

Science in Autism Treatment

Newsletter of the Association for Science in Autism Treatment

Vol. 11 No. 4

Fall 2014

Fall 2014 Issue Dedicated to Christina Danos & Jason Dolby

am both pleased and proud to share that we are dedicating this issue of Science in Autism Treatment to Christina Danos of <u>Kettlebells 4 Autism</u> and Jason Dolby of <u>One Hour Long Cycle</u> who raised over \$38,000 for ASAT.

On behalf of the Association for Science in Autism Treatment, thank you so much for your passion, strength, and generosity. We don't lift kettlebells at ASAT but we do try to lift the conversation about autism treatment so that science remains at the forefront, parents can assume the necessary role of the savvy consumer, and those touched by autism have a clear path to effective treatment. Your perseverance, commitment, and endurance are all qualities needed by families attempting to navigate the overwhelming landscape of autism treatment. These qualities make your event and associated efforts even more meaningful and inspirational to us all. Thank you Jason and Christina from the bottom of our hearts!

As you will read in the article that starts on page 4, scores of individuals participated in the October 18th event. A truly international effort with an incredible community of athletes from the following countries: Argentina, Australia, Bermuda, Canada, France, Germany, Ireland, Italy, Indonesia, Japan, Mexico, New Zealand, Russia, Sweden, the United Kingdom including England, Scotland and Wales, and the United States. I had the good fortune to meet Rory Pollock, Kaseedee Jermain, Donica Storino, and Diana Sherman Whittles at the Hoboken, New Jersey location of this event (see photo on page 7).

As we approach the closing of 2014, we have the opportunity to reflect on the accomplishments of this year. I would like to highlight some of them with our readers, and will report on our goals for 2015 in the Winter 2015 issue of the newsletter. In 2014 ASAT:

★ Published numerous Media Watch letters in response to news articles and broadcasts related to autism treatment.

★Successfully carried out an array of fundraising efforts with Dine InDeed, <u>AmazonSmile</u>, Kettlebells4Autism, NYC Marathon, Rock'n 4 Autism Awareness, and Bidding for Good.

★ Established Team ASAT for the 2014 <u>NYC Marathon</u>, which included two young men with autism who garnered national media coverage last year.

★Launched a comprehensive, new <u>website</u> and expanded features to include translation of content into 29 languages including Hebrew, Spanish, Italian, French, Portuguese, and Mandarin. We will share more details in the next issue of our newsletter.

★ Graduated several Externs, many of whom have assumed coordinator-level roles within our organization.

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★ Welcomed Leanne Tull, Corey Robertson, Zachary Houston, and Tracie Lindblad to the <u>Board of Di-</u><u>rectors</u>.

★ Increased our use of social media to reach families and professionals (e.g., Twitter, Facebook, You Tube and Fundly) and amassed over 8,500 Facebook "Likes!"

★Increased Science in Autism Treatment (SIAT) newsletter subscriptions to over 10,400 individuals and met our goal of subscribers from at least 95 countries:

Afghanistan	Colombia	lceland	Malaysia	Singapore
Albania	Costa Rica	India	MALTA	Slovakia
Andorra	Cyprus	Indonesia	Mexico	Solano
Argentina	Czech Republic	Iran	Moldova	South Africa
Aruba	Denmark	Iraq	Myanmar	South Korea
Australia	Dominican Republic	Ireland	Netherlands	Spain
Austria	Ecuador	Israel	New Zealand	Sri Lanka
Bangladesh	Egypt	Italy	Nigeria	Sweden
Belarus	England	Jamaica	Norway	Switzerland
Belgium	Ethiopia	Japan	Pakistan	Tanzania
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Bosnia and Herze-	France	Kazakhstan	Peru	Trinidad and Tobago
govina	Germany	Kenya	Philippines	Turkey
Brazil	Ghana	Korea, Republic Of	Poland	Uganda
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Central African Repub-	Honduras	Lebanon	Russia	Venezuela
lic	Hong Kong	Libya	Saudi Arabia	Vietnam
China	Hungary	Macedonia	Serbia	Zimbabwe

★ Attained 1000 followers on Twitter.

★ Held the 4th Annual <u>Rock'n 4 Autism Awareness</u> concert in Hoboken, New Jersey. The event was a huge success with over one hundred businesses lending their support and raising \$12,500 dollars to promote autism awareness on both the national and local level.

★ Raised over \$38,000 dollars through Kettlebells 4 Autism and One Hour Long Cycle.

★Was showcased in a 30-minute interview on W-KTU radio in New York City.

★ Published 4 issues of Science in Autism Treatment content-packed with topics of interest to families and professionals, and new features (e.g., International Interviews).

In the spirit of the upcoming Thanksgiving holiday, I would like to take this moment to thank you, our readers, for all your support. It truly takes a village to promote the relevance of science in autism treatment.

Warmly,

David Celiberti

ASAT Executive Director

OUR REAL SCIENCE, REAL HOPE 2015 SPONSORSHIP INITIATIVE

Does Your Agency Share ASAT's Values?

ASAT believes that individuals with autism have the right to effective treatments that are scientifically-demonstrated to make meaningful, positive change in their lives. We believe that it should not be so challenging for families to find accurate information about the efficacy of various autism interventions. ASAT works toward a time when ...

- ⇒ All families will be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.
- ⇒ The media will educate and not confuse parents by providing accurate information and asking the right questions.
- ⇒ All providers will be guided by science when selecting and implementing interventions and use data to demonstrate effectiveness.

PARTNER \$5,000

Behavior Analysis Center for Autism Little Star Center

Little Star Center

CHAMPION \$2,000

Autism New Jersey Autism Partnership Organization for Research and Learning

BENEFACTOR \$1,000

ELUA Foundation ELUA School Long Island Behavior Analysis Group New England Center for Children Princeton Child Development Institute Rethink Autism Therapeutic Pathways, Inc.

What It Means to Be a 2015 Sponsor:

ASAT's Sponsors indicate their support of the following tenets:

- 1. All treatments for individuals with autism should be guided by the best available scientific information.
- 2. Service providers have a responsibility to rely on science -based treatments.
- 3. Service providers should take steps necessary to help consumers differentiate between scientifically validated treatments and treatments that lack scientific validation.
- 4. Consumers should be informed that any treatment lacking scientific support should be pursued with great caution.
- 5. Objective data should be used when making clinical decisions.

Become a 2015 Sponsor Now!

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.

The tasks of educating the public about scientificallyvalidated intervention and countering pseudoscience are daunting ones, and ASAT appreciates the support of all of our sponsors.

If you are interested in becoming a 2015 Sponsor, please visit the sponsor page on our website at

www.asatonline.org/ about_asat/ sponsors.htm#learn.

Thank you for your consideration!

ALLIANCE \$500

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Providing Accurate, Science-Based Information - Promoting Access to Effective Treatment

Thank You, Kettlebells 4 Autism

and One Hour Long Cycle!

By Alice Bravo, MEd



e owe another big thank-you to <u>Kettlebells 4 Autism</u> (KB4A) for continuing to support the **Association for Science in Autism Treatment** (ASAT) and families affected by autism in a major way!



As you may recall, KB4A's founder, Christina Danos, is dedicated to promoting evidence-based treatments for autism. She has done so by working with children with autism in an Intensive Behavior Intervention (IBI) setting and by creating, in February 2013, KB4A – an organization that uses kettlebell training and sport (the use of a cannonball-shaped weight with a handle) to convey her commitment to

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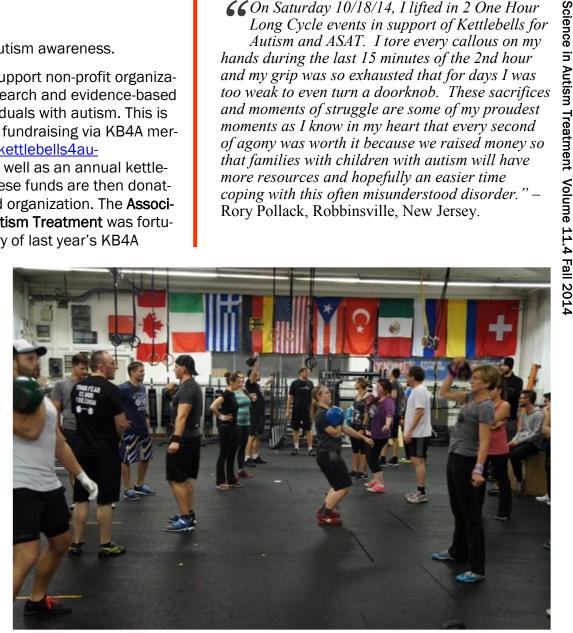
science and to raise autism awareness.

KB4A's mission is to support non-profit organizations that focus on research and evidence-based interventions for individuals with autism. This is accomplished through fundraising via KB4A merchandise sales (www. kettlebells4autism.storenvy.com), as well as an annual kettlebell sporting event. These funds are then donated to a pre-determined organization. The Association for Science in Autism Treatment was fortunate to be a beneficiary of last year's KB4A

C On Saturday 10/18/14, I lifted in 2 One Hour Long Cycle events in support of Kettlebells for Autism and ASAT. I tore every callous on my hands during the last 15 minutes of the 2nd hour and my grip was so exhausted that for days I was too weak to even turn a doorknob. These sacrifices and moments of struggle are some of my proudest moments as I know in my heart that every second of agony was worth it because we raised money so that families with children with autism will have more resources and hopefully an easier time coping with this often misunderstood disorder." – Rory Pollack, Robbinsville, New Jersey.

sporting event, "90second swings for autism," in which participants engaged in 90 seconds of kettlebell swings (see "Weight to Go Kettlebells 4 Autism!"). Sponsors pledged donations per swing and the funds raised were donated to both ASAT and the Geneva Centre for Autism in Toronto, Canada.

For this year's KB4A fundraising event, Danos teamed up with Jason Dolby, founder



Participants from Ansbach, Germany, including parents of children with autism

of the One Hour Long Cycle (1HLC) charity event. In Dolby's annual 1HLC event, kettlebell lifters lift together for 60 minutes without setting their kettlebell down. Participants lift solo or relay-style, in which a team member lifts for two minutes and then passes the kettlebell to a teammate. This year's collabo-

C Through kettlebells our members have learned far more than simply lifting heavy things and getting fit. Autism is a subject very close to some of our hearts." – 1HLC participant from Scotland

ration between KB4A and 1HLC happened to mark the fifth anniversary of the 1HLC. Previous beneficiaries of the event have been the Children's Hospital in Los Angeles; relief efforts fol-

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Participants from Seattle, WA

lowing the tsunami in Japan; Tuberous Sclerosis Alliance in the name of Anthony Brewer; and the Jimmy V. Foundation for cancer research. What started as an event consisting of 20 lifters in a single room has since expanded immensely. Seventy-one satellite locations were created this year to support KB4A/1HLC's event total of over 750 participants from 15 countries – a truly global effort!



Participants from Queensland, Australia, including parents of children with autism

Participants took part in the 1HLC for a variety of reasons - some due to a passion for kettlebell lifting, others wishing to support science-based treatments for autism, and many interested in both. "Kettlebell training has expanded my world. This event represents a chance to reach people in my community with a message of health, (Continued on page 7)

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and support a community I care for deeply," wrote one participant from Mississauga, Canada. Additionally, participant and kettlebell trainer Marissa Luchau from Seattle, WA set a world record during the 1HLC as the first woman to lift a 44 lb. kettlebell for an hour straight. This major accomplishment also earned Luchau the rank of Master of Sport International, indicating a valuable contribution to the kettlebell sport.

Kettlebells 4 Autism and 1HLC raised over \$35,000 on behalf of ASAT and we are incredibly grateful to both organizations and all of the participants for their hard work and support of evidence-based treatments for autism. The funds raised from this event will be used to create, design, and disseminate an information resource for parents and other caregivers of newly diagnosed children with autism. We will share details about this resource in the



Hoboken, New Jersey Participants: Rory Pollack, Kaseedee Jermain, Donica Storino, and Diana Sherman Whittles (parent of a child with autism)

months ahead, and will also be taking steps to share our resources abroad.

66 Kettlebells 4 Autism was such an amazing event for me. I got to spend a beautiful afternoon on the waterfront in Hoboken with my amazing team, but the best part was knowing I was doing what I love for a cause I love! Every time that bell went over my head it brought a tear to my eye thinking about why I was there and about 2 amazing little boys in particular and their amazingly strong families, that are misunderstood on a daily basis. I hope that I am lucky enough to continue to work with such amazing groups and raise more awareness and needed funds for ASAT." – Kaseedee Jermain, New York City, NY

66 We want to help parents navigating the world of autism treatment to have the wonderful help made available through the Association for Science in Autism Treatment!" – 1HLC participant from Pennsylvania

Interested in learning more about kettlebell lifting?

Check out KB4A's blog,

www.kettlebells4autism.com/blog. Monthly posts include kettlebell workouts from kettlebell trainers and athletes!

Interview with Molly Ola Pinney, Founder and CEO of the Global Autism Project By Nicole Pearson, PsyD, BCBA-D

The need to educate parents, professionals and communities as a whole about the importance of evidence-based treatment in autism is great, and perhaps even greater in countries outside of the United States. The Global Autism Project is one organization committed to doing exactly that by partnering with local treatment and education centers in countries around the world including Peru, India, Kenya, Indonesia and the Dominican Republic. I had the privilege of traveling with this organization to Kenya in 2013 and seeing their great work – including their efforts to promote science in autism treatment first hand. Recently, I had the opportunity to interview Global Autism Project's founder and CEO, Molly Ola Pinney, so that she can share with our readers more about how her organization is promoting this important mission.



Molly Ola Pinney

Nicole Pearson, PsyD, BCBA-D

Molly, having had the privilege of working and traveling with the Global Autism Project, I know you celebrated a big milestone in 2013 - 10 years since its founding! Can you share with our readers what led you to found the Global Autism Project?

As is the case for many of us in this field, I began my work as an ABA therapist in Seattle for one 6 year-old boy with autism. His family asked me to work with him and part of the reason that I accepted the position, even though it was not at all in line with my plans at the time to become a Developmental Pediatrician, was because the job would end in nine months as the family was moving to Ghana in West Africa.

If there was anything I knew at the time, it was that I was most certainly NOT going to be moving to West Africa. Less than a year later, that's exactly what I did – I moved to Ghana to continue providing services for their son. Shortly thereafter, people began showing up at my house asking for the lady who knew about autism.

As I began having conversations with families of children with autism, I would hear time and again the same story of fear and misunderstanding about what autism was and about the locally accepted belief that these children were possessed or taken by 'bad spirits.' Shortly thereafter I met "Auntie Serwah"-- a parent of a child with autism who had started the Autism Awareness Care & Training center in Ghana. The Autism Awareness Care & Training center was a beacon of hope for families, a safe space management.

This model fosters the dynamic of sustainable development, ensuring that our partner sites receive training that will persist in our absence. It is imper-

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ative that our work be carried out in this manner, as it is neither culturally appropriate nor practical for the Global Autism Project to be ever-present at our partner sites. Our partnerships are intended to last for years in order for the centers to stand on their own and further disseminate science in autism treatment in their communities.

We currently have partnerships with centers in Peru, India, Indonesia, Kenya, and the Dominican Republic. We are thrilled to work with individuals who can align their passion for helping children with autism with the need for science in treatment.

Having travelled with your organization as a former SkillCorps team member, I can attest to the unique experience the Global Autism Project offers In subscribing to a model of sustainable developto practitioners to see autism treatment in another ment, we also recognized that our own work was country. Can you tell our readers more about this program and why you created it?

SkillCorps is our travel abroad program in which teams of four to six skilled professionals have the sources in order to round out clinical skills. Volunteers are selected from a competitive pool of applicants, who are required to submit applications and interview for the trip of a lifetime.

SkillCorps was founded for multiple reasons. Primarily, we recognized the unique and meaningful experience our work abroad provides for both our partners and ourselves. We wanted to share that experience with other skilled clinicians who could not only have the transformative experience our work entails, but offer their skills in a meaningful and enduring way. By creating SkillCorps, we have opened the door for cultural empathy and increased understanding of both the plights and strengths of people working in autism treatment and education in under-resourced areas.

not sustainable if we tried to do it alone. With a relatively small staff, we could not realistically provide all of the in-person training needed as well as the distance supervision and support. SkillCorps allows the privilege of providing training and sup-

opportunity to travel to one of our partner sites. During these two-week trips, teams provide hands-on, in vivo training to staff working with children with autism. That training can encompass programming, behavior management and how to teach utilizing the principles of ABA. Teams may also provide support to parents and caregivers and hold awareness events in the community. Our trips ensure that partner sites are receiving training from diverse



Learning to wear a horse riding helmet in Kenya

port to be shared amongst many skilled professionals.

The final reason for the inception of Skill-Corps is the unique training opportunity that is created when individuals from diverse backgrounds and skill sets come together as a unified team. The contributions of our team members are shaped by that diversity and enrich our trainings and our work.

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What do you find to be the most challenging aspect of your work?

The most challenging aspect of our work requires cultural empathy and purposeful optimism. We meet parents, caregivers, and staff around the world who are relying on instinct in the absence of scientifically supported interventions and finding that they come up short. Without the training required to provide evidence-based interventions, those providing services to children with autism are becoming disheartened and the children themselves are ostracized from communities who lack knowledge or understanding. At times we feel our impact is too small and we may become discouraged by slow progress. This, of course, is thwarted by the successes (however small) of our partner sites and the empowerment they receive through training. We find that we must not only remain diligent in our mission, but also remain open to feeling and experiencing what those working in the autism field abroad are feeling and experiencing.

It is only through cultural humility and empathy that we can meet people where they are at to provide meaningful support.

I know an important part of your work is to build sustainability and capacity at partner sites. How do you do that and ensure evidence-based practice is a part of that?

We require a few things from our partner sites: Commitment to sustainable change, commitment to evidence-based practice, and openness to the changes required in programming to foster evidence-based practice. Our partners desire the same things we do: to engage with interventions that are proven effective and professionals who can foster the development of these interventions.

What role does the Global Autism Project play in terms of advocacy and working with parents?

The Global Autism Project is fortunate to work with partners who support parents and caregivers in a variety of ways. One-on-one meetings, home visits,



A big smile from a small girl in India

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and support groups often play an important role in the child's learning. The Global Autism Project supports our partners' efforts by hosting some of these support groups and accompanying them on home visits during our SkillCorps trips. We also help to host advocacy events, provide networking opportunities and foster connections to make efforts more effective. Each year on Autism Awareness Day, we find our partners' taking meaningful action by lobbying their government and engaging their communities to cultivate acceptance and understanding on both a local and international level.

What treatments have you found to be most popular in other countries? Are there any that you see more commonly across countries or does it vary greatly?

We find that in the absence of training and resources to nurture evidence-based practice, those working in autism treatment rely on instinct. Specific treatments are not engaged in many of the communities we work with – instead we find students and teachers frustrated by academic demands and behavioral requirements of "typical" classrooms. We have, over time, found the awareness of applied behavior analysis to be growing with more sites and more countries reaching out for training and support daily. This is largely due to



Laughter and connection in Kenya



Imitation in India

the efforts of those in the ABA community working to disseminate scientific practices.

What are your future goals for Global Autism Project?

When the Global Autism Project began in 2001, it was with the intention of "changing the world for people with autism." Thirteen years later, this remains our long-term goal. In order to change the world, we must mobilize those with expertise in scientifically sound interventions to come together as a conduit for change. Short-term this will entail recruiting a greater network of volunteers for our SkillCorps programs, increasing the number of people reached through our training by fostering additional partnerships. We also hope to provide more training according to the prerequisites for board certification in behavior analysis in order to train professionals in under-resourced areas to the

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Summer 2014 team at the entrance to the Taj Mahal

gold-standard of evidence-based practice through courses and supervision.

What do you see as the greatest need for promoting science in autism treatment internationally?

Increasing access to training whether through university partnerships, access to materials in multiple languages, or greater dissemination of evidence of applied behavior analysis. We additionally see the need to recognize behavior as communication, as supported through scientific evidence, in order to reach a point where practitioners believe in the potential for change in their communities.

What can we as practitioners here do to support your work and organization as well as the work of promoting evidence-based treatment abroad? We would love to have more professionals share their expertise in the international community through ethical and sustainable means. One way of doing this is to travel with us, but we also have opportunities to volunteer through distance clinical supervision and support. If you're interested in traveling with SkillCorps, you can apply on our website (http://www.globalautismproject.org). There you'll also find information about our other volunteer opportunities and how to get involved. We also ask that, to start, professionals in the scientific field would be aware of the boundaries to dissemination born of language barriers and lack of access to effective training. In order to mobilize our community, we must first be aware. During our orientation process with SkillCorps team members, that's always where we start and then we can build and educate more effectively from there. There are 70 million people in the world with autism. 85% of them live in developing countries. We have a ways to go!

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From the Archives

The Pitfalls of Testimonials By Daniel Mruzek, PhD, BCBA-D

In this edition of 'From the Archives,' we resurrect a piece by Dr. Daniel Mruzek regarding a staple of our society - testimonials. Testimonials are commonplace in companies touting their interventions for individuals with autism. They provide a quick, compelling endorsement of a particular intervention. While compelling, testimonials are often not grounded in the data and provide subjective opinions of those individuals who were exposed to a particular treatment. Dr. Mruzek explains the pitfalls of testimonials, and offers guidance to those parents and consumers looking to understand and navigate the complex maze of interventions for individuals with autism.

Patrick O'Leary, MS, BCBA SIAT Editing Coordinator

When searching for a great restaurant or choosing a movie to go see, often we consider the personal reports of neighbors, work associates and friends. Why not? Their "testimonies" give us a quick method for judging the probability that a particular restaurant or movie will be a good investment. Of course, our friends and associates are not always right, but their testimonials serve as either short-cuts or as corroboration of other sources of information (e.g., restaurant or movie reviews). As such, they contribute to efficient decision-making about relatively lowstakes events.

We commonly see testimonials made by happy consumers presented by marketers of autism treatments. Indeed, testimonials are a standard feature on websites marketing pills, exercises, devices, interventions and therapies to potentially unwary consumers. Many testimonials take the form of simple, quoted statements (e.g., "The [marketed treatment] has had an amazing effect on my son!"). On the internet, video testimonials may be particularly compelling. Marketers know that the testimonials of some people, including attractive people, familiar celebrities, and people who may remind the potential consumer of him- or herself may be particularly effective. Adding pleasant theme music and using artful filming may complete the effect and increase the probability that families separate from their hard-earned money.

But, how should we use testimonial evidence in selecting potential autism treatments? When confronted with testimonials about possible autism treatments, it is recommended that families be especially cautious, particularly when the testimonials are the only source of support for the intervention. Marketers can find a few individuals who provide testimony that their product is effective, even when the product is wholly ineffective. This is because, as consumers, our opinions about the quality of a product- including perceived effectiveness- are colored by our previous experience, what we have been told by others, and our expectations. Furthermore, because human behavior- including the behavior of individuals with autism- is variable (i.e., changes across time), a treatment benefit may appear to exist, even when it does not exist at all.

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For example, imagine that a marketer sold a "special" trampoline to 100 parents with the guarantee that daily use of the trampoline by their child would "open learning channels" and "promote language acquisition." Of those 100 parents, it is reasonable to expect that at least a small number of them- perhaps 5 or 10%- may report that the product "seems to help," even if the trampoline is not at all effective as an intervention in the way described by the marketer. A savvy marketer is watching for members of this small subgroup of consumers as their source of new testimonials!

And, how about all of the parents who purchased the trampoline, and subsequently recognized that it did not "open learning channels" and "promote language acquisition?" You can be assured that their opinions will not grace the marketer's website, social media or glossy print advertisement. As a result, the marketers promote an illusion of product effectiveness where one may not exist at all.

It is for these reasons that parents and other consumers of autism "treatments" are cautioned to view testimonials skeptically. Testimonials are a wonderful way for business people to market merchandise but a poor way for families to determine true effectiveness of a treatment, device or intervention. Decisions regarding autism treatment are best guided by the scientific record, as supplied by trusted sources (e.g., a competent physician, psychologist or other autism expert). When it comes to making decisions about expensive autism interventions and the allocation of precious resources, persons with autism- and their families- deserve nothing less.

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Shout Outs, Accolades, and Appreciations! By Kerry Ann Conde, MS, BCBA

ASAT's mission is to promote "safe, effective, science-based treatments for people with autism through: the dissemination of accurate, timely, and scientifically-sound information; advocacy for the use of scientific methods to guide treatment; and the countering of unsubstantiated, inaccurate and false information about autism and its treatment." With this in mind, ASAT is striving to reach 12,000 subscribers by the end of the year. We are currently at 10,396 subscribers. Help us reach 12,000 subscribers by clicking on the following link: www.asatonline.org/newsletters/signup. You can also *like* ASAT's Facebook page at www.facebook.com/ASATonline.

If you are a supervisor or administrator, please consider passing along a sign-up sheet to help us recruit new subscribers. We have an individual version and group version. After these are completed, they can be emailed to <u>newslet-</u> ter@asatonline.org or mailed to ASAT PO Box 3250 Hoboken, New Jersey 07030.



ASAT would also like to recognize those individuals and organizations who strive to support our mission. Specifically, we would like to thank and send a "shout out" to...

★ Emily Callahan of the Virginia Institute of Autism for distributing ASAT fliers to University of Virginia medical school interns and families inquiring about services.

★ Lindsey Scholl, clinical project coordinator at Little Star Center, who was able to recruit over 100 new *SIAT* sign-ups at the Michigan Autism Conference at Western Michigan University in Kalamazoo.

★ Victoria Blessing and **Shawna Hood** who recruited more than 50 new *SIAT* newsletter sign-ups at the Answer for Autism Indiana Walk in Carmel, IN.

If you would like to share information about any initiatives you have undertaken to support ASAT, please write us at <u>publicity@asatonline.org</u>.

Clinical Corner: Adaptive Skills and Independence

By Diane Adreon, EdD

As individuals with autism move towards adolescence and adulthood, teaching skills that will enable greater independence becomes an increasingly important focus. Dr. Diane Adreon provides our readers with recommendations to assess such skills and identify which are most critical, and identifies specific adaptive skills that are often overlooked.

Nicole Pearson, PsyD, BCBA-D Clinical Corner Coordinator

e are older parents and often lay awake at night worrying about our daughter's ability to function independently when we are no longer able to care for her ourselves. She is 17 years old and is becoming more and more independent. We have read the "Hidden Curriculum" and that resource has opened our eyes to subtle social skills that may be missing in her repertoire. Are there adaptive skills that my wife and I should be considering that are often overlooked?

Individuals with autism spectrum disorders (ASD) typically have an uneven profile of skills (Ehlers et al., 2007). Regardless of cognitive ability, individuals with ASD often have difficulty with independent living skills. In fact, in many cases, areas of strength can mask significant deficits in adaptive skills. Adaptive behaviors are a reflection of the way an individual applies his or her cognitive skills in actual life situations. Research has shown that individuals with ASD have significantly lower adaptive behavior functioning than their measured cognitive abilities (Klin et al., 2007; Lee & Park, 2007; Mazefsky, Williams, & Minshew, 2007; Myles et al., 2007). This suggests that, no matter the individual's level of functioning, we need to focus on teaching adaptive skills.

When identifying what skills to teach, it is important to remember that goals should be individualized. Some questions to ask in identifying goals for your daughter include:

- Is the skill a reasonable one to teach given her age and her opportunities to perform the skill?
- Will she be transitioning to a new environment in the next few years? If so, what skills will she need to be successful in that environment?
- If your daughter is currently in a program that can address daily living skills, can the goals be formalized making them a part of her IEP or IHP?

The Adaptive Behavior Assessment System-Second Edition (ABAS-II; Harrison & Oakland, 2003), Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1997), or the Vineland Adaptive Behavior Scales-Second Edition (VABS-II; Sparrow, Cicchetti, & Balla, 2005) are all adaptive behavior assessment instruments that can yield information helpful in identifying goals. Although the overall scores will provide a global picture of your daughter's adaptive skills, going over the specific items on the protocol will provide substantially more useful input in the identification of goals.

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The science of applied behavior analysis (ABA) provides numerous strategies to assist in teaching skills. Baseline data supply information on current skill levels and can help identify target behaviors. A task analysis assists in breaking down complex tasks into smaller components and behavior chaining procedures can help determine which steps to teach first. In addition, behavioral shaping procedures and carefully constructed prompting hierarchies can help ensure that we are teaching skills in the most efficient and effective manner. Moreover, identifying reinforcers and using data to determine schedules of reinforcement can address motivational issues. Finally, teaching strategies to address generalization challenges can increase the likelihood of the individual learning to perform the skills in a variety of situations.

Since the scope of skills associated with independence is quite broad, the remainder of this response will focus on some adaptive skills that are often overlooked. When such skills are taught to individuals with ASD, they can become more independent.

Teach safe and practical money skills. When making purchases out in the community, it is a good idea to not "show" others how much money you have. Therefore, consider teaching your daughter practical strategies such as getting her money out of her wallet ahead of time, counting her money in her wallet and taking out just the amount of money she needs for a purchase. You may also want to teach her to make purchases using a debit card and the protocol for withdrawing money at an ATM. This includes teaching her to maintain an appropriate amount of space between her and others in the ATM line, putting the money into her wallet before walking away from the ATM, and so forth. It cannot be overstated that practice is essential for learning any of these skills. Some ways you can create more opportunities for your daughter to practice these skills include establishing a bank account and giving her a check for her allowance; thereby creating a reason for her to learn how to make deposits and withdrawals from an

ATM. You can also have her practice making deposits and withdrawals inside the bank with a teller.

Teach your daughter to use a calendar to track upcoming events. For most of us, the number of things we need to remember increases significantly when entering adulthood. In addition, some of what we may need to remember occurs only periodically, and outside of our daily routines, thus it can be much harder to rely on one's memory in those instances. Depending on your daughter's level of functioning, your primary goal might be having her check her schedule to see what is happening that day or to prepare her for upcoming events and activities. In other instances, you can work with her on marking a calendar with upcoming events or reminders (e.g., return library book at school, swimming at Jake's - bring swimming suit) and reviewing them daily. Teach her to get in the habit of referring to the calendar for information. Individuals with ASD need practice to use visual resources.

Teach your daughter to create and use her own todo list. Remember, a to-do list can use any kind of visual or cue so that your daughter understands what to do. Individuals of all functioning levels can learn to follow a to-do list if it is written at the appropriate level (may use pictures instead of words) and they have been taught to refer to it and do each task independently. For some, you may want to start early in having them write or type their todo list and learn to refer to it and check things off when done. It is also a good idea to help them identify and build in preferred activities to reinforce "work before play."

Teach your daughter to take medication independently. Most of us use visual cues or create a routine to remind us to take our medication, so work to establish similar ones for your daughter. If the medication regime is complicated, consider using a weekly pill box and organizing the medication on Sundays. Or perhaps you have a visual reminder present at the breakfast table that says,

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"take medication." In some instances, this might mean having the medication bottle or pill box on the breakfast table. Establish the routine of having your daughter take the medication right before breakfast (if the prescription allows) as this will decrease the likelihood that she will forget it. Once Lee, H. J., & Park, H. R. (2007). An integrated literyou have introduced this routine, decrease your verbal reminders to take the medication and direct her attention to the visual reminder. If she has a smart phone, you can also teach her how to set up a daily reminder to take the medication at specific times.

Hopefully these suggestions and examples of possible targets have provided you with a few additional ideas on ways to ensure your daughter continues to make progress towards greater independence. Assessment of her skills across a number of domains (home, community, health, safety, and work) as well as reviewing her individual goals and progress on a regular basis can ensure an ongoing conversation about priority adaptive skills to help her continue moving forward. It does take time and practice, but the pay-off is worth it in the long run.

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little star center

Little Star Center is a truly unique and special place for children and families living with autism. This organization was established in 2002 as Indiana's first center providing applied behavior analysis (ABA) services. Little Star allows families to have the best of both worlds: (1) the intense one-on-one personalized therapy that used to only be avail-

able in a home program, and (2) the community feel of a center-based program that allows children with autism access to peers, materials and a sensory-friendly facility. Along with Little Star's staff of professionals, families are an integral part of their child's programming which is why Little Star prides itself on having a "family first" philosophy. Based on the fundamental principles of applied behavior analysis (ABA), Little Star provides an atmosphere where children, therapists, and families can interact, support each other and receive on-going training so that each child can reach their full potential in a variety of settings.



Behavior Analysis Center for Autism (BACA) has been providing efficacious applied behavior analysis services to children and young adults with autism since it was established in 2009 by Dr. Carl Sundberg and a group of highly trained board certified behavior analysts (BCBA's). BACA improves the quality of life for every client by ensuring that

staff receive and apply intensive, on-going training. BACA is committed to the continuous education and training of its staff by hosting regular seminars and training sessions from its esteemed clinical team; visiting consultants from all over the country are welcomed to come in and consult with staff, deliver training sessions, and to consult with clients to enhance the skills of both staff and clients. Treatment of clients is based on current research findings from the most experienced scholars in the field of behavior analysis in the teaching areas of: language, social, self-help, academic, and employment skills.

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Autism Partnership was formed in 1994 by Drs. Ronald Leaf and John McEachin to meet the tremendous need for effective services for children diagnosed with autism and their families. Based upon the founders' extensive and unique experiences in providing behavioral treatment to children, adolescents and adults, they have developed a comprehensive program that provides a variety of services, including individual treatment, social skills groups, school consultation, staff training and development,

counseling services, crisis intervention, and an intensive consultation service called Jump Start. Autism Partnership's current work incorporates the knowledge gained from the directors' intimate involvement with the treatment program developed at the UCLA Young Autism Project during the period of 1975-1987; this approach is combined with their more recent experience delivering services in community based settings. As knowledge about effective behavioral treatments continues to advance, they have also made innovations 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. Originally based out of California, Autism Partnership has expanded throughout the world with offices in England, Australia, Canada, Hong Kong, and Singapore.

organization for research and learning

The **Organization for Research and Learning, Inc. (ORL)** was originally formed in 1998 as Fabrizio/Moors consulting, and reorganized itself as ORL in 2007. Beginning as a small organization in Seattle with two staff members who served four children during their first year, ORL has since grown to include ten clinical staff members who serve approximately 65 children and families within their private practice. ORL outreach services have affect-

ed hundreds of children from places such as Toronto, Pennsylvania, Texas, California, and British Columbia. Throughout this growth and expansion process, they continue to maintain high levels of quality in the services provided. ORL believes that families have the right to receive science-based services that are individually tailored to the unique needs of their children and the family as a whole. Their services continue to support individuals from the Puget Sound area, in addition to reaching those across the United States and other countries.



Autism New Jersey is the largest statewide network of parents and professionals dedicated to improving lives of individuals with autism spectrum disorders. The organization was originally formed in 1965 by a group of concerned parents frustrated by a lack of programs and support from their local school districts. In 2009 the organization changed its name to Autism New Jersey, reaffirming its devotion to creating a compassionate society for

individuals affected by autism, their families, and all who support them. Self-advocates, families, the professionals who work with them, government officials, the media, and concerned state residents all turn to Autism New Jersey for information, compassionate support, and training in autism treatment strategies. Autism New Jersey is committed to science in autism treatment and devoted to creating a society of compassion and inclusion for all those touched by autism. They offer a wealth of information and resources to families and professionals, including a toll-free information and referral line, webinars, professional resources, an annual conference, workshops, advocacy resources, and additional benefits for Autism New Jersey members. Autism New Jersey basic membership includes subscription to Autism New Jersey's e-newsletter, discounted conference registration, access to members-only services such as IEP reviews, among additional benefits for silver and gold Autism New Jersey members. For more information, please contact the helpline: 800.4.AUTISM.

Research Review

Both of our article summaries for this newsletter are on studies evaluating social skill interventions. The first study compared types of social skill interventions that included the child with autism and/or with a peer of typical development in a public school. The second summary evaluated imitation as a procedure to increase social skills, including joint attention. Enjoy!

Sharon A. Reeve, PhD, BCBA-D Research Corner Coordinator

Making the connection: Randomized controlled trial of social skills at school for children with autism spectrum disorders.

Reviewed by: Katelyn Selver, Rutgers University

Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: Randomized controlled trial of social skills at school for children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 53, 431-439.

Why research this topic?

The development and maintenance of peer relationships are important parts of a child's success in academic and social environments. Individuals with ASD often have difficulty developing strong relationships with their peers due to their social skills deficits. Researchers have sought to develop interventions to teach individuals with autism to interact appropriately with their peers. Some models emphasize a peer-mediated approach, while other approaches involve direct social skills training and instruction either in a group or individual setting. Although social skills intervention has

empirical and theoretical support, research has yet to directly compare the efficacy of different approaches to social skills training.

The present study compared two interventions for improving the social skills of high functioning children with autism spectrum disorders in general education classrooms. One intervention involved a peer-mediated approach (PEER) and the other involved a child-assisted approach (CHILD).

What did the researchers do?

The authors randomized 60 participants (six females, 54 males), all with an autism diagnosis, to two levels of treatment. Thirty students were randomized to receive the CHILD intervention and 30 were randomized to receive the PEER intervention. Within these levels, 15 students were randomized to receive no treatment and 15 were randomized to receive both treatments. All interventions took place in children's public schools.

Those participants who were randomized to the CHILD condition met with interventionists twice a week for 20-minute sessions for six weeks. The intervention began by identifying social skills to target. Once these skills were identified, instructors used didactic instruction and role-playing to teach the target skills. PEER interventionists aimed to increase appropriate and meaningful so-*(Continued on page 23)*

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cial interaction by teaching typical peers to interact with children with autism. Three typically developing children from the target child's classroom were taught strategies for engaging individuals with social difficulties on the playground. Peer groups met for a total of 12, 20-minute sessions over a span of six weeks (2x per week). Typically developing peers were taught how to identify isolated children and engage them and how to lend social support via direct instruction, modeling, role -playing, and rehearsal. The authors measured the students' prominence within their classroom social network, behavioral observation, and teacher perception of social skills to evaluate the effectiveness of intervention.

What did the researchers find?

Overall, results indicated that participants who received *both* the CHILD and the PEER interventions made the greatest gain in social network salience (SNS) with a large effect size. However, it seemed that the PEER intervention caused greater movement than the CHILD intervention toward a central role in the classroom social network in a shorter time period and that this improvement was maintained at the 12-week follow up. Participants assigned to the peer mediated intervention were more involved with their peers on the playground and scored higher on measures of teacher perception of social skills.

What do the results mean?

These results suggest that social skills interventions can be delivered effectively in public schools and with the involvement of typically developing models. The authors suggest that these schoolbased, peer-mediated interventions may be preferable to the two of the most common alternatives: conducting social skills training off-site (in a clinic setting) or assigning a one-to-one aide to support students at school. Currently, the most common

social skills interventions are one-to-one instruction with an adult and child-mediated. These results suggest that children may not generalize the social skills they learn in a one-on-one context with an adult to interactions with their peers. Several points are worth noting in regards to these findings. Reciprocal friendship ratings did not change from baseline to post-treatment. Although children exposed to the PEER mediated intervention were more likely to be nominated as a friend by their classmates after treatment, the participants themselves were unlikely to nominate their peers as friends. A similar phenomenon was observed when examining engagement on the playground. Although individuals randomized to the PEER intervention were less likely to engage in solitary play and more likely to be involved with their peers, no such gains were seen in students receiving the CHILD intervention alone. Both of these findings suggest that reciprocal friendships and playground engagement may be more complex skills that require a more intensive and specific intervention. However, the study indicates that short-term interventions can help children with autism join peer networks.

Brief report: Effect of a focused imitation intervention on social functioning in children with autism.

Reviewed by: Sarah Luem, Rutgers University

Ingersoll, B. (2012). Brief report: Effect of a focused imitation intervention on social functioning in children with autism. *Journal of Autism and Developmental Disorders*, 42(8), 1768-1773.

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Why research this topic?

Imitation is a skill that emerges early in life and plays a critical role in typical social development. Because children with autism exhibit deficits in both early imitation and subsequent social behavior, teaching imitation to children with autism may ultimately improve social functioning. Reciprocal Imitation Training (RIT) is a child-led, play-based imitation intervention for children with autism. Research has shown RIT is effective for increasing spontaneous gesture and object imitation in this population, and one study found secondary improvements in coordinated joint attention (looking back and forth between an activity and an adult) for most of the study's participants. However, it was unclear whether gains in imitation were responsible for these improvements in joint attention.

The purpose of the present study was to investigate whether RIT leads to improvements in social functioning in children with autism. The researchers examined two indicators of social functioning: Initiation of joint attention and parent reports of their child's social-emotional skills. Additionally, the researchers examined whether improvements in social functioning were the result of RIT's effect on participants' imitation skills.

What did the researchers do?

Twenty-seven children diagnosed with autism between 27- and 47- months participated in the present study. Participants were randomly assigned to the treatment group or a control group. Children in the treatment group received three hours of RIT per week for 10 weeks. Children in the control group received treatment as usual in the community. Children in both groups continued to receive their existing educational services throughout the study, which included special education, speech therapy, occupational therapy, and in-home applied behavior analysis. All children received the

same type and amount of these services.

Treatment took place in a small room with pairs of identical play materials. To promote reciprocity, the therapist contingently imitated the child's verbal and nonverbal behaviors and expanded the length of the child's utterances. The therapist also used simplified language to describe the child's behavior. To teach imitation, the therapist modeled an action approximately once per minute while also verbally describing the action. The therapist modeled the action a maximum of three times: if the child did not imitate the action within 10 seconds of the third model, the therapist physically prompted the child to imitate the behavior. After imitation, the therapist praised the child and returned to promoting reciprocity through contingent imitation and describing the child's actions.

The researchers measured participants' initiation of joint attention using the Early Social Communication Scales (ESCS). The measure was administered at pre-treatment, post-treatment, and two-to three- month follow-up. The Social-Emotional Scale of the Bayley Scales of Infant Development, 3rd Edition was used to measure participants' social and emotional development (e.g., selfregulation, communicating needs, establishing relationships, etc.) according to parent reports. This measure was administered at pre-treatment and at follow-up. Lastly, the researchers used the Motor Imitation Scale and the Unstructured Imitation Assessment to measure each child's motor and gesture imitation skills at pre- and post- treatment. Results from these last two scales were used in the mediation analysis.

What did the researchers find?

The researchers found that children who received RIT made significantly greater gains in their initiation of joint attention than children who did not receive RIT. These gains were maintained at twoto-three month follow-up. Additionally, children in *(Continued on page 25)*

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the treatment group made significantly greater improvements in social-emotional functioning than the control group, as measured by parent reports at follow-up. The mediation analysis revealed that improvements in imitation were not responsible for the treatment's beneficial effect on social functioning. As a result, the researchers argue that RIT's effects on imitation recognition, rather than imitation production, may partially account for gains in social functioning. Future research is needed to dismantle RIT and determine which treatment components affect social functioning.

What are the strengths and limitations of the study?

Several limitations to the present study are noted. First, parents, therapists, and examiners were not blind to the children's treatment conditions, which may have affected their expectations. Next, although all children received the same type and amount of services outside of their group assignments (i.e., speech, occupational therapy, special education, and ABA), the two groups may have differed in the types of skills that were targeted during these services, as well as treatment strategies. Also, the study enrolled a fairly small sample size, and results may not be generalizable to other groups of children with autism. Finally, although treatment gains were observed at two-to-three month follow-up, longer-term gains were not measured in this study. Despite these limitations, the findings suggest that RIT—a focused, low-intensity, and brief imitation intervention—can significantly improve social deficits in children with autism.

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