



Center for Autism & Related Disorders at Kennedy Krieger Institute

Director's Corner

A Message from CARD's Executive Director, Dr. Rebecca Landa, PhD, CCC-SLP

As 2022 comes to a close, we reflect on all that we learned and accomplished this year. Through our highly integrated interdisciplinary clinical service, research, and outreach and training work, we interact with thousands of autistic individuals, family members, researchers, community agencies, and trainees around the world each year. Through these interactions, we continually learn about the unique experiences of autistic individuals, what is working well and about barriers to success.

What we learn shapes our clinical service models, guides our research, and influences our training content. For example, we learned that anxiety is a common experience for our patients. Therefore, Drs. Keefer and Vasa set out to identify systematic signs of, and design treatments for, anxiety in children at younger ages than the field had thought possible. Our patients, and children around the world, are benefitting from this cutting-edge work. We continually work to increase access to our innovations by translating our approaches into formats that can feasibly be implemented by [teachers, child care providers](#), and doctors around the globe. To serve the autism community better, we continue to [recruit staff](#) and expand to new sites.

People often ask how to help us make a difference. One way is to join Friends of CARD, a group that provides input on our work, assists with information dissemination and events, and designs helpful information for autistic individuals and their families. Another way is through monetary gifts or purchasing from our Amazon Wish List. Please feel free reach out to us at FoC@KennedyKrieger.org for further information.

I wish you all a happy holiday season, and send best wishes for a healthy and fulfilling 2023!



Rebecca Landa, PhD, CCC-SLP
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Clinic Update

CARD's Efforts to Support Mental Health Needs in ASD

Individuals with autism spectrum disorder (ASD) are more likely to have mental health conditions than are individuals without ASD, [according to research](#). Autistic people have higher rates of anxiety, depression, obsessive-compulsive disorders and other conditions. The research emphasizes the importance of careful diagnosis of, and treatment for, mental health conditions in the ASD population. At the Center for Autism and Related Disorders (CARD), clinicians and staff members have implemented several initiatives to protect and care for the mental health of our patients.

The COPE Project

In the new year, CARD will offer a 10-week, group-based clinical service called COPE (CBITS Over Telemedicine Provides Empowerment). COPE groups are for pre-teens and teens with ASD who have experienced stressful life events. The groups will focus on stress management skills to decrease symptoms of anxiety and depression. COPE will also have an optional research component.

The project team will recruit 48 adolescents over a period of two years to participate and will adapt and deliver CBITS (Cognitive Behavioral Intervention for Trauma in Schools) via telehealth. CBITS is an evidence-based intervention for 11- to 17-year-olds exposed to trauma and is designed to teach children and families coping skills and resilience and foster a sense of community. It has been shown to improve functioning in youth with anxiety and depression, and CARD aims to extend this to the neurodivergent community. We will evaluate the feasibility and acceptability of offering CBITS to adolescents with neurodivergent conditions from low-resourced communities to prevent and reduce negative mental health outcomes following trauma exposure.

Suicide Prevention

According to the [Centers for Disease Control and Prevention \(CDC\)](#), suicide is the second-leading cause of death for adolescents ages 10–14. CARD is committed to suicide prevention through the implementation of standardized and evidence-based tools and safety assessments.

CARD uses the Ask Suicide-Screening Questions (ASQ) tool to screen patients over age 8. The ASQ was designed by the National Institutes of Mental Health (NIMH). If a patient screens positive for suicide risk on the ASQ, clinicians perform a safety assessment. The safety assessment focuses directly on suicidal thoughts, plans or intent, as well as risk and protective factors. The purpose of the ASQ and follow-up risk assessments is to determine the patient's overall risk for self-harm and to develop a safety plan. The ultimate goal of CARD's suicide prevention strategies is to ensure all patients are safe and that, if necessary, mitigation strategies are implemented to prevent any self-harm or suicidal action.

Professional Crisis Management Training

On rare occasion, a patient with autism may experience significant distress and there is concern that they, or someone else, could be injured. CARD staff are ready to help. Many CARD staff complete a training called Professional Crisis Management (PCM). During PCM training, staff members learn about crisis management procedures and different crisis prevention, de-escalation and reintegration strategies. These strategies and procedures are designed to support patients experiencing distress in the clinic and to reduce the need for more intrusive interventions. PCM practitioners strive to carefully protect patients, their families and our clinicians while maintaining a safe environment. Over 100 CARD staff members are PCM-certified and are adept at responding to patients experiencing distress.

Meet Matt!

Get to Know CARD's Project SEARCH Intern

Project SEARCH at Kennedy Krieger Institute is a program that provides hands-on job training and work experiences to young adults ages 18–24. Project SEARCH interns have nonpaid internships at local organizations where they learn employment skills in workplace environments. Meet **Matt O'Conner**, the Project SEARCH intern for the Center for Autism and Related Disorders (CARD)!



Matt with a CD of his current favorite band, Def Leppard

- Matt O'Conner is 23 years old.
- He started working at CARD in 2022.
- He is from **Lutherville, MD**, and graduated from **Dulaney High School**. He previously worked at Brick Bodies, Dick's Sporting Goods, and Food Lion.

- Matt's interests: **music and radio**. Matt says his favorite band right now is Def Leppard. Matt always brings a CD or cassette into work each day to show to others. He also **likes appliances and enjoys cleaning**.
- Favorite part of working at CARD: **cleaning the gym and doing the laundry**. Matt enjoys cleaning! He also likes socializing and has enjoyed **meeting the CARD team**. When asked about Project SEARCH, Matt said that he likes "hanging around" and has enjoyed **making friends** through Project SEARCH.

Matt has a lot of responsibilities and has been incredibly helpful to CARD's occupational therapists (OTs) and speech-language pathologists (SLPs). Emily Nemec, an OT, and Valeria Swartz-Diaz, a SLP, work with Project SEARCH to support Matt's internship. His tasks include cleaning the gym, cleaning treatment rooms and observation rooms, cleaning toys after use in sessions, doing laundry (including ADOS and Life Skills materials), and cleaning the Life Skills room. He is also extremely helpful with extra requests when SLPs and OTs are busy with patients!

"He is such a **fun personality** and such a **diligent worker**."

Sapna Bansil, OT at CARD Ashland

"Matt has been an **amazing asset to our team** since the first day he started. We can and do **depend on him** to help us by sanitizing all of our toys and treatment items after each session, which has become increasingly important. He also **regularly assists our therapists with cleaning and restoring treatment areas** that have been hardly used during patient care. All of his hard work contributes to better time management and our overall energy, knowing we have someone **so dependable** to help us out.

We are **so thankful to have had the opportunity to work alongside Matt** and will greatly miss his singing, occasional dancing, excellent work ethic and warm smile!"

Megan Halscheid, OT at CARD Ashland

Season of Giving

During this season of giving, we would be honored if you would consider [making a gift to CARD](#). Gifts of all sizes are appreciated—you can make a difference!

Anytime of the year is the right time of year to purchase a toy from [CARD'S Amazon wish list](#)! These toys will be replacing some of our "well-loved" toys and will help patients with their developmental skills.

EDI in CARD's Mission

In each of CARD's three areas of focus – outreach and training, research, and clinical care – equity, diversity and inclusion (EDI) principles guide our progress and inform our work. Read below to explore highlights of some of CARD's EDI initiatives.

Outreach and Training

Training in school systems: The Outreach and Training team works with public school systems to provide training, coaching and consultation to professionals, with the goal of supporting the successful inclusion of students with disabilities in general education classroom settings. Consultants provide information on evidence-based interventions, discuss existing barriers to successful inclusion, and identify strategies for overcoming those barriers.

Research

SPARK in Spanish: SPARK is an online study with the goal of moving autism spectrum disorder research forward and improving lives. In the summer of 2022, the SPARK team at CARD began to offer SPARK in Spanish, which provides families who primarily speak Spanish with recruitment, registration and other research materials in their preferred language. Please email Kyla Minton at Minton@KennedyKrieger.org to learn more.

African American Family Advisory Board: As part of a diversity, equity and inclusion (DEI) supplemental grant funded by the Simons Foundation, CARD researchers created the African American Family Advisory Board (AAFAB). Members of the AAFAB include local physicians, professionals and parents. The group advises on equitable and inclusive research practices. Contact Eva Queen at Queen@KennedyKrieger.org to learn more.

Clinical Care

Linguistic Access: We are streamlining and improving our work with interpreters. This effort includes the development of a survey that is used to collect feedback on the use of interpreters at CARD. The CARD Equity, Diversity and Inclusion (EDI) Committee also created a one-page tip sheet that interpreters who work at CARD can review before appointments. The document contains specific recommendations as well as a list of commonly used medical phrases and concepts in several languages, including Spanish, Arabic, Korean and Mandarin.

Bilingual Materials: Clinic staff members developed bilingual materials that can be shared with families. The materials include handouts on CARD support groups, community resources, treatment materials and more

Neurodiversity affirming language: The EDI Committee created a chart of neurodiversity-affirming alternatives to traditional terms and concepts for adoption by CARD staff members. This information comes from a [recent paper published by the American Academy of Pediatrics](#).

Research Opportunities

Your Family Can Participate in Research at CARD

The Center for Autism and Related Disorders (CARD) has several research studies open to new participants. Read about some of CARD's current studies below, and visit the [Participate in Research](#) page of our website for more information. There is no charge for research assessments or intervention.

- Researchers at Kennedy Krieger Institute (KKI) are studying a new social communication screening tool for children ages 12–36 months. Participation includes:
 - Brief online questionnaire about you and your family
 - Online developmental screening
 - Telehealth developmental assessment with you and your child, and feedback with a developmental specialistYou can [view the study flyer](#) or email Reach@KennedyKrieger.org to learn more.
- Researchers at KKI are studying whether there are differences between in-person and virtually delivered social communication interventions for toddlers with autism spectrum disorder. Participation includes:
 - Questionnaires about your child and you
 - Developmental assessments
 - Random assignment to either virtual or in-person intervention sessionsYou can [view the study flyer](#) or email Reach@kennedykrieger.org for more information.
- Researchers at KKI are studying how infants (under 6 months) learn language early in life. By learning more about your child's development, we hope to improve ways to identify children who may benefit most from early intervention. Participation includes:
 - Developmental assessments
 - Hearing screening
 - Non-invasive EEG

- Questionnaires about you and your child

You can [view the study flyer](#) or email Reach@KennedyKrieger.org to learn more.

- SPARK is an autism research study and a growing community of autistic individuals, their families, and researchers on a mission to advance the understanding of autism. SPARK's mission is to improve the lives of people with autism by identifying the causes of autism and informing more effective therapies, treatments, services and supports.

Visit the [SPARK website](#), view the [study flyer](#), or email Kyla Minton at Minton@KennedyKrieger.org to learn more

Publication Spotlight

[Diagnostic stability and phenotypic differences among school-age children diagnosed with ASD before age 2](#)

Authors: Rebecca Landa, Rachel Reetzke, Calliope Hologue, Dana Herman, & Christine Hess

Autism spectrum disorder (ASD) affects development in a number of ways. In this study, we showed that, in young children diagnosed with ASD, development can fluctuate more than was previously known. We carefully studied development in 210 younger siblings of autistic children. These younger siblings were assessed three times between ages 15 months and 5 years. Most children were identified as non-autistic at all three ages. For autistic children, half were diagnosed near the time of their first birthday, and their diagnosis was stable across all the ages assessed. About 10% of the children diagnosed with ASD between their first and third birthdays no longer met diagnostic criteria for ASD by age 5½ years. Most of the remaining children diagnosed with ASD had clear symptoms by age 3 years, and these symptoms persisted through age 5 years. The take-home message is that screening for ASD across the first three years of life is important, even if an earlier screening did not detect ASD. Early identification opens access to enriched learning experiences that build on children's strengths to help them achieve their potential.

Research Highlights

CARD Research Publications

Faculty and staff members at the Center for Autism and Related Disorders (CARD) conduct research on a range of different topics, from autism spectrum disorder (ASD) and anxiety in preschool-aged children to gastrointestinal concerns in children with ASD. The goal of CARD's research is to develop and then answer meaningful questions about ASD and neurodevelopment. Below are some highlights from a busy year in research discoveries from CARD faculty and staff members.

Understanding Language Impairment in Autism

[Profiles and correlates of language and social communication differences among young autistic children](#)

Rachel Reetzke, PhD, and her co-researchers used a person-centered latent profile analysis to identify language and social communication patterns in autistic children. The researchers identified three distinct and clinically meaningful profiles. They found that, overall, young autistic children from the lowest-resource households exhibited the lowest language and social communication abilities, and the lowest nonverbal problem-solving and fine motor skills. This underscores the need for effective community-based implementation strategies for low-resource households.

The Experience of Families Caring for Children with ASD and GI Symptoms

[Gastrointestinal concerns in children with autism spectrum disorder: A qualitative study of family experiences](#)

Calliope Holingue, PhD, led a research team that interviewed 12 parents of children with co-occurring ASD and gastrointestinal (GI) symptoms. The researchers identified four major themes across the interviews, which highlighted the stress that GI symptoms can place on the overall wellness of children with ASD and their families.

Anxiety and Intolerance of Uncertainty

[Exploring the symptom profiles of intolerance of uncertainty in autistic children](#)

Amy Keefer, PhD, along with several other CARD researchers, examined the presentation of intolerance of uncertainty (IU) in autistic children, with and without anxiety, and neurotypical (NT) age peers. The results indicate that autistic children have higher IU symptoms in emotional, behavioral and cognitive domains. Importantly, the study highlights the importance of considering IU symptom profiles in assessment and treatment.

ADHD, Anxiety and ASD in Males and Females

[Co-occurring attention-deficit/hyperactivity disorder and anxiety disorders differentially affect males and females with autism](#)

Ericka Wodka, PhD, and a team of researchers used data from the SPARK Research Consortium to investigate sex differences in symptomology in individuals with ASD with and without attention-deficit/hyperactivity disorder (ADHD) and or anxiety disorder. The results suggest that for both boys and girls, the presence of co-occurring conditions leads to increased concerns for social communication and motor functioning, while delaying the age of initial ASD diagnosis. That said, the impact of co-occurring anxiety and or ADHD was greater for girls, contributing to a delay in their initial ASD diagnosis by up to four additional years, and even worsening social communication, repetitive behaviors and motor challenges.

International Reach

CARD Helps Establish Autism Center in Saudi Arabia



Tamakkon Comprehensive Autism Center in Kingdom of Saudi Arabia

Autism exists around the world. Yet few countries offer the comprehensive and evidence-based care provided by experts at the Center for Autism and Related Disorders (CARD) at Kennedy Krieger Institute. In the Kingdom of Saudi Arabia (KSA), diagnostic, intervention and educational services for autistic individuals are not readily available. So, when asked to assist in the establishment of a comprehensive autism spectrum disorder (ASD) center in KSA, we were pleased to lend our expertise. We provided consultative and coaching services to the **Tamakkon Comprehensive Autism Center (TCAC)**, the first specialty medical center for autistic individuals in KSA. A CARD interdisciplinary team supported the TCAC clinical team during this past year, with CARD staff members training a diverse team of professionals representing seven disciplines.

To tailor the training to the cultural and specific needs of the TCAC team, CARD conducted a needs assessment, provided clinical case consultations, and developed neurodiversity-affirming clinical training coursework. Our goal was to prepare the TCAC team to conduct thorough assessments to understand each child's and teen's strengths, needs and priorities, and then implement state-of-the-science approaches to support these priorities, as well as patients' learning needs and goals.

The inclusion of a bilingual CARD staff member familiar with the cultural and linguistic profile of the region ensured that the training was culturally responsive, with translated materials and adapted information and training approaches. The CARD team is grateful for the opportunity to collaborate with the TCAC team to support autistic individuals in the region.



Looking Forward to 2023

Although the weather is turning colder, we are setting our sights on next summer! Mark your calendars for **August 14, 2023**, for the second annual **CARD Golf Outing**. Once again, this event will be held at the Country Club of Maryland in Towson.



Contact Joy Johnson at JohnsonJoy@KennedyKrieger.org if you are interested in signing up for this event as a golfer or member of the planning committee, and contact Leslie Marsiglia at Marsiglia@KennedyKrieger.org for sponsorship information. See you on the course!

CARD Kudos

Big Accomplishments in 2022

Faculty and staff members of the Center for Autism and Related Disorders (CARD) received recognition for many accomplishments and triumphs in 2022, including being awarded nine high-profile research grants. The CARD team made great strides in breaking through barriers to success faced by the autism community!

In November, the American Speech-Language-Hearing Association (ASHA) presented CARD Executive Director Rebecca Landa, PhD, with the Honors of the Association award. This award recognized Dr. Landa's meaningful contributions to speech and hearing sciences and the important impact she has had on the field. It is the highest honor that ASHA gives. Congratulations, Dr. Landa!

Deepa Menon, MBBS, CARD's Assistant Medical Director, was promoted to Clinical Associate Professor in Neurology and Neurodevelopmental Medicine. Well done, Dr. Menon!

Here are a few other important awards and special recognition titles that CARD's faculty and staff members earned this past year:

- Luke Kalb, PhD, received an Excellence in Teaching Award and the Hexcite Accelerator Fellowship, both from Johns Hopkins University.
- Calliope Hologue, PhD, won the Excellence in Teaching Recognition Award for her summer course, "Mental Health and The Gut," at the Johns Hopkins Bloomberg School of Public Health. Dr. Hologue also received the Suzanne Wright Memorial Research Accelerator Grant from the Autism Science Foundation for her proposal on understanding gastrointestinal issues in autistic adults.
- Stephanie Morris, MD, joined CARD as our Medical Director. Dr. Morris is a board-certified pediatric neurologist, a mother of three, and an advocate of quality, comprehensive and accessible pediatric healthcare. She brings a broad clinical background in pediatric neurology, with specific expertise in diagnosing and managing children with intellectual and developmental disabilities, especially as they occur in neurogenetic conditions. Welcome, Dr. Morris!
- Deepa Menon, MBBS, was recognized by Kennedy Krieger Institute as a Quality and Safety Champion. The award distinguishes her commitment to quality improvement initiatives.
- Rachel Reetzke, PhD, and Rebecca Landa, PhD, received the 2022 Human Cognitive and Behavioral Science Explorer Award for their highly innovative project, "Validation of a Digital Movement-based Measure of Early Social Communication." The award was bestowed by the Simons Foundation Autism Research Initiative.
- Sheila Umayam, PNP, DPNP, won a scholarship from the American Academy of Pediatrics (AAP) Section on Developmental and Behavioral Pediatrics (SODBP) to support her registration for an intensive clinical course in developmental-behavioral pediatrics.
- During Social Work Month (March), Kennedy Krieger Institute hosted the Social Work Awards Ceremony. Several CARD social workers were recognized at the ceremony. Sarah Michaels, LMSW, was nominated for the Social Justice Award, and Catherine Debus, LCSW, was nominated for the Clinical Excellence Award. Elie Sollins, LCSW-C, won the Clinical Excellence Award!