

# Center for Autism & Related Disorders



Center for Autism and Related Disorders  
at Kennedy Krieger Institute

February 2021

## Clinic Update

### What's New at the CARD Clinic

We are pleased to share that the assessment, evaluation and treatment services offered at the Center for Autism and Related Disorders by our interdisciplinary team of professionals continue to be available for families. In March of 2020, we transitioned 90% of our clinical activities to a telehealth model, and we're using that model to continue to serve patients ranging from infancy to young adults.

We take patient and family privacy and security very seriously, and we only use HIPAA-compliant corporate videoconferencing accounts for the delivery of our telehealth services. The telehealth platforms that we use are far more secure than personal videoconferencing accounts.



It is important for families to know that our professionals continue to coordinate with one another closely to provide the highest possible quality of patient care. We continue to expand our team of professionals to serve as many patients as possible. And, we recently welcomed several exceptionally well-qualified licensed nurse practitioners to our team of medical providers.

In addition to offering services via telehealth, we have remained open for on-site services. Universal masking protocols are in place for all Kennedy Krieger Institute employees. Additionally, clinical providers are required to wear both a face mask and a face shield. All visitors and patients are provided with a cloth or procedural mask when they arrive at our building. We are adhering to guidelines and recommendations published by the Centers for Disease Control and Prevention in our housekeeping procedures and to reinforce social distancing.

### Director's Corner

Page 2

### Family Spotlight and Winter Training Series

Page 3

### Quarantine Tips

Page 4

### Equity, Diversity and Inclusion at CARD

Page 5

### "CLUB" at CARD

Page 6

### Research Update and Life Skills

Page 7

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## Director's Corner

### A Message From Dr. Rebecca Landa, CARD's Executive Director

As we enter 2021, I'm delighted to send my warmest greetings to you. The past 11 months have been transformative for the world. While the hardships have been widespread, the amount of resilience I've seen in people has been truly inspiring. I've been grateful for the amount of genuine compassion, kindness and creativity in people. For the autism spectrum disorder (ASD) community, the team at Kennedy Krieger Institute's Center for Autism and Related Disorders (CARD) has pulled out all the stops to do the impossible upon the onset of the COVID-19 pandemic. Beginning on March 15, we had to shift most of our clinical care to a telehealth model and stop all face-to-face research and training meetings with families and community providers. We rolled up our sleeves and designed many innovative ways to ensure high-quality, personalized care for our patients, support teachers in the community, and make high-impact discoveries in our research program. This newsletter offers a brief peek into our efforts, which we believe will bring help and hope to many in 2021.

In the clinic, we created innovative and effective ways of conducting assessments and interventions. Close collaboration between our eight clinical disciplines, intake and triage specialists, Care Center, and administrative teams enables patients and their families to have their needs met. We work with families to explain what will happen in telehealth clinical care, how to practice connecting with their clinician remotely, and how to prepare their child and their home to achieve the goals of the telehealth session. We have established systems to enable clinicians to observe physical and behavioral features that are informative for diagnosing ASD and determining need for other types of assessments. Creatively designed visual scenes on the Zoom screen and the use of carefully selected videos and communication icons/pictures when appropriate support new learning in children and youth. Even group intervention sessions are offered! Families have been very satisfied. Some services are provided on-site, with lots of infection control in use to protect everyone's health.

In the Research and Education for Autism in Children (REACH) research program, all face-to-face visits were stopped in March 2020. Recently, some such visits have resumed, with our infection control protocols strictly enforced. To keep the discovery process moving forward, the REACH team coded more than 2,500 videos of teacher or child behavior and entered data about the behavior in databases for statistical analysis. Many important findings emerged. We are now sharing those findings around the world through virtual talks and peer-reviewed, published manuscripts.

In our Outreach and Training program, support to parents, teachers and other professionals is provided via Zoom. Through a new web-based platform, our trainees are able to upload videos for us to view and insert moment-to-moment supportive and constructive feedback linked to specific events unfolding in the video. In follow-up Zoom meetings, the feedback is discussed and action planning occurs. The effectiveness of this approach is uplifting for the recipients.

In addition to the work described above, all CARD staff members have engaged in intensive equity, diversity and inclusion training and quality improvement activities. We've gathered and implemented new materials and resources, we're providing forms and services in other languages (e.g., Spanish), and we've established employment initiatives to further diversify our staff.

All members of the CARD team are fully committed to making meaningful differences in the lives of individuals with ASD and their family members. If you made a gift of any size to CARD last year, we appreciate your generosity. Every gift makes a difference, enabling us to find new ways to detect ASD and anxiety earlier, to help children who are minimally verbal communicate more effectively, to understand sensory processing and motor functioning in individuals with ASD, to help teens prepare for their transition to adulthood, and much more.

Thank you!

Warmest wishes for a healthy and happy 2021.



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

## Family Spotlight

### The Hybrid Experience

Dr. Elgiz Bal Sener recently evaluated a wonderful young man, Jack,\* who has autism spectrum disorder (ASD) and will soon be transitioning to adulthood. To minimize safety concerns during the COVID-19 pandemic, Dr. Sener completed an interview with Jack and his parents via telehealth, during which she learned more about their concerns and expectations for the evaluation. Specifically, Jack's parents wanted to gain a better understanding of his strengths and needs, as well as receive guidance on how to help Jack better plan for his future. For example, Jack's parents wanted to know if Jack should pursue postsecondary education or vocational training, and what barriers existed to Jack being independent.

Following the interview, Dr. Sener completed a face-to-face evaluation of Jack in the clinic while wearing personal protective equipment. She assessed Jack's intellectual, language, adaptive, attention/executive function and functional academic skills. The evaluation also provided some insights into Jack's emotion/behavior regulation difficulties. Dr. Sener used this information to help Jack's parents better understand Jack's cognitive difficulties and the impact of these difficulties on his independent living skills. Collectively, the evaluation documented Jack's developmental disability (ASD) along with his cognitive challenges, adaptive functioning needs, and need for coordinated care, all of which are required to obtain services from the Developmental Disabilities Administration (DDA). This information also helped identify a career path that maximizes Jack's strengths.

*Dr. Elgiz Bal Sener is a neuropsychologist. She serves on a committee established by Kennedy Krieger Institute's Department of Neuropsychology, the Maryland Center for Developmental Disabilities, the Intellectual and Developmental Disabilities Research Center at Kennedy Krieger Institute and Johns Hopkins University, and the Maryland Developmental Disabilities Administration (DDA). Along with other members of the committee, she provides final disposition decisions to the DDA as well as consultation regarding rare cases.*

\*The patient's name has been changed for confidentiality purposes.



## Winter Training Series

### Hosted by Kennedy Krieger Institute's Center for Autism and Related Disorders

Join Kennedy Krieger Institute's Center for Autism and Related Disorders (CARD) beginning February 16<sup>th</sup> for the CARD Winter Training Series, a virtual event for education, clinical, and research professionals working in the autism spectrum disorder (ASD) field, as well as for community members and family members of children with ASD.

The series will consist of live and on-demand sessions delivered by knowledgeable and engaging CARD clinicians and researchers. Professional event attendees will be able to earn continuing education units (CEUs).

Attendees may register for live or on-demand sessions individually, allowing for flexible learning as work and home schedules permit. All live sessions will occur on select **Tuesdays** from **11:30 a.m. – 12:30 p.m.** Each session will consist of a 45-minute presentation and a 15-minute Q&A segment. After a session is presented live, it will be available on demand.

#### Sessions:

- “**Behavioral Strategies to Support Students With ASD During Remote and Hybrid Learning**,” presented by Ebony Holliday, PhD, NCSP, school psychologist
- “**Early Intervention: Essential Things to Know About Play**,” presented by Rebecca Landa, PhD, CCC-SLP, founding and executive director of CARD
- “**Life Skills Program at CARD: A Collaborative Approach Between Occupational Therapy and Speech-Language Pathology**,” presented by Valeria Swartz-Diaz, MS, CCC-SLP, speech-language pathologist II, and Melissa Teitelbaum, MS, OTR/L, occupational therapist
- “**Managing Anxiety in Children and Adolescents With Autism Spectrum Disorder**,” presented by Roma Vasa, MD, director of psychiatric services at CARD
- “**Promoting Functional Communication: Thinking Within and Outside the ABA Paradigm**,” presented by Biji Philip, PhD, CCC-SLP, assistant director of clinical operations for CARD

Visit [KennedyKriegerCARD.Eventbrite.com](https://KennedyKriegerCARD.Eventbrite.com) for registration and updates!

# Quarantine Tips

## Resources to Help Your Family During Times of Uncertainty

From new routines to play ideas and communication supports, here are some tips and resources to help your family during quarantine.

### Routines:

Try to stick to typical daily routines, especially meal and sleep schedules, even if you are staying at home all day. Prepare your child for any changes in these routines by talking about these changes, marking appointments and events on a calendar, and/or using social stories.



### Behavior:

Maintain your typical expectations and rules, including following through with reward systems and other consequences.

### Communication Supports:

Social activities—even virtual ones—can have a positive impact on the development of your child's vocabulary and social skills during this time. Consider calling family members and friends on Facetime or Zoom with your child, and talk about what you do at your house and what they do at theirs. If your child uses a speech-generating device or picture-based communication system, make sure it is available and fully charged, with all of the pictures your child uses, at all times. Include words in your child's communication system that they may find useful during virtual activities.

### Play:

You can use play to help your child practice new situations! If you have an upcoming birthday or other holiday, practice giving and receiving gifts with your child with an empty gift box or bag. You and your child can take turns being the one to find a toy, put it in the box and give to someone, and being the one to take the gift, open it and show what's inside. Depending on your child's language goals, you could model or prompt simple comments such as "Here you go!" or "Happy birthday!" when giving, and "I like it!" or "Thanks!" when receiving. These simple phrases can also be programmed on your child's device.

### COVID-19 precautions:

If your child will need to wear a mask during medical appointments, travel or other activities, be sure to prepare for this. Practice wearing masks at home and putting masks on preferred stuffed animals or dolls. This can help your children feel more comfortable when they see family members and others wearing masks. You can also assist your child with getting prepared to wear a mask by helping them make one! They can decorate their own mask. Visit [abcyah.com/games/make-a-mask](http://abcyah.com/games/make-a-mask) for ideas!



# Equity, Diversity and Inclusion at CARD

Throughout the past year, Kennedy Krieger Institute has expanded programs and services that focus on diversity, equity and inclusion throughout the Institute. In August, Kennedy Krieger launched the Office for Health, Equity, Inclusion, and Diversity (O-HEID), led by Dr. Harolyn Belcher. Dr. Rebecca Landa, executive director of the Center for Autism and Related Disorders (CARD), and Dr. Garland Jones, a neuropsychologist at CARD, are on the O-HEID's leadership council. The new office is designed to promote the health and well-being of those who work, train and receive services at the Institute through culturally relevant, evidence- and equity-based approaches that assure diversity and inclusion.

In 2019, CARD created an Equity, Diversity and Inclusion (EDI) Committee to ensure these values are woven throughout all dimensions of the center. CARD leadership and staff members are actively defining initiatives, activities and resources to foster an environment of equity and inclusion in relation to patient practices and employee life. CARD's EDI Committee comprises staff members from various CARD departments and roles. All three CARD sites are represented on the committee.

## CARD's EDI Committee



CARD's EDI Committee comprises staff members from various CARD departments and roles. All three CARD sites are represented on the committee.

### Members of CARD's EDI Committee:

- Rebecca Landa, Ph.D., CCC-SLP, founder and executive director of CARD
- Melanie Pinkett-Davis, LCSW, director, clinical operations (Greenspring Campus)
- Jorge Granados, certificate in sustainable food and farming, certified bilingual clinician for Spanish, scheduling coordinator (Greenspring Campus)
- Mindy Cavendish, M.S., CCC-SLP, speech-language pathologist (Odenton Campus)
- Aishah AlFadhalah, M.S., CCC-SLP, speech-language pathologist (Greenspring Campus)
- Elgiz Sener, Ph.D., neuropsychologist (Ashland Campus)
- Fatima Salem, M.S., CCC-SLP, speech-language pathologist (Greenspring Campus)

## CARD's EDI Committee



### EDI initiatives underway at CARD:

- Committees within CARD departments meet regularly to define actionable and measurable plans to address issues of equity, diversity and inclusion related to increasing CARD's recruitment and retention of diverse staff members who reflect our patient population, ensuring that treatment and assessment materials (e.g., books, toys, artwork) reflect the diverse population we serve, revising policies and creating decision trees for referrals and service delivery to ensure equity of services to all patients, translating clinic materials into common languages, and identifying resources and speakers to educate CARD staff members on issues related to different communities. For example, Dr. John Strang, PsyD, director of the Gender and Autism Program at Children's National Hospital, presented a seminar on understanding gender identity in the autism spectrum disorder population.
- We created a resource library accessible to all CARD staff members that features trusted sources and materials regarding anti-racism, as well as treatment materials related to talking with children with special needs about race, protests and police interactions.
- All CARD departments are participating in a series of 14 workshops, facilitated by a doctoral-level psychologist consultant. Discussions are focused on the content of the "Seeing White" podcast, which explores the history of race in America.
- A Spanish-speaking diagnostic team has been established. Bilingual team members include an intake specialist, scheduling coordinator, speech-language pathologist, developmental pediatrician, psychologist and social worker.
- We distribute materials provided by the Johns Hopkins Office of Diversity, Inclusion and Health Equity to provide information about cultural observations and community events to celebrate diverse communities and promote community engagement.

As the CARD EDI Committee continues to work and grow, we hope to continue to create an environment that celebrates and embraces the diversity among us and promotes health equity and culturally-informed care for the patients we serve. We are aware that systemic racism exists across the U.S. and that this affects individuals from underserved communities. Through targeted efforts and education, we are working to create a more equitable and inclusive environment for all.

# Connecting Language Using Books (CLUB) at CARD

## “CLUB” at CARD

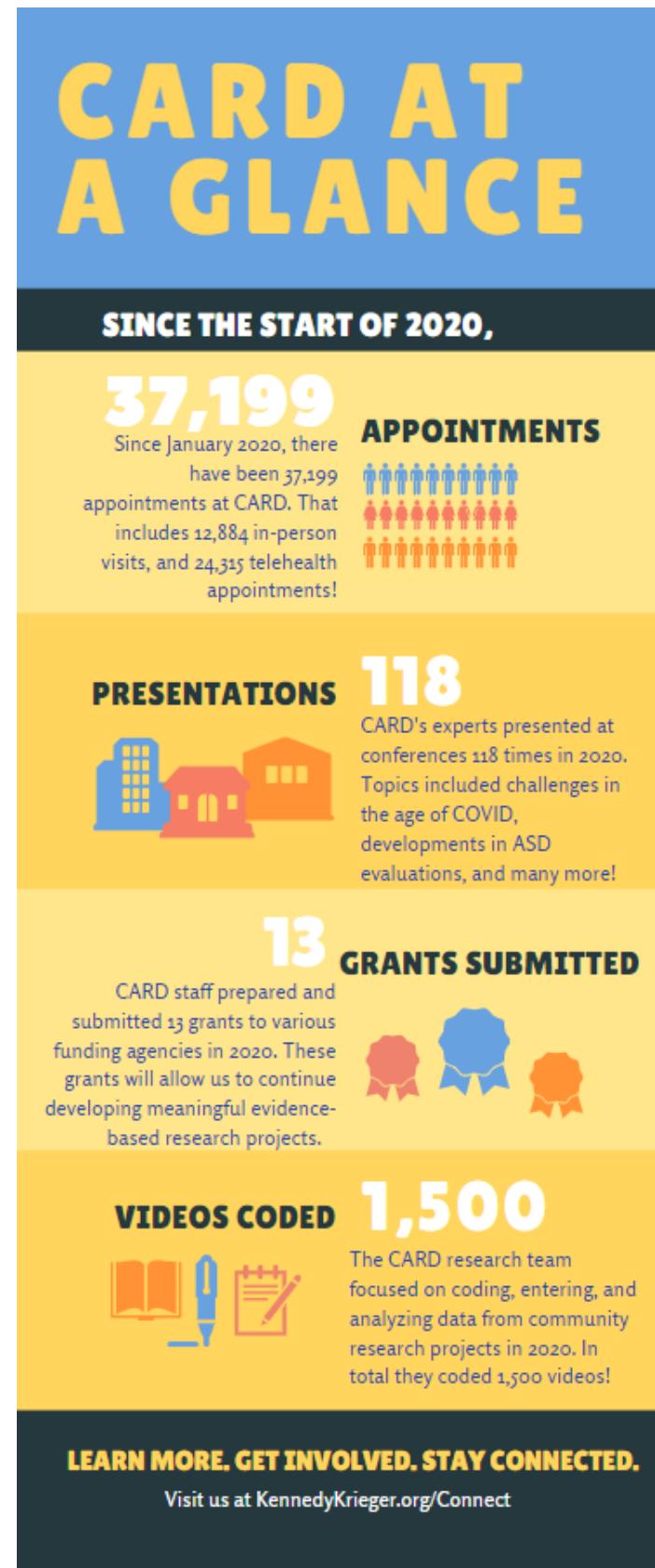
This past summer, Center for Autism and Related Disorders (CARD) speech-language pathologists Sharon Conty and Alyson Fagan offered the second annual summer CLUB (Connecting Language Using Books) program. Eighty students with ASD participated! CLUB is an annual summer program offering group speech-language therapy to build reading, comprehension and classroom-based social skills for students with ASD in kindergarten through the 12th grade. Groups consisting of four to six children or teens, grouped by ages and language abilities/needs, meet one to two times per week for 90 minutes. During this time, a clinician reads a modified, age-appropriate chapter book to the students. The sessions recreate a small classroom setting while providing language strategies to increase social awareness and understanding of relevant information in the text.

A variety of language strategies is introduced and practiced to promote the understanding of written text and social situations. Before a clinician begins reading to the students, the clinician introduces pertinent vocabulary. While reading to the students, the clinician helps students focus on understanding emotions, making inferences and predictions, and problem-solving. Students are encouraged to use text, visuals, and prior knowledge and life experiences to define vocabulary, answer comprehension questions, and discuss conflicts described in the text, as well as possible solutions to those conflicts. Objectives are individualized for each student and may address skills such as responding to “Who, what, when, where, why and how?” as well as problem-solving, defining vocabulary, and making logical inferences and predictions. Decoding and reading mechanics are not addressed in this group, as clinicians read the story aloud. Writing skills are addressed informally. Students do not have to be able to write on their own to participate in CLUB.

To address social skill development, clinicians encourage students to make appropriate greetings, participate in conversations, share opinions and negotiate within group activities. Students receive explicit practice guidelines for use at home and at school to promote social and self-advocacy skills. Parents of children who have participated in CLUB report that their children were excited about group sessions, and that their children have shown growth in their social skills and in their abilities to comprehend and explain what they have read.

Recently, CLUB offered an Executive Function Boot Camp for middle and high school students. They completed a project using a variety of executive function strategies, including inhibition, delayed gratification, planning, prioritization and organization. The groups ran for five days, for 90 minutes each day. **The next phase of CLUB will offer a Note-Taking and Study Skills Boot Camp from March 29 through April 9.**

Contact Alyson Fagan at [Fagan@KennedyKrieger.org](mailto:Fagan@KennedyKrieger.org) or Sharon Conty at [Conty@KennedyKrieger.org](mailto:Conty@KennedyKrieger.org) for more information.



# An Update on CARD's Research Efforts

## New findings, and new publications

The faculty members at the Center for Autism and Related Disorders (CARD) are international leaders in autism spectrum disorder (ASD) research. Our research examines many facets of life and experiences for individuals with ASD. We study causes of ASD, learning mechanisms, early detection of ASD and co-occurring disorders (such as anxiety and attention-deficit/hyperactivity disorder [ADHD]), innovative interventions, and ways to advance community providers' use of evidence-based intervention strategies.

We also develop tools to detect ASD early (such as the Social Communication, Interaction, and Play Screener), diagnose anxiety, identify mental health crises, assess pragmatic communication skills (with the Pragmatic Rating Scale) and more. In 2020, CARD faculty members submitted 18 grants, published 26 peer-reviewed scientific papers and conducted detailed behavioral coding of more than 2,500 video recordings of child or adult (engaging with the child) behavior. Here are a few of our findings:

- “Attention Deficit Hyperactivity Disorder Symptoms in Young Children with Autism Spectrum Disorder” (Hong et al., 2020): ADHD symptoms are highly prevalent in young children with ASD and are associated with increasing parenting stress and a greater level of other psychopathologies, both internalizing and externalizing problems.
- “Early Behavioral Profiles Elucidating Vulnerability and Resilience to Later ASD Outcomes” (Landa et al., 2020): Nearly 15 years ago, we discovered that younger siblings of children with ASD had a greater chance of developing ASD than children without a sibling with ASD. In fact, one in five younger siblings of a child with ASD will also have ASD. We recently found that children having stronger language, play and social skills, along with fewer repetitive behaviors, at 14 months old were much less likely to develop ASD by 3 years old.
- “Investigating Mental Health Crisis in Youth with Autism Spectrum Disorder” (Vasa et al., 2020): Using data from a large sample of individuals with ASD, we found that 32% of parents reported that their child had experienced a mental health crisis during the last three months. In younger individuals with ASD, the most frequent behaviors contributing to crisis were elopement (88%) and self-injury (81%). In older individuals, physical (60%) and verbal (42%) aggression were the most frequent crisis behaviors. Correlates of crisis included younger age, increased parental depressive symptoms, and lower family quality of life. Approximately 75% of individuals in crisis had seen a psychiatrist or behavioral therapist/psychologist within the last three months, and 25% were not engaged in any mental health treatment.

None of these discoveries would be possible without the participation of individuals with and without ASD and their family members, and the participation of community-based professionals.

# Life Skills Goes Virtual

The Center for Autism and Related Disorders' Life Skills Program is providing telehealth services in both group and one-on-one settings, at times including siblings. In general, we've shifted the focus toward coaching parents in how to support their children in successfully performing life skills at home.

The many benefits of providing home-based telehealth services are evident. The youth benefit from having a familiar physical environment and materials. Parents have shared the many creative ways that they have arranged activities and chores for their children to be successful, and how they are promoting their children's independence. We support families' success by sending visuals (such as the schedule of steps in a task) in advance of, or providing visual support to youth through screen-sharing during, Zoom sessions. Conducting services via telehealth allows families who otherwise wouldn't be able to attend in-person sessions to access our services.

## 21 PUBLISHED PAPERS

In 2020, CARD staff published 21 manuscripts in some of the leading science journals. Paper topics included anxiety and autism, speech development, ADHD and autism, and others!



## Participate in Research!

Research visits can be completed virtually or in-person. Send an email to [REACH@KennedyKrieger.org](mailto:REACH@KennedyKrieger.org) or visit [KennedyKrieger.org/Research/Participate-In-Research](https://KennedyKrieger.org/Research/Participate-In-Research) to learn more.