

NEWS & UPDATES FROM THE Center for Autism & Related Disorders AT KENNEDY KRIEGER INSTITUTE



Center for Autism and Related Disorders
at Kennedy Krieger Institute
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We ROARed for Kids and for Autism!

On April 29th, more than 1000 people registered to run, walk, or support Kennedy Krieger in the annual ROAR for Kids event. We raised over \$130,000 to support research and programs for kids here at the Institute. The Center for Autism and Related Disorders (CARD) Dream Team was well represented, raising almost \$5000 for our center! If you didn't join us this year, we hope to see out out there with us next year!



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CARD staff and friends enjoyed creating unique art at the 3rd annual Paint for Autism Night on April 14th!



A Word from Our Director

Dear Friends,

It is hard to believe that 2017 is nearly half way 'over'! Time has flown by for us CARD. During the winter and spring months, we have been busy sharing in the lives and hope of the families who receive care through CARD. This is by far the most fulfilling part of our work. In addition, we've been busy disseminating knowledge and skills to parents, professionals, and policy makers. We are just wrapping up a research study involving child care providers in Baltimore and some of the children with developmental delays for whom they care. This study involved training, through workshops and on-site coaching, the providers to use elements of the Achievements intervention approach during Circle time in their classrooms. The aim was to increase the rate and depth of learning of all the children, with a special emphasis on the children with language and social delays or Autism Spectrum Disorder (ASD). The feedback from the providers was incredible- they felt that this training was unlike anything they had ever experienced before and that they became equipped to help children learn in an exciting and powerful new way. As soon as the data about their instructional methods and children's learning are available, we will submit our findings for peer review in a highly respected journal, and then share the results with you.

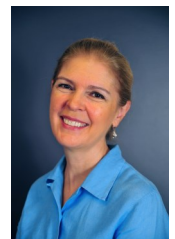
We will launch a study this summer to evaluate a new, video-guided screener for social-communication delays and ASD. Stay tuned for more information on that!

Our staff is growing, enabling us to do more for children and families. This summer and fall, we welcome two new child and adolescent psychiatrists, four new psychologists and seven new speech-language pathologists, and an epidemiologist/informatics expert. We continue to seek neurodevelopmental or developmental behavioral pediatricians for our team, so spread the word to potential candidates.

I wish all of you a lovely summer, and hope to see you at our annual conference October 12-13.

Warm Regards,

Rebecca Landa



What Does My Child Need? It's Hidden in Plain Sight!

By Jen Horton, LCSW-C

All parents struggle at some point with questions like “Why is my child behaving like this?” “What does my child need?” and “What can I do?” Circle of Security (COS), acting on decades of research about parent-child relationships, helps parents make sense of their children’s needs, so that parents can help their children successfully manage their own emotions. CARD therapists use the COS Parenting program to support caregivers in strengthening their relationships with their children and in developing a different understanding of their children’s emotional world and needs.

The COS Parenting program is offered at CARD in individual, couples and group therapy formats. At eight to 12 weeks long, the program is considered short-term treatment. COS group meetings of parents of children with ASD often take place on weekday mornings. For individuals and couples, there may be flexibility to attend sessions on weekday mornings, afternoons or early evenings. You do not need to bring your child with you to any of the sessions. COS is most appropriate for parents of children between the ages of 2 and 10 years old.

Here’s what parents who have participated in the COS Parenting program have to say about it:

“COS has helped me to understand my children better and to be able to help them cope with their feelings and emotions in a positive way. I am very glad for classes like these because they really open up your perspective as a parent. It’s great to be able to fill your children with love, understanding and support, and then be able to watch them go out into the world and then come back to you.” – C.R.

“I have found COS to be so valuable, for the sake of my children and for myself as I strive to be the best parent and human being I can be. Interacting with other parents who face similar challenges, as well as working with facilitators who care so deeply about each participant, was of great benefit, and the curriculum itself outlined truths and strategies that can be applied to virtually any relationship in life. This course has given me so much, and I am forever grateful to CARD for the opportunity to be more mindful and less stressed in my approach to parenting.” A.S.

If you are interested in learning more about COS or participating in the COS Parenting program individually, as a couple or in a group, please contact Jen Horton, LCSW-C, clinical social worker, at 443-923-7529, or Kate Johnson, MA, psychology associate, at 443-923-4151.

Feeding Problems in Children With ASD

By Beth Nottingham, CCC-SLP, CLC

Did you know that Leo Kanner, one of the first medical professionals to write about ASD, included feeding problems as a feature of this disorder? Did you also know that recent estimates suggest that 70 percent of children with ASD also have challenges with eating? A report published by Autism Speaks recently highlighted several health conditions that accompany ASD. One of the six topics covered was feeding and eating problems, and the related topic of gastrointestinal (GI) upset was also explained.

Feeding Problems in Children With ASD *(Continued from Page 3)*

Most children can be picky eaters at times. Usually, these issues resolve on their own with time. However, children with ASD may have difficulties that go beyond typical picky eating and may be related to features inherent in the disorder. Some children with ASD may only eat a certain brand of a food. Children with ASD tend to like routine and sameness. This can lead to resistance to trying new foods and exploring different food groups, which can make it tricky to develop a healthy diet. It can be difficult to identify when the picky eating habits of a toddler or child become a problem requiring extra help. Some of the red flags to look for include:



- Meals that take longer than 30 minutes
- A child who eats less than 20 different foods
- A child who stops eating foods that he or she used to enjoy
- A child who has difficulty eating age-appropriate textures (for example, he or she may continue to rely on pureed food)
- A child who limits the range of food groups he or she consumes (for example, he or she doesn't eat any fruits or vegetables or relies only on starchy carbohydrates or excessive milk intake)
- A child who melts down at the sight of new or non-preferred foods
- Mealtimes are a battle due to the child's feeding challenges

Having a child who has difficulty with eating can be stressful, and it can impact the entire family. If your child exhibits any of the above characteristics, he or she may benefit from feeding therapy with a trained provider. Kennedy Krieger Institute offers several options for the treatment of problem eating behaviors. If you are concerned that your child may need some help, please discuss your concerns with your provider, who can share options for evaluation and treatment at the Institute.

Free Upcoming STAR Trainings

Life Skills Program at CARD

Wednesday, Aug. 23, 11:30 a.m. to 12:30 p.m., presented by Sarah Welch, MS, OTR/L; and Zaneta Liu, MS, CCC-SLP

Getting an Autism Spectrum Disorder Diagnosis: Where Do I Go From Here?

Monday, Sept. 25, 9:30 to 11:30 a.m., presented by Cathy G. Groschan, LCSW-C

What Is Transition Planning for a Teen With an ASD Diagnosis?

Monday, Sept. 25, 1 to 3 p.m., presented by Cathy G. Groschan, LCSW-C

For more information or to register, visit

KennedyKriegerCARD.eventbrite.com.

'But I Want Him to Talk!' Augmentative Communication and Its Impact on Speech Development and Overall Communication (Part 2)

By Fatima Salem, MS, CCC-SLP, and Melissa Subock, MS, CCC-SLP

In our April 2017 issue, we covered the benefits of Augmentative and Alternative Communication (AAC) devices for children with ASD. Here are the stories of two CARD patients and their families. In the stories, we discuss everything from making the decision to use AAC to the struggles and benefits the families have encountered in the process.

Shannon came to CARD before his second birthday. He was evaluated by a multidisciplinary team of professionals and was found to have delays in language and fine motor development. He was also diagnosed with ASD. At the time, he did not use any words and communicated mostly through his behavior. Following his diagnosis, his parents were determined to provide him with all the services and supports he could get. He was enrolled in individual speech therapy at CARD and received services through his local early intervention program. When he turned two, he began attending the Early Achievements Program.

Over the next ten months, Shannon made considerable progress in his understanding of language and in his social development. He learned to use the Picture Exchange Communication System (PECS) like a pro! Even with all of the intensive intervention, he still struggled with verbal communication, and his speech was very limited. He was becoming increasingly frustrated with his difficulty communicating. Knowing his potential, his therapist referred him to another speech pathologist at CARD to see if he was a candidate for an AAC device. After several sessions, it was clear that an AAC device would be the perfect fit for Shannon. He received his AAC device and very quickly learned to use it. He had so much to say!



Melissa Subock, MS, CCC-SLP, programs an AAC device

Since then, Shannon has been using his device in the Early Achievements Program, his other therapies and at home to communicate and interact with his therapists, family and peers. When the program's fall session started, something amazing happened: Shannon started talking! He quickly learned phrases and sentences, likely because of his experience putting words together on his AAC device. He still uses his device when others have difficulty understanding him, but he now prefers to communicate verbally.

Dennis also started his journey with AAC at CARD. In June 2015, Dennis enrolled in the Early Achievements Program. He had a previous diagnosis of ASD and apraxia, and was, at that time, a non-verbal communicator. His difficulties with motor movements affected his ability to produce a variety of speech sounds, and he was only producing open vowel sounds (like "ahhh") and one consonant sound ("mmm"). Despite this, he demonstrated a great interest in communicating and found many alternative ways to communicate his messages.

Dennis used descriptive gestures, eye contact and eye gaze to make his needs known. It was very obvious that he had a lot to say and that he understood significantly more than he was able to express. Given Dennis' strong communicative intent, his clinician had him trial several low-tech options, including the GoTalk 20+. He mastered this program quickly, and soon it was time for Dennis to move to a more dynamic system that could grow with him and meet his increasing language skills.

In consultation with his parents, his team of school teachers and administrators, and his clinicians at CARD, Dennis was matched with the TouchChat WordPower 42 program, and his language use took off! After a few months, he had mastered combining up to three words to make short telegraphic phrases, moving on to using verb tenses, articles and pronouns to make complete sentences. Dennis' flexibility to formulate novel phrases increased as did the variety of the communicative intents he was able to express. He is now able to talk about past events, recall stories, and answer and ask a variety of questions. As his ability to communicate increased, so did his ability to make speech sounds. Dennis started producing a wider variety of consonant sounds. He began using the initial sound of the word he was communicating. He has since initiated PROMPT (short for Prompts for Restructuring Oral Muscular Phonetic Targets) therapy to focus on supporting his speech production in conjunction with his AAC device. He now uses total communication in the true sense of the word! He produces sounds, word approximations and descriptive gestures in conjunction with his device to make his full message known.

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"But I Want Him To Talk!" (Continued from Page 5)

Dennis' and Shannon's parents, Stephanie and Nicole, shared their thoughts with us about their experience introducing the devices to their children at such an early age and how it has impacted their son's communication.

Can you tell us a little bit about your child's communication before he started using the device?

Shannon's mom (SM): He was mostly just physical. When we were at home, he would drag me to the refrigerator or to the cabinet where his food was if he wanted a snack. Then we would try to find the PECS picture. He used that really well, the PECS. He was also very much frustrated. It was us saying, "no," and him throwing a fit. It was like him telling us "you can't understand what I'm trying to tell you," and he would get so mad. Then he would just start having a meltdown.

Dennis's mom (DM): It was more so with gestures and just pointing to things that he wanted. He was making loud noises but he wasn't trying to put words together.

What were your thoughts when the speech pathologist recommended the device?

SM: I was leery at first but I said, "If this is going to help, we need to try it, at least try. So I was definitely up for it."

DM: I liked it. He's nonverbal so that, to me, was his way of communicating. I liked the idea.

Were you worried that it would prevent him from communicating verbally?

SM: "At the very first thought, yes, but the more I read about it and the more [the speech pathologist] told me about it, I was open. I definitely wanted to try it."

DM: Yes. That was my only concern, really. Just making sure that he's not dependent on using his device and that he still wants to learn how to speak. That was my only concern.

How did those feelings change over time?

SM: "Oh, they changed right off the bat. He started using it so well and then he started [saying] 'buh-buh' and then the 'm' letter, then he starting [saying] different letter sounds and I was like, 'Okay, he's getting somewhere.'"

DM: I still have that feeling.

How did your child's communication change after he started using the device?

SM: Words started coming August or September 2016 and he was still having meltdowns but it wasn't like before at all.

DM: I see that he goes to [the device] a lot to communicate and he tries to use sounds now. He wasn't doing that before but now he's trying to put sounds together to make words and if that doesn't work then he'll go to his device. Before he was using it a lot but now he's weaning off of it because he's ready to wean off of it. Maybe the device helped him get ready to transition to talking. He'll try to say [a word] first and if he can't, I'll say, "Use your device," or he'll just go to the device on his own.

Do you feel your child benefitted from using the device? If so, how?

SM: Oh, one hundred percent. Definitely. I think it opened up and let him hear different sorts of sounds and how people said [them]. Not just looking at mom saying, "buh-buh," all the time. He could finally hear them [from somewhere else]. We [programmed the device] in a child's voice because we thought it would be more similar to him and I think it really helped him hearing it all the time and him [initiating] it."

What is one thing you would want to tell the parent of a child who was recommended to use an AAC device?

SM: I would just want them to know that it is beneficial for a child that's nonverbal because it helps them to communicate and get out what they are trying to say. I can only imagine it's frustrating when you're trying to speak and you can't get the words out so the device helps that to happen. I would highly recommend it if there's a parent out there that's a little hesitant about getting it for their child.

Is there anything else you'd like us to know?

SM: Just, I don't know where I'd be without you guys.

**Questions or Comments? Please email:
CARDnewsletter@KennedyKrieger.org**