

Center for Autism & Related Disorders



Center for Autism and Related Disorders
at Kennedy Krieger Institute

June 2021

CARD Clinic Update

What's New at the Clinic

By **Melanie Pinkett-Davis, MSW, LCSW-C**, and **Ericka Wodka, PhD, ABPP-CN**

There are some exciting updates to announce at the Center for Autism and Related Disorders (CARD) this spring. **Melanie Pinkett-Davis, MSW, LCSW-C**, who has been CARD's clinical director since 2011, is expanding her leadership role within Kennedy Krieger Institute and is now the Institute's assistant vice president of clinical services. She will carry cherished memories of her time at CARD with her as she transitions to her new position. We congratulate her and welcome **Ericka Wodka, PhD, ABPP-CN**, to the role of CARD's clinical director. Dr. Wodka is a board-certified pediatric



Dr. Ericka Wodka

neuropsychologist who has worked closely with CARD's leadership since 2013 as the supervisor of CARD's neuropsychology team. She was a Kennedy Krieger fellow from 2006 to 2008 and joined the CARD faculty in 2008. She completed her undergraduate studies at the University of Maryland, College Park and earned her doctorate at Drexel University.

In addition to the administrative duties she will perform in her role as clinical director of CARD, Dr. Wodka will continue to provide clinical evaluations for children with autism spectrum disorder (ASD). She will remain active in Kennedy Krieger's mentoring programs and will participate in neuropsychology training programs for externs, predoctoral interns and postdoctoral residents. Dr. Wodka holds a faculty appointment at the Johns Hopkins University School of Medicine, and her broad research interests include examining the cognitive and behavioral aspects of neurodevelopmental disorders specifically related to brain-behavior relationships involving attention and language. Dr. Wodka is currently collaborating with researchers at Kennedy Krieger on projects examining the cognitive and neuroanatomical aspects of motor and sensory difficulties observed in children with ASD and their relation to attention.

Outside of work, Dr. Wodka enjoys running, cooking and spending time with her family. She is a Baltimore native and remains dedicated to serving the community so close to her heart.

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Director's Corner

A Letter From Rebecca Landa, PhD, CCC-SLP

Hello everyone!

With the start of summer, we celebrate increased opportunities for children, teens, and families to enjoy the outdoors and a range of leisure and learning activities!

This is an exciting time at the Center for Autism and Related Disorders (CARD). We've had a transition in our clinical leadership, welcomed numerous new staff members who bring exciting new talent to our group, transformed the Friends of CARD group, and we're starting six new major research and training initiatives between now and September. Only a team as seasoned and expert as ours could accomplish all of this!

This year, CARD faculty were awarded three foundation and three federally funded grants. The science that will be conducted through these grants range from use of high-tech methods (EEG, machine learning) to community-based education research. The high-tech projects will advance understanding of information processing and early social communication differences in infants with high likelihood of autism spectrum disorder (ASD) or language delays. The other projects focus on examining access to COVID vaccines in youth with developmental disabilities, comparing telehealth to in-person early intervention approaches, and investigating the effects of training teachers to use evidence-based approaches to improve literacy learning in students with language disorders. We stay on the cutting edge of care and research for you, and to expand the capacity of our clinicians, researchers and community members to improve access to high-quality collaborative services for neurodiverse individuals and their family members. Our partnerships with neurodiverse individuals, families and colleagues, locally and globally, are key in achieving our high-impact goals.

Over the past several months, we offered our Winter and Spring Training Series free of charge. In May, CARD faculty members presented three panels and five posters at the annual meeting of the International Society for Autism Research (INSAR). We also expanded European researchers' understanding of how ASD develops from infancy through an invited presentation I gave to a cutting-edge group of European researchers on June 3. Virtual training opportunities such as these allow us to advance the innovation and impact of our work around the world.

We will keep you updated on our work and team through our newsletters and website—visit [KennedyKrieger.org/CARD](https://www.kennedykrieger.org/CARD) for more information. As always, thank you for your support!



Best wishes for a wonderful summer,

Rebecca Landa, PhD, CCC-SLP
Founder and Executive Director, Center for Autism and Related Disorders
Vice President, Kennedy Krieger Institute

Neurodiversity Webinar Series

Discussing Ableism, Autism and Neurodiversity with Zosia Zaks

By Betsy Cross, PhD

At the Center for Autism and Related Disorders (CARD), one of our core values is embracing neurodiversity. This is evident in every aspect of our service delivery, hiring practices and research. This past spring, CARD staff members participated in four training sessions led by Zosia Zaks, MEd, CRC, an autism spectrum disorder (ASD) self-advocate, parent and manager of programs and education at the Towson University Hussman Center for Adults with Autism. Zaks teaches unique undergraduate diversity education courses and has developed and implemented various programs for students and adults with ASD. He's also conducting research and developing best practice guidelines for working with neurodiverse and gender-diverse teens and adults.



Zosia Zaks

During the training sessions he led at CARD, Zaks discussed the neurodiversity model of care, where autistic individuals' traits are embraced as human diversity. Each individual's unique skills, interests and specialized expertise are viewed as being enriching to society.

The neurodiversity model contrasts with the traditional medical model in which disability is viewed as something to be fixed or cured.

With the neurodiversity model, treatment is focused on helping a child or adult reach their individual goals, rather than focusing on "normalizing" them. For example, acknowledging others during social interactions may be an important foundational step for goals related to forming friendships or engaging in meaningful employment. However, this does not necessarily have to focus exclusively on the societal norm of making eye contact; a treatment goal could focus instead on acknowledging others through body orientation, vocalizations and/or eye contact. Zaks also emphasized that treatment goals should be individualized for each patient, considering the patient's interests, culture, values and dreams.

CARD staff members will continue to learn from the ASD community as part of providing meaningful services that emphasize each individual patient's strengths, interests and values.

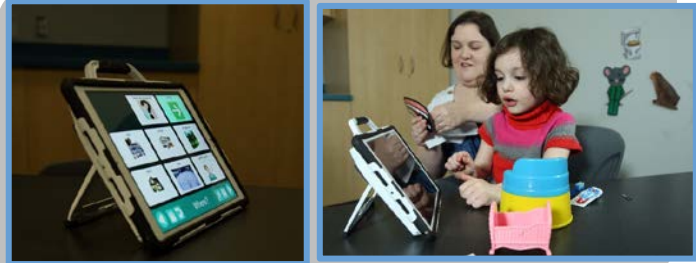
All About AAC

Why an AAC Device Can Be an Important Tool

By Melissa Subock, MS, CCC-SLP

Augmentative alternative communication (AAC) refers to all forms of communication other than verbal speech. Examples of AAC include gestures, facial expressions, written communication, picture-based communication supports (e.g., Picture Exchange Communication System, topic boards, etc.) and voice output devices. Many people use AAC throughout their day to support their verbal communication. Using AAC with individuals with autism spectrum disorder (ASD) can be particularly useful.

Research indicates that approximately 30% of people with ASD do not use verbal speech as a primary means of communication. At the Center for Autism and Related Disorders (CARD), we strive to use AAC supports as early as the need is indicated to give our patients the best opportunity to achieve their communication and interaction goals. Our team of interventionists introduces PECS, topic boards and voice output devices, in addition to classroom-wide AAC systems, to help our patients participate in their intervention programs, interact with their peers and therapists, and communicate more effectively in home and community settings.



There are many benefits to using AAC supports for people with ASD at all ages. When children are young, providing tools that can support emerging verbal communication can have the positive impact of decreasing behavioral difficulties that are rooted in communication-related frustration. Being able to use AAC supports to indicate a need, request a break or even simply say “I’m mad” can help young children express themselves through positive communication and avoid meltdowns. With increasing age and greater opportunities to interact with peers, AAC supports can help children and youth participate actively in social interactions in the classroom, on the playground and during playdates. Teenagers and young adults can use AAC to help build independence by increasing participation in daily living activities and job skills.

We know from research that AAC supports do not hinder verbal communication development. In most cases, verbal communication improves after consistent implementation of AAC supports. Because of this, clinicians at CARD regularly assess whether AAC may help support the development of communication and interaction skills, and tailor AAC interventions to the identified needs.

Family Profile

A Family’s Decision to Use AAC, and the Struggles and Benefits Encountered

By Melissa Subock, MS, CCC-SLP

Names have been changed to protect patient privacy.

Shannon came to the Center for Autism and Related Disorders (CARD) before his second birthday. An interdisciplinary team of professionals evaluated him, identified delays in language and fine motor development, and diagnosed him with autism spectrum disorder. At the time, Shannon did not use any words and communicated mostly through behavior.

After Shannon was diagnosed, his parents were determined to provide him with as many services and supports as possible. They enrolled him in individual speech therapy at CARD, and a local early intervention program provided him with additional services. When Shannon turned two, he began attending CARD’s Early Achievements Program. Over the next 10 months, Shannon made considerable progress in understanding language and social development. He learned to use the Picture Exchange Communication System (PECS) like a pro! But even with all of the intensive intervention, he still struggled to communicate verbally, 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-language pathologist at CARD to see if he was a candidate for an augmentative alternative communication (AAC) device. After several sessions, it was clear that an AAC speech-generating 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! Shannon began using his device in the Early Achievements Program, his other therapies, and at home to communicate and interact with his family members and peers. When the fall Achievements session began, Shannon started talking! He quickly learned phrases and sentences, likely because of his experience in putting words together on his AAC device.

Today, Shannon is in the third grade and prefers to communicate verbally. He was recently discharged from speech and language therapy because he no longer needs the services. He is an excellent student who enjoys making animations in his free time.

The Parent Perspective

Shannon’s mom, Stephanie, shared her thoughts with us about her experience introducing the AAC speech-generating device to her child at such an early age and how it has affected her son’s communication.

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

(Cont. on page 4)

Stephanie: 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 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.

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

Stephanie: 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.

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

Stephanie: At the very first thought, yes, but the more I read about it and the more [the speech-language pathologist] told me about it, I was open.

How did those feelings change over time?

Stephanie: 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 started [saying] different letter sounds, and I was like, “Okay, he’s getting somewhere.”

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

Stephanie: Words started coming the summer after he started using the device, and he was still having meltdowns, but it wasn’t like before at all.

Was it difficult to get it started? Was there anything you would change?

Stephanie: I had a harder time than he did learning how to use it. I wouldn’t change it but I would make a training class for parents, maybe. I would call the company that makes [the device], but they are techs and they don’t really want to sit there and explain every little thing to you over the phone. So we basically had to do everything on our own. I got the hang of it, but learning it at first was very hard. [Shannon] knew where everything was.

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

Stephanie: Oh, one hundred percent. Definitely. I think it opened [him] up and let him hear different sorts of sounds and how people said [them]. Not just looking at mom [and] 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?

Stephanie: I would tell them: “Definitely. You have to try it, because we have had such a good experience.”

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

Stephanie: Just, I don’t know where I’d be without you guys.

Friends of CARD Update Renewing Friends of CARD

By Megan McTaggart, MA, and Kyla Minton, BA

We’re excited to announce that an executive committee, made up of Center for Autism and Related Disorders (CARD) staff members and parents, is currently working on growing the Friends of CARD group and renewing the group’s operations after a pause initiated by the COVID-19 pandemic.

Founded in 2017, Friends of CARD was originally a parent support and CARD advocacy group and a source of connection, support and knowledge for families of CARD and the wider community. The group hosted several events, including an Early Achievements Program parent night, a research briefing and several CARD fundraisers.



Parents and CARD staff at a Friends of CARD research briefing in 2018.

For parents and families, the Friends of CARD group has always served an important purpose, and we’re excited to continue to be able to support families, promote research and develop our local and global network. The new Friends of CARD executive committee will expand upon the original group’s objectives and transform Friends of CARD into a more productive, rewarding and mission-driven entity.

For the last several months, the executive committee has been meeting two times per month to lay the groundwork for the redefined group and establish an organizational structure and goals. We’re excited to begin the process of opening Friends of CARD up to new volunteers! Please email **Friends of CARD** at FoC@KennedyKrieger.org if you or anyone you know is interested in joining. The group is looking for dedicated families and friends of CARD and community partners who can help us advocate for, promote and support CARD’s mission.

In the coming weeks, the Friends of CARD volunteer application will be available on the CARD website, and we’ll have more information to share about the group’s upcoming events. Let us know if you’d like more information!

Research Updates

Department of Defense Funded Social Communication Intervention for Toddlers with ASD

By Rachel Reetzke, PhD, CCC-SLP

The Center of Autism and Related Disorders (CARD) Director **Rebecca Landa, PhD, CCC-SLP**, and speech-language pathologist **Rachel Reetzke, PhD, CCC-SLP**, have been awarded the Department of Defense Congressionally Directed Medical Research Programs Autism Research Program Clinical Trial Award. They will conduct the first study to examine the efficacy of telehealth naturalistic developmental behavioral intervention (NDBI) parent coaching compared to in-person coaching.

The researchers will work with 188 parents, coaching each one to use NDBI strategies to support communication and social development in their toddler with autism spectrum disorder (ASD). If the telehealth intervention group gains are not less than those of the in-person intervention, this study's results could have a major impact on early intervention for ASD. Results could translate into increased accessibility and intensity of intervention for young children with ASD anywhere internet capabilities exist, especially for military or other families not located near qualified service providers or located in areas with few qualified service providers.

This research study includes:

- Questionnaires about each participating child and their parents
- Developmental assessments
- Random assignment to either virtual or in-person intervention sessions
- No significant risks associated with participation

For more information, email REACH@KennedyKrieger.org

Social, Communication, Interaction and Play Screener (SCIPS)

By Melissa Le Gette, MS

Our Research and Education for Autism in Children (REACH) lab is examining the effectiveness of the new video-guided developmental screening tool called the Social, Communication, Interaction, and Play Screener (SCIPS). Developed by **Rebecca Landa, PhD, CCC-SLP**, director of the Center for Autism and Related Disorders, the tool detects early social and communication delays in children 12 to 36 months old. Based on our research following the development of hundreds of children, from infancy to school age, we have specifically defined the early indicators of social and communication delays.

Using videos from our research assessments of 1- and 2-year-olds who did and did not show early signs of social and communication delays, we developed this screening tool, which is easy to use and understand. Parents can complete this screener online, using a smart phone, tablet or computer. Using the SCIPS, parents watch pairs of videos contrasting children with and without delays. As the videos play, they hear a voice-over explanation of the signs of typical development versus signs that indicate a possible delay. These video pairs and narration help parents accurately answer screening questions about their child.

This research investigates whether the SCIPS is easier for parents to use than other existing screeners, and whether the SCIPS is more accurate at detecting early social and communication delays than other screeners. To date, our research lab has enrolled 170 children 12 to 36 months old, including children whose parents are concerned about a social or communication delay (or even autism spectrum disorder), and children whose parents have no concerns about their child's development. Our hope is to make it easier for parents to recognize if their 1- or 2-year-old could benefit from extra enrichment or even early intervention. The SCIPS increases parents' understanding of child development and provides them with the language they need to effectively communicate their child's needs. We plan to make the SCIPS available for use by pediatricians, parents and professionals around the country.

We are currently offering a telehealth version of our SCIPS study protocol. Please contact **Melissa Le Gette** at LeGetteM@KennedyKrieger.org if you're interested in participating or receiving more information.

SPARK at CARD



SPARK is celebrating its fifth anniversary! The Center for Autism and Related Disorders is a proud member of SPARK: Simons Foundation Powering Autism Research for Knowledge, the largest research study of autism spectrum disorder (ASD) ever. SPARK's mission is simple and vital: to speed up research on and advance our understanding of ASD. Visit sparkforautism.org or email **Megan McTaggart** at McTaggart@KennedyKrieger.org or **Kyla Minton** at Minton@KennedyKrieger.org to learn more.

SPARK | 5 YEARS OF SPARK

250,000
PARTICIPANTS
JOINED

Since SPARK launched in 2016, over **250,000** participants have joined.

SPARK | 5 YEARS OF SPARK

32
SCIENTIFIC
PAPERS

Since 2016, there have been **32 scientific papers** published using SPARK data.

Education News

How the Pandemic and Remote Learning May Have Affected Your Child's IEP

By Linda Myers, EdD, Hillary Stalknecht, MS, and Bonnie Van Metre, MEd, BCBA

The pandemic has been disruptive to many aspects of our lives. One area that has been significantly affected is education. In March of 2020, schools across the world closed their doors in an effort to combat COVID-19 and protect students. At that time, there was a necessary and unexpected shift to remote learning and distance education. Many school systems struggled initially with how to provide instruction to students during this period, and some students with an individualized education program (IEP) may not have fully received the free appropriate public education (FAPE) afforded to them by the law. The Individuals with Disabilities Education Act (IDEA) states that when students lose the supplementary services deemed necessary to them, compensatory services may be provided. In short, compensatory services are used to help students “catch up” in cases where they were not provided the FAPE they were supposed to receive based on the individualized needs identified in their IEPs.

The Maryland State Department of Education (MSDE) has released [a framework](#) for determining whether a student is due compensatory services as a result of their education being modified for an extended period of time. Some factors being considered include the amount of time school was closed during the COVID-19 pandemic, the length of time a student went without appropriate instruction, and the evaluation of a student's ability to catch up on progress toward meeting their IEP goals independently. In addition, schools are also considering what alternative services a student may have received and will look at any available data to determine their progress toward meeting their IEP goals. In some cases, children will not be provided compensatory services if their team feels they were not affected negatively by remote learning. Given how widespread the impact of the pandemic was, this is the first time the state has had to evaluate the need for compensatory services for such a large number of students. This will certainly be a complex process and will create the need for strong home-school collaboration.

Parents who would like to find out if their child is eligible to receive compensatory services related to the COVID-19 pandemic education modifications should first start a discussion with their child's IEP team. Teams will use data to determine if students have made progress or regressed over this time, so it will be important for parents to share their observations with the team as well as any data they might have. This could include completed work or projects. Other things to consider before meeting with your child's IEP team include what the current areas of concern are, what an appropriate compensatory service might be, and what supports are needed to access added services.

Stay Connected with CARD

CARD's Annual Autism Conference

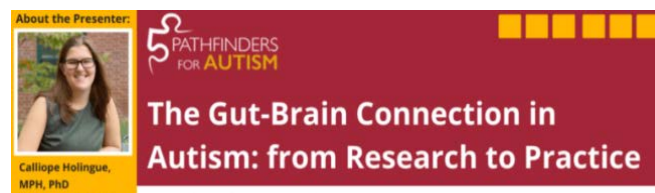
Save the date! The Center for Autism and Related Disorders' 20th Annual Autism Conference (CARDAAC) will be held this **October 7 and 8, 2021**. More information is coming soon.

Join our mailing list or visit us online at www.KennedyKrieger.org/CARDO Outreach to receive updates.

SPARK and Pathfinders for Autism Webinar Series

SPARK: Simons Foundation Powering Autism Research for Knowledge and Pathfinders for Autism have teamed up to host a series of webinars for the autism spectrum disorder (ASD) community. CARD's own genetic counselor, **Alyssa Blesson, MGC, CGC**, presented the first webinar on Thursday, April 22, focusing on demystifying the journey to finding genetic links to ASD. The webinar was a big success, and it provided great information for the SPARK and Pathfinders communities. Thank you, Alyssa! A recording of the webinar is available [here](#).

The second webinar of this series will be held on **Tuesday, July 6, at 11 a.m.** **Calliope Hologue, MPH, PhD**, a CARD researcher, will present “The Gut-Brain Connection in Autism: From Research to Practice.” There will be a question-and-answer session with Dr. Hologue after the presentation. SPARK team members will also be available for support and to answer any questions participants may have about SPARK, the registration process and the saliva collection process.



Visit the [Pathfinders for Autism website](#) to register for “The Gut-Brain Connection in Autism.”

Supporting CARD

At CARD, we are changing lives. Won't you join us? Even a small contribution can have a huge impact. By making a **gift of just \$10 a month**, you'll help us **deliver meaningful support** to individuals with ASD and their families. Click [here](#) to join our club of dedicated monthly givers now.

CARD in the Community

CARD Partners With The Bryn Mawr School for Toy Drive

Recently, Director **Rebecca Landa, PhD, CCC-SLP**, completed a study funded by the National Institute on Deafness and other Communication Disorders focusing on an intervention for infants with social and/or communication delays. The Infant Achievements intervention was effective in improving the infants' social and communication development. Given the positive findings, Dr. Landa initiated the Infant Development Public Health Initiative (IDPHI), which is being coordinated by **Ebony Holliday, PhD**, a CARD researcher. Through this initiative, CARD is partnering with community organizations to make the Infant Achievements program accessible to under-resourced and underrepresented families.

In April, CARD staff members on the IDPHI team met with several students from The Bryn Mawr School, a girls' school in Baltimore. The students helped coordinate a toy drive for the IDPHI and delivered the toys to CARD at Kennedy Krieger Institute's Greenspring Campus!



The students also had the opportunity to discuss the project with Dr. Holliday, and they asked focused and thought-provoking questions. The CARD team is excited about growing the relationship with the students at The Bryn Mawr School and providing them with opportunities to engage with innovative researchers and have a meaningful impact on society.

CARD Team Provides Virtual Training for Hawaii Professionals

Throughout March and April, several CARD clinicians provided virtual training to the Hawaii Maternal and Child Health (MCH) Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. The goal of the training was to provide additional expertise in autism spectrum disorder (ASD) evaluation and treatment.

The trainees in the Hawaii MCH LEND Program represented a variety of disciplines, including pediatrics, speech-language pathology, occupational therapy, social work, dentistry and others. Training activities included an expert panel discussion moderated by **Kate McCalla, PhD**, CARD's assistant director for clinical operations, and featured CARD clinicians. The training also included a virtual tour of CARD, in-depth clinical discussions, and reviews of interdisciplinary evaluations and treatments.

The topics highlighted during the training sessions led to thoughtful discussions about family-centered services, barriers to accessing specialty services, conducting evaluations with bilingual patients, and other important topics. There was unanimous agreement from the CARD and Hawaii MCH LEND teams that this promises to be the start of a long-lasting collaboration, despite the distance between the sites!

Special Kudos!

Dr. Rebecca Landa Selected for INSAR Award

We congratulate Director **Rebecca Landa, PhD, CCC-SLP**, for being selected by the International Society for Autism Research (INSAR) as its 2021 fellow. This award honors researchers who have made significant international impact on the scientific understanding of autism spectrum disorder, clinical practice and/or policy. This award demonstrates the international community's recognition of Dr. Landa's impact worldwide. Congratulations, Dr. Landa!

ROAR Recap

Did You Catch Us At ROAR This Year?

For the first time, the Center for Autism and Related Disorders (CARD) hosted a hybrid ROAR for Kids event, with both in-person and virtual activities. The weeklong celebration included a virtual yoga class, a virtual pep rally, a drive-through CARNival at Kennedy Krieger Institute's Greenspring Campus, and other fun and engaging events for CARD's patients and their families. Thank you to everyone who participated and volunteered. You helped make ROAR an outstanding event in 2021. Check out some pictures from the drive-through CARNival below.

