violin lessons and



music therapy. He still takes voice lessons, and sings occasionally in church (he auditioned for and got into the high school variety show and will be singing Can You Feel the Love Tonight!). He plays the drums in church sometimes and after his dad told me how much he enjoyed playing the video game Rock Band, I sent him for lessons. He is exposed to and hears rehearsals and piano lessons at my house so basically he has to go out of his way to escape music! As for the visual arts, when he was very small — perhaps as young as three or maybe even younger — he drew things that I came to recognize as the clues he'd seen on the tv show Blues Clues, and I would draw things for him to color by number. He also drew some of

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the Dr. Seuss characters so many times, he can still do them from memory (Aunt Annie's Alligator, for example).

As far as Malcolm's behaviors, I had to get to a point where I really believed he could control his meltdowns. It was very stressful, because I wasn't always sure I could get him to stop his temper tantrums. At a younger age, when frustrated, he would scream repeatedly - not just at me, but also at his sister, and sometimes in class. He would also throw objects and trash his room. So, I decided to use a firm approach: using a no-nonsense voice, standing my ground even if he was really pushing the limits, I would say, and still do, "if you want that, you need to do this." He could trash his room, scream, whatever, but he had to clean it up. He was smaller then--now he's 6 feet tall, so I'm glad I nipped that in the bud! And, of course, he would also get hugs after he cleaned.



Because Malcolm had difficulty speaking to express the reason for his anger, I would offer him what my best guesses were as to what I thought he was angry about and thus give him the opportunity to let me know the source of his anger or frustration. I want to add that all children are different, so I'm not suggesting that my strategies would work for everyone. This was my attempt at not letting his bad behaviors overshadow his good nature and talents.

Franca: Your dedication and perseverance are commendable! As you say, let's focus on Malcolm's strengths. I'm assuming that the idea of starting a business of decorating tiles for Malcolm started from his love of the visual arts.

Dr. Corley: Yes, it did. Malcolm started decorating tiles in 9th grade, at the request of his learning support teacher. His creations, often custom made, were relatively simple cartoons which were very popular when sold at local bazaars to benefit the classroom. I mentioned to a friend that I thought it would be nice if he could create tiles for his own benefit. Having seen examples of his artwork, she expressed an interest in buying five of them, promising to supply designs later. Prior to all this coming to pass, his grandmother commissioned him to decorate tiles with Celtic crosses as souvenirs for her friends back in Canada. We found a public domain Celtic cross on the Internet and he customized the

color schemes. His attention to detail and amazing fine-motor control are the key factors. What he does freehand is astounding. I know because I tried to touch up a spot where the marker had skipped a bit, and had to call him in to repair the damage I made! Soon after, his aunt created a website for him (www.malcolmstiles.com) and his fledgling business was launched.

Franca: So, does this mean that because he loves drawing so much he is self-motivated to decorate tiles as his primary daily activity?

Dr. Corley: Malcolm loves art, but, like many of us, he needs a strong incentive to work hard. For the moment, the driving force behind his mini-business is his desire to earn money to travel to an amusement park in Amsterdam he'd seen on Youtube, Julianatoren. Malcolm loves amusement parks, but there's something about this one that fascinates him to the point of near-obsession. I'm grateful for his focus. However seemingly trivial a trip to an amusement park may seem, in the process, he is learning about bank accounts, delayed

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gratification, and being an entrepreneur - the latter a stretch for me, too. Together we are growing.

Franca: Has Malcolm had any form of therapy or has he received any services that you think have been crucial in his development? If so, which ones and how?

Dr. Corley: Malcolm started receiving ABA in preschool and he's had a number of wonderful Therapeutic Support Staff and Behavioral Specialist Consultants. He has had speech therapy since he was three and used to have OT mainly for self-care. I always made sure Malcolm spent at least part of the day with neurotypical children. His progress has been gradual. I think the biggest breakthrough came when there was a family emergency and a friend had to watch him. She discovered how much Malcolm wanted to be told he was a good boy. The discovery of his desire to be praised has made a huge difference in motivating him. Alternatively, he can always be reinforced with the promise of McDonald's french fries - I wish broccoli did the job!!

Franca: Do you have any advice for other parents/caregivers of young adults with autism who are thinking about their future?

Dr. Corley: My foremost advice is find out what your child is interested in. I always try to let Malcolm do the things that interest him. I also don't assume he can't do something until he's tried. There are so many things he COULD do, but I don't have the time or skills to explore all of

them. It's just a matter of finding people interested in giving him a chance, and there are more of those out there than one might think. My son is very loving and even-tempered, but he used to have meltdowns. I have no way of knowing if his creative outlets have helped him in this regard, but I suspect that they have. What surprises me is that people are impressed that I do my best to find outlets for Malcolm. I say, "Why wouldn't I?" So, my second piece of advice to parents is focus on your child's strengths. For me, the most important part of all of this is finding a way to validate Malcolm's gifts, even in a world where academic-based pursuits are the Holy Grail. It is my hope and prayer that even though artistic fields are an uncertain way to earn an income (something that, as a musician, I know first-hand), Malcolm's art may provide a key to a future for him doing something he truly loves.

I don't want to pretend I have it all figured out — I have very real concerns about how he will get along after I'm gone and I pray with him and for him every day. Nothing about this journey is easy. But there's nothing better than seeing my son wanting to do his very best, and then doing it.

Franca: Thank you, Dr. Corley, for sharing your very personal experiences regarding Malcolm's journey to become the young man he is today and the unique business he has created. To learn more about Malcolm's Tiles, go to <http://malcolmstiles.com>.

Dr. Maria Thompson Corley lives in Pennsylvania with Malcolm and his sister, Kiana.



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- ★ All providers will be guided by science when selecting and implementing interventions and use data to demonstrate effectiveness.

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4. Consumers should be informed that any treatment lacking scientific support should be pursued with great caution.
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These sponsorships not only provide financial support used specifically for our dissemination efforts, but also send a clear message that ASAT's vision is shared by others within the professional community.

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2015 CHAMPION SPONSORS

In this issue of *Science in Autism Treatment*, we are showcasing our 4 **Champion** level sponsors.



Autism Partnership

In 1994, Drs. McEachin and Leaf formed Autism Partnership to meet the tremendous need for comprehensive services to families of children and adolescents with autism. Based upon the founders' extensive and unique experiences in providing behavioral treatment to children, adolescents and adults, they have developed a comprehensive treatment program that provides a variety of services and serves as a model of excellence for the autism community.

Autism Partnership's senior staff started their work together back in the 1970's at the UCLA Young Autism Project. Under the mentoring of Dr. Ivar Lovaas, a pioneer in the treatment of autism, John McEachin, Ron Leaf, Mitch Taubman, Tracee Parker, Sandy Slater and Andi Waks learned their profession. They were involved in all aspects of this groundbreaking project including development of curriculum and behavioral intervention strategies, implementing and supervising treatment, training therapists, teachers and parents, teaching classes, and conducting research. While at UCLA, they contributed to seminal works including books, research publications, and scientific conference presentations. They continue to speak at national and international conferences, have authored numerous research articles which have appeared in peer-reviewed scientific journals, and have published some widely used books including:

- *A Work in Progress: Behavior Management Strategies & A Curriculum for Intensive Behavioral Treatment of Autism*
- *It's Time for School: Building Quality ABA Educational Programs for Students with Autism Spectrum Disorders*
- *Sense and Nonsense in the Behavioral Treatment of Autism: It Has to be Said.*

As knowledge about effective behavioral treatments continues to grow, they have also made advancements to increase accessibility to greater numbers of children in a variety of settings. Specifically, they have extended the application of this specialized teaching methodology to children who are older, as it has been established that many older children have greatly benefited from intensive behavioral treatment as well. Originally based in California, Autism Partnership has expanded throughout the world with offices in England, Australia, Canada, Hong Kong, and Singapore.

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Organization for Research and Learning, Inc. (O.R.L.)

The mission of O.R.L. is to provide very high quality services to the clients served, to contribute to the larger behavior analytic community through their activities as scientist-practitioners, and to act as advocates for the autism community. O.R.L. was originally formed in 1998 as Fabrizio/Moors consulting, and reorganized itself as O.R.L. in 2007. Beginning as a small organization in Seattle with two staff members who served four children with autism during their first year, O.R.L. has since grown to include 17 clinical staff members serving dozens of children and their families.

O.R.L. works primarily with children, adolescents, and young adults from all points along the autism spectrum in the Puget Sound area. Their clients are as young as 18 months, and currently their oldest client is 24 years old. In addition to working with individuals with autism, O.R.L. also works with a small number of youth who have severe learning disabilities in the areas of reading, writing, or mathematics. Beyond their clinical work with youth and young adults, O.R.L. also consults with other ABA agencies across the United States to help them improve the quality of the clinical services that they provide their own clients.

Their philosophy about the applied behavior analysis (ABA) services they deliver is rooted firmly in the principles of behavior analysis and espouses the following beliefs:

- **All children can learn:** Regardless of what diagnosis a child has or how affected by their disability they may be, their philosophy states that all children are capable of learning and progressing toward a more normalized, self-determined future.
- **Children have the right not only to effective intervention but also to efficient intervention:** The ABA services that a child receives should not only help ensure that they make meaningful progress, but also that they make that progress as rapidly as possible while still ensuring their happiness through the process.
- **Children have the right to intervention that is based on science and that has been shown to be effective through scientific study:** Wherever possible, children should receive intervention services that have been thoroughly researched and proven to be effective.
- **Families have the right to receive services individually tailored to the unique needs of their children and their family as a whole:** No two families are exactly alike and because of this, families should expect that the ABA services their child receives are designed to fit comfortably within the lives of all members of the family.

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- **Clinical practice should inform applied research and applied research should inform clinical practice:** The exchange between ABA research and practice should be rich and continuous so that clinical practice constantly evolves and improves.



Autism Curriculum Encyclopedia

The Autism Curriculum Encyclopedia (ACE) is the culmination of over 35 years of research and practice conducted at The New England Center for Children (NECC). It provides an interactive database containing assessment tools, lesson plans, teaching materials, and student performance reports for over 1,300 skills drawn from the curriculum at NECC used to educate individuals with autism. The New England Center for Children is a private, nonprofit autism research and education center dedicated to transforming the lives of children with autism worldwide through education, research, and technology. Based out of Southborough, MA, the NECC provides home-based programs, intensive classroom instruction, and a day program for older children. Their vision is to be a global leader in the provision of effective, evidence-based educational services for the millions of underserved children with autism and their families by:

- Educating teachers and parents around the world so that they may benefit from the knowledge and methods developed at NECC;
- Using the power of technology to help teachers and families transform the lives of children with autism;
- Defining their future success by the number of children being served by the ACE curriculum; and
- Bringing help to hundreds of thousands of children and their families.

Their commitment extends to creating a positive, professional environment for staff so that they can work cooperatively toward achieving NECC's goals. NECC understands the difference its teachers and staff can make in the lives of children with autism and other related disorders. Because of this, NECC provides a unique opportunity for individuals to become highly skilled and experienced teachers through its specialized professional development model.

They strive to be at the forefront of conducting and publishing research to further the understanding and treatment of autism and related disabilities, and will use only those methods that show results. Science is consistent in showing that early, intensive instruction using the principles of applied behavior analysis help children with autism learn and reach their maximum po-

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tential. For that reason, NECC has developed a wealth of curricula grounded in the principles of behavior analysis and compiled it into the web-based Autism Curriculum Encyclopedia (ACE). With all of NECC's students, the ACE is extremely effective in teaching critical skills to a wide range of individuals with autism.

The ACE is designed to provide teachers, administrators, and other school professionals with easy access to applied behavior analytic procedures and an effective and efficient way to aggregate and understand student performance data. Every lesson plan within the ACE can be customized to the learning profile of the individual student being taught. Thus, this web-based curriculum fills an enormous need for an easy-to-access, comprehensive and rigorously tested resource allowing teachers and schools to provide effective and individualized services to their students. Features include:

- **Assessment** - ACE assessments provide teachers and service providers with a clear indication of where to begin instruction and how to motivate learners.
- **Curriculum** - The ACE provides the tools which guide teachers to design and implement highly effective, individualized curricula.
- **Data and Reporting** - With ACE, one can quickly and easily evaluate student performance for a single learner or look at progress across groups of learners.
- **Behavior Management** - The ACE provides teachers and service providers with tools for monitoring challenging behavior.



Lovaas Institute Midwest

From its headquarters in Minneapolis, Minnesota, the Lovaas Institute Midwest provides early intensive behavioral intervention utilizing the principles of applied behavior analysis. The Lovaas Institute is committed to providing the highest quality treatment available to children who suffer from the symptoms of autism. They approach this treatment, one child at a time, by individualizing each child's program to meet his or her needs.

The Lovaas Model of applied behavior analysis has undergone rigorous research at UCLA under the direction of Dr. O. Ivar Lovaas, proving its effectiveness in treating children with autism, through long-term outcome data published in peer-reviewed journals, and replicated by additional long-term outcome research as recently as 2006. The Lovaas Institute Midwest is currently organizing and analyzing its extensive body

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of multi-modal clinical data, which was collected on the treatment of over 200 children over more than a decade.

Treatment follows the procedures described by Lovaas in his 2002 book, *Teaching Individuals with Developmental Delays: Basic Intervention Techniques*, as well as the latest innovations in the field of applied behavior analysis, as developed both at the Lovaas Institute and internationally. An extensive clinical management system ensures that each child's treatment is dynamically adjusted on a daily, weekly, and annual basis to result in the most rapid recovery from all of the defining symptoms of autism.

Intervention is based on shaping behavior through reinforcement of successive approximations, prompting and fading procedures, and use of positive reinforcers that are child-specific and functional (i.e., serve the intent of increasing behavior). Initially, powerful intrinsic reinforcers are selected to maximize engagement and an acceleration in response to treatment. As intervention progresses, reinforcement is expanded, whenever possible, toward more natural and complex conditioned social reinforcers. The intervention is continuously modified so that appropriate behaviors are maximized through the most effective schedules of positive reinforcement. Debilitating behaviors are reduced by managing the schedules of reinforcement and teaching alternate, more socially acceptable means of attaining the child's needs.

At the Lovaas Institute, services are provided in four ways:

1. **Direct Treatment services** are provided to families in their homes and communities. A team of 3-6 staff members, extensively trained and supervised, provide the intensive, daily intervention. The focus of treatment is on training the parents to conduct the most effective behavior therapy 24 hours-a-day, 7 days-a-week. During this treatment a behavior analyst clinical supervisor is in the child's home for 8 hours a week.
2. **Family Consultation services** are designed to help remote families set up their own intervention programs, modeled after all aspects of the direct treatment service. During this treatment a behavior analyst clinical supervisor travels to the child's home for 12 hours per month.
3. **Consultation services** to behavioral treatment organizations on the latest innovations in the Lovaas model.
4. **State-wide and National Advocacy services** to assist families in gaining improved access to fully funded treatment services.

For more information, please visit the [website](#) of Lovaas Institute or the [Facebook page](#) of Lovaas Midwest.

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