



Center for Autism and Related Disorders at Kennedy Krieger Institute

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Our Dream Team invites you to read our 2019 Newsletter!

CARD Locations



Greenspring

3901 Greenspring Avenue
Baltimore, MD 21211



Ashland

1741 Ashland Avenue
Baltimore, MD 21146



Odenton

1130 Annapolis Road
Odenton, MD 21113

A Message to Our Readers

Dear Friends of CARD,

As I reflect on the past year, I am filled with gratitude for all that has been done. I think about the many children and families who walk through the doors of our two sites (at our Odenton and Greenspring campuses) to receive services, participate in research or share in a special event we are hosting. They share with us their precious loved ones, concerns about the present and hopes for the future. They depend on us to give them accurate information, and to offer them the most scientifically up-to-date assessments and treatments. We do that, and more. To be able to give families what they seek and deserve, we strategically plan, evaluate the effects of what we do, and open ourselves to the critical eyes of autism and child development experts from around the globe.

Together, our more than 150 staff members represent at least 18 different professions. Each staff member's primary appointment is with the Center for Autism and Related Disorders (CARD), and most work full time. They represent a broad spectrum of diversity, and collectively speak at least nine different languages fluently.

Some of our main accomplishments from last year include:

- Caring for more than 5,000 different patients in 2018.
- Providing care for children, youth, teens and young adults, and their families, across more than 35,000 different appointments.
- Developing new clinical programs for children with more specialized needs (e.g., a clinic for children with seizures and mental health problems).
- Expanding our training program so we are able to train more professionals who can go out into the world and care for children with autism.
- Applying for federal, state and institutional grants to conduct innovative research and provide unique services to benefit children across the United States—three new grants were funded (for work led by Dr. Gazi Azad, Dr. Roma Vasa and me), and existing grants were re-funded.
- Hosting 94 trainings, including our annual conference that was attended by families and professionals from as far away as Venezuela.
- Publishing 46 articles in peer-reviewed journals.
- Starting the Friends of CARD parent organization (see article by Shannon Carmen).
- Hosting internationally renowned clinical researchers (colleagues from Harvard, Vanderbilt and Drexel, to name a few) to obtain input on groundbreaking new initiatives we are planning.

Our research breakthroughs are helping to effectively identify infants, toddlers and school-aged children in need of services. We are working to identify clearer indicators of developmental disruption, and to develop a new screener (the web-based, video-guided Social Communication Interaction and Play Screener, SCIPS, for toddlers), and a new social communication assessment (Pragmatic Rating Scale-School Age). We are testing the effectiveness of an infant intervention for those showing possible signs of a social and/or communication delay, as well a teacher intervention for preschoolers with autism spectrum disorder (ASD) in public schools. We are developing and evaluating a professional training program for child care providers who have at least one child in their classrooms with a developmental delay. We are developing new ways to detect anxiety in preschoolers with ASD, with the aim of developing early preventive interventions for anxiety in ASD, and we are focusing on how to identify individuals who are at risk for serious mental health crisis. These are just a few of our major activities, all aiming to improve the lives of individuals with ASD and their families, and to build capacity in community-based professionals who are shaping the future of children.

In 2019, CARD will grow again. On January 2, we began providing services in a new building, in space we have specially designed for individuals with ASD. The building is located at 1741 Ashland Avenue, Baltimore, near the existing main Kennedy Krieger Institute buildings. A parking garage connects to the new building, there is free valet parking, and there are wonderful places to eat within walking distance. The special features of this new space will enable us to expand the types of services we provide to adolescents and emerging young adults with ASD.

On April 3rd from 3:00 to 7:00 PM, we welcome you to join us as we celebrate the opening of our 3rd location. You will have the opportunity to learn about our services, our research and meet expert clinicians and researchers from CARD. [Click here to RSVP](#). We hope to see you there!

Warmest wishes



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

Friends of CARD

By Shannon Carmen, Parent, Friends of CARD Committee Member

In late 2017, staff members of Kennedy Krieger Institute's Center for Autism and Related Disorders (CARD) joined hearts and minds with a small group of parents of graduates of CARD's Achievements Therapeutic Day Program, an early intervention program, to form a support organization at CARD.

The group's initial vision was to embrace newly diagnosed families and offer comfort and guidance at a time that's often a whirlwind of emotion. The group first referred to

itself as the Achievements Alumni Association and held its first event, "Achievements First Welcome Home Event," on June 2, 2018. All past and present families of the program were invited—children and adults alike. The June event had a storybook theme thanking families for being "part of the story" and inviting families, no matter how long or short their history with CARD, to "be a part of the next chapter."



The event proved to be a success, with sensory-friendly storybook activities, fun for the children and an opportunity for children and parents to reunite with former classmates and teachers from their respective Achievements groups. Many of us met new friends from the CARD community.

Through this event, families had the chance to learn more about the mission of the new group. Families' interest soared! Families quickly became part of this new and energetic association. As the core leadership committee of the group grew, families agreed that the mission of the group should be expanded to include all families served through CARD, and even families who have a child with autism who has not been served by CARD, but who believe in the mission of CARD. Thus, the group changed its name from Achievements Alumni Association to Friends of CARD.

The shifts that have occurred during the inaugural year of this parent-CARD collaborative group show that ideas can grow quickly when families join hands. Friends of CARD is reaching out to anyone seeking connection and support at CARD, and the group's members are bursting with so many new and exciting ideas! Some of our goals—just to name a few—are to:

- Build strong connections throughout the CARD community,
- Encourage children in any CARD program to continue their friendships with one other after graduating from the program.
- Provide support and mentorship to newly diagnosed families.
- Ensure there's a forum where families may share their experiences throughout the autism journey.
- Enhance parent knowledge of autism spectrum disorder (ASD) management with webinars and meet-and-greets.

- Host multiple events per year to bring children and families together.
- Help promote further research.

Our second event, “Connect with Autism Researchers,” was held on November 8 and was another huge success. The third-floor conference room of CARD’s Greenspring Campus was bustling with adult friends and families of CARD, while an interactive and entertaining child care event was available for children. Individuals enjoyed refreshments, mingled, and shared stories and memories of CARD and ASD. CARD autism researchers Dr. Rebecca Landa, Dr. Roma Vasa and Bonnie Van Metre gave research briefings and held question-and-answer sessions. It was a beautiful evening highlighting the importance of research, revealing new research breakthroughs, and connecting more CARD families with one another.

The energy around Friends of CARD is contagious, as the budding group continues to grow and make plans for more exciting events in 2019. Send an email to AAA@KennedyKrieger.org for more information or to get involved.

Achievements Early Intervention Program By Carrie Roylance, MS, CCC-SLP

The Achievements Therapeutic Day Program at Kennedy Krieger Institute’s Center for Autism and Related Disorders (CARD) provides individualized treatment in small-group settings for children with autism spectrum disorder (ASD) who experience developmental challenges affecting communication and social interaction.

Achievements includes programs for children from infancy to 6 years old. These programs include:

- Infant Achievements (an eight-week, home-based, free program for 8-to-12-month-olds, via Dr. Rebecca Landa’s National Institutes of Health-funded research study)
- Achievements for Little Learners (a training program for parents of 1-year-olds showing signs of risk for ASD or social communication delays)
- Early Achievements (for 2-year-olds)
- Achievements (for children ages 2 years, 9 months, to 6 years old)

The Achievements programs provide enriching environments for social discovery through language mastery. Children immediately apply what they are learning in a variety of authentic social and communication interactions. For example, a book may become more “real,” as children are able to participate in a play routine based on a story in the book. Our goal is for treatment sessions to become not only places for learning, but also places to form friendships.

We recognize that each child has individual strengths. By combining aspects of the most recent, research-based therapeutic techniques, we create programs that fit each child’s needs. Groups are led by certified speech-language pathologists and supervised speech-language pathology assistants, along with one or two therapeutic assistants. These staff are trained to fidelity in implementation of Naturalistic Developmental Behavioral Intervention strategies, the latest evidence-based approach to early intervention. Student-to-staff member ratios are low, and parent involvement is encouraged. Groups meet for between one and a half to two and a half hours per day, two to four days per week. In the groups, children are active participants in theme-based learning activities that provide a motivating context for addressing individualized goals that target language, social, play and cognitive skills.



New Programs to Promote Early Friendships

For many years, the Achievements Therapeutic Day Program has partnered with the Center for Autism and Related Disorders' (CARD) Model Inclusion Childcare Classroom (MICC). Through this partnership, 3-to-5-year-olds who are developing neurotypically enter Achievements groups for children with autism spectrum disorder (ASD) as playmates and peer models. This program provides the children developing neurotypically with access to high-quality, language-rich preschool classrooms and teaches them about diversity and empathy at an early age, while exposing children with ASD to natural and age-appropriate play, language and social skills.

One of the ways we support high quality peer engagement in Achievements is through our use of the "Buddy Skills" program, a formal, evidence-based curriculum for peer-mediated intervention. Based on the work of English, Goldstein, Shafer and Kaczmarek, the program emphasizes three simple concepts: **stay**, **play** and **talk**. These three words provide expectations for the students in the MICC during their time in Achievements groups. The students who are neurotypically developing learn to become peer models and to join their peers with ASD in play, engaging in conversations with them, and even helping children who use speech-generating devices to communicate.



Roary, CARD Mascot

Early Achievements for Child Care Providers (EA-CP)

By Julie Feuerstein, PhD, CCC-SLP



With funding from the Institute of Education Sciences, Dr. Rebecca Landa and her research team are partnering with child care centers in Baltimore to investigate the effectiveness of a professional development training designed to help child care teachers implement high-quality, evidence-based instruction in their everyday classroom routines. This research takes Dr. Landa's Early Achievements (EA) model, an evidence-based intervention to improve social and communication outcomes in toddlers, and adapts it for implementation by child care teachers in authentic community-based settings. This exciting new partnership has the potential for high impact on the quality of instruction in early childhood care and education settings, and to promote the educational outcomes for children with language, social and/or cognitive delays.

Empowering Patients Through Evidence-Based Practice

"It was refreshing to visit a center that is actively striving to achieve its mission statement. The intellectually curious, passionate group at the Center for Autism and Related Disorders [CARD] at Kennedy Krieger Institute is clearly empowering its patients—and the well-being of the families it serves—through evidence-based practice. The center has contributed great things to autism research and the realm of clinical practice. I look forward to CARD's future work and continued opportunities for collaboration."

By Howard C. Shane, PhD

Director, Autism Language Program and Center for

Communication Enhancement, Boston Children's Hospital

Associate Professor of Otolaryngology and Laryngology, Harvard Medical School

Expansion of Social Skills Group

By Betsy Stratis, PhD



The social skills groups at the Center for Autism and Related Disorders (CARD) are based on a variety of evidence-based curricula and use a combination of strategies to improve social skills, including direct instruction, role-playing activities, video modeling, and fun games and activities that are full of learning opportunities. Below is a description of some of the groups.

Meaningful Activities that Enhance Social Skills (MATES) was designed for 6-to-10-year-old children with average to above-average language skills. **MATES** covers skills that enhance children’s ability to make friends, including compromising, being flexible, good sportsmanship and conversation skills. The **MATES** group is offered at both our Greenspring (with Shawmickia Simmons, a social worker, and Lindsey Bernard, a speech-language pathologist) and Odenton (with Dr. Tiffany Lin, a clinical psychologist) locations. Participants in the **MATES** group have said they look forward to the “social club” and think it is a “fun way to learn how to make friends.”

Fun Active Social Training (FAST) was designed for 8-to-11-year-old children with average to above-average language skills. **FAST** provides instruction in social skills such as initiating relationships, identifying and interpreting social cues, conversational skills, and age-appropriate play skills, while facilitating opportunities for real-life practice of these skills. **FAST** is offered at our Greenspring location by a clinical psychologist and speech-language pathologist.

The **Navigators** group was designed for youth ages 11 to 14 with average to above-average language skills. **Navigators** covers several skills important for social interactions and friendships, including nonverbal communication, conversational skills, use of social media, having get-togethers with peers, and managing conflict and disagreements. **Navigators** is offered at both our Greenspring (with Dr. Betsy Stratis, a clinical psychologist, and Sarah Griffin, a speech-language pathologist) and Odenton (with Dr. Lin) locations.

Relationships, Emotions and Dating for Youths (READY) is a psychoeducation group recently developed by Dr. Amrita Singh, a CARD postdoctoral fellow. **READY** was designed for adolescents ages 15 to 17 who have an interest in learning dating etiquette skills. Other topics covered in **READY** include emotional awareness, conflict resolution and social media safety. **READY** is offered at the Greenspring location with Dr. Jeung Eun Yoon, a clinical psychologist.

Connections is a newly designed group for teens ages 13 to 17 with average to above-average language skills. **Connections** will focus on teaching teens skills critical to making and keeping friends (e.g., conversation skills, use of electronic communication and social media, having get-togethers, handling teasing and bullying) as well as training parents to be effective social coaches. It is anticipated that **Connections** will be offered starting in winter 2019 at our Greenspring location with Dr. Kate McCalla, a clinical psychologist, and Marissa Houdek, a speech-language pathologist.

Several other social skills groups are available at CARD for children ages 6 through 17 with a range of language abilities. We receive wonderful feedback about the impact of these groups. For example, one parent shared that her child became “more open to new friendships and has learned to appropriately handle difficult situations as they arise” by being a part of the Navigators group.

If you are interested in having your child participate in a social skills group, please talk to your child’s CARD clinician or contact our general information line at 443-923-7680.

Father Panel

By Rico Winston, Parent, Friends of CARD Committee Member



It was an honor to be invited to participate in the Fathers Panel at the Center for Autism and Related Disorders (CARD). Initially, I was a little apprehensive, as I had never participated in anything like it, and doing so would take me outside my comfort zone. But as the single parent of an amazing son, whose name is Israel, I came to realize that all parents—with or without a child or children with autism—face experiences and situations that may take them outside their comfort zones. These uncomfortable moments and challenges define, shape and strengthen me to become a better parent, friend and advocate.

As I reflect on my participation with the Fathers Panel, I think of the wonderful, enlightening and important topics pertaining to fathers, as well as to all parents, that we discussed. Some resonate particularly strongly with me.

The first is **self-care**. Several times before I joined the Fathers Panel, I was asked, “How do you replenish yourself?” For some reason, I never could understand the necessity and significance of self-care. I believed that as long as a man fulfilled and met his commitments and obligations, nothing else mattered. I’ve come to realize that, in order to fulfill my commitments and obligations to the highest level of my abilities, it is imperative, first and foremost, to take time to care for myself.

The second is **self-reflection**, and the realizations that come with it. The panel encouraged me to think about something positive that had come from our experience, what I was looking for in my son’s journey, and how my being on the panel had affected my son and me. As I pondered those questions, I had an epiphany.

I realized that, above and beyond anything I can give to or share with Israel, it’s the gift of love—and the significance of and rewards that come from giving and sharing love; understanding Israel’s value and worth as an individual; and respecting, appreciating and finding worth in the individuality of others—that’s the most important thing. By helping our children strive to be the best human beings they can be, by making a difference in their lives as well as in the lives of others, and by believing in ourselves and our children, we can not only change the world, but heal the world—one child, one individual, one human being at a time.

About 13 percent of children display a late onset of spoken language. During the early period of word learning, children with a language delay and late talkers show underdeveloped connections of meaning across the words in their vocabulary. That is, toddlers with slow language onset are not learning the meaning of words as quickly as children with typical language development. Research has shown that children with early language delays are at increased risk for having a language impairment. In addition, early language is the single best predictor of school readiness and academic achievement.

The good news is that early language enrichment or intervention can boost language and social development, even in children with neurotypical development. During infancy, the brain is developing rapidly and is influenced by the input children receive during interactions with objects and people. Parents can learn simple strategies to help babies learn more while playing with objects and interacting with people. Offering babies this type of enrichment before they show the full signs of a communication disorder could have long-lasting, positive effects on development.

With grant funding from the National Institutes of Health (NIH), Dr. Rebecca Landa and her research team are investigating Infant Achievements, an innovative, short-term, pre-emptive social communication intervention and enrichment program developed by Dr. Landa for 9-to-12-month-olds. Babies need not have a disorder or diagnosed delay to be eligible to participate. Babies with early signs of developmental delay also may be eligible to participate.

By intervening during early development and shaping a child's communication system while it's being built, we hope to interrupt or reduce an impending delay. In this randomized controlled trial, families are randomly assigned to one of two enrichment programs. In both programs, families are visited by a developmental specialist, either once or twice weekly in their homes (or at our center, if

families prefer). In both groups, families receive developmental information as well as toys (which they can keep) to use to play with their children. Through this study, we will examine how parents are using developmental strategies through play to help foster their babies' emerging communication skills, and in turn, how babies progress and make gains in their communication skills when their parents use certain interaction strategies with them.

Families with a child between 9 and 12 months old who are interested in the study (regardless of whether they have concerns about their child) and who live within 40 miles of the Center for Autism and Related Disorders (CARD) may receive a free developmental evaluation of their child at our center.

Children who show a low frequency of certain social or communication behaviors will be invited to participate in the research study. Anyone interested in learning more about or participating in the Infant Achievements study can contact the Research and Education for All Children (REACH) Child Development Center by emailing email REACH@KennedyKrieger.org or calling 877-850-3372.

The protocol number for this study is IRB00065698.



A mom interacting with her daughter, seeing the benefit of using strategies mom learned in CARD's Infant Achievements project.

James' Success Story

By James' Mother

Sometimes I can hear James speak in my head, even though he has not said a word. He takes my hand and leads the way, helping me locate the pieces of the puzzle that connect us between our two worlds. One verbal (me) and one non-verbal (James), but together we share one language of love and hope.

James' lack of eye contact and interest in other children, his inability to verbally communicate or even gesture, his constant spinning and running, and worse, his likeliness to elope or run away were not because he was shy or taking his time to develop. These are signs of ASD.

The long days of tests for cognition, speech and socialization were upon us, and I knew at the end I was going to hear one word: AUTISM! Inside my heart of hearts, I knew this was coming, but nothing prepares you for the day you are told that about your child. To know James is to know autism.

James was diagnosed with autism at 18 months old by a psychologist at Kennedy Krieger Institute. After that, the Institute's team of doctors and social workers lead us through a list of programs that would benefit James. He began in Little Learners, a six-month program for children diagnosed by age 2. This program works with both the child and his or her parent, preparing the child to learn, with the hope that he or she will develop language, both expressive and receptive. The program also helps children learn how to play and interact with others, and it offers extensive parent training.

Currently, James attends Early Achievements four days a week. James now can say "mama" and relates that word to me, his mother. And if you ask him, he will hand out high-fives to celebrate anything. In the past year, he has gone from crying through a class session to entering with excitement, checking his schedule, and preparing to learn in a classroom setting. James is now 2, and in the past six months, he's met many milestones, and that's brought us the inspiration that we, as a family, needed. We no longer think there is something better or different out there for James; we have learned patience and love.



Community Partnership: Jewish Community Center

By Hadassah Bauerle, Research Assistant

Too often, parents dismiss fears that their child isn't developing properly and ignore signs that something isn't right, simply because they are afraid of the answers they might get, or because of the uncertainties that begin even with attempting to book an appointment with an expert. Many parents believe that making an appointment at Kennedy Krieger Institute means their child has severe disabilities, and that it should be a last resort to seek help from the Institute's professionals. This belief may keep concerned parents from seeking reputable services at Kennedy Krieger. Many teachers also have these beliefs and hesitate to recommend evaluations at Kennedy Krieger for the same reasons.

But what if, instead, parents and teachers were afforded the opportunity to interact with providers from Kennedy Krieger's Center for Autism and Related Disorders (CARD) in a more familiar setting, rather than a clinical environment? What if these parents were able to get answers to commonly asked questions about parenting from the experts? What if teachers had the opportunity to interact with, and receive training from, CARD staff members on relevant topics within education? What if parents and teachers were able to have a sneak peek into what we do at CARD every day, to receive glimpses of the opportunities available to all concerned parents, and to see that Kennedy Krieger is not a scary place for only the worst-case situations? This is the vision Dr. Rebecca Landa, CARD's founder and executive director, has had, and it's what has fueled a recent push for increased community outreach. Through this push for more outreach, several exciting new initiatives have been launched, or are in the process of being launched.

One of these initiatives is a partnership with Baltimore's Jewish Community Center (JCC), a community resource for the city's Jewish community. The JCC has historically had a positive relationship with CARD, primarily through participating in various research projects conducted through CARD's research division, known as REACH (Research and Education for All Children). In a shared vision for collaboration, several different programs are in the process of being created for teachers, children and families associated with the JCC. Two of the key CARD staff members working to define these collaborative programs are Hadassah Bauerle and Dr. Julie Feuerstein.

One such CARD-JCC collaborative effort is the creation of a Parent Education Series offered to parents of students enrolled at the JCC's Early Childhood Education Centers. This series is a once-a-month seminar for parents to learn about various topics on parenting infants, toddlers and preschoolers. Different CARD experts will present on topics about which parents tend to wonder, such as toilet training, the "terrible twos," bedtime routines and other hot-button issues. This will give parents the opportunity to hear about evidence-based approaches to common issues and ask professionals about specific questions and concerns they might have.

Another collaborative effort is through a research project that Drs. Landa and Feuerstein are conducting with early childhood teachers. This research project helps train teachers on evidence-based practices that will improve teaching effectiveness. Teachers will learn about fun, motivating and interactive book-sharing instruction and other methods developed by Dr. Landa as part of her development of a classroom curriculum and teaching methods based on cutting-edge discoveries in the developmental and behavioral sciences. Two classrooms at the JCC's Early Childhood Education Center are participating and loving it!

CARD also has been invited to participate in JCC events. Most recently, CARD participated in the JCC's Community Block Party, with more than 5,000 community members attending. CARD provided informational materials on the clinical and research opportunities within CARD. These events help to bring Kennedy Krieger's expertise into the everyday world of children and their families and teachers. Lasting personal connections are made at these events, and that leads to even more fruitful Kennedy Krieger-community partnerships and extends the impact of the work being done at CARD. Stay tuned for more exciting developments!

Model Inclusion Child Care (MICC) By Courtney Fisher, MICC Teacher

The Model Inclusion Child Care (MICC) classroom is known as a "hidden gem" here at the Center for Autism and Related Disorders (CARD). Our program started off with grant funding in 2007. At that time, we only accepted children of Kennedy Krieger Institute employees. Now, 11 years later, we enroll children from outside Kennedy Krieger as well. We have been rated at Level 5 (the highest level) by the Maryland Excels program.

The MICC is a wonderful place for children to learn and develop friendships. There are eight full-time spots for students, a full-time teacher, and an assistant in the MICC classroom. Our program runs year-round. Two evidence-based curricula are used: the "World of Words" curriculum, which has monthly themes like "Pets," "Ponds," "Wild Animals" and "Human Body," and the "Connect-4-Learning," where math, science, literacy and social-emotional development are targeted in an integrated, instructional and themed approach.

Each year, the MICC class attends four field trips, visiting the Maryland Zoo in Baltimore, the National Aquarium, Clark's Elioak Farm and the Irvine Nature Center. Also in the summer, we have "Water Days," ice cream parties and other wonderful events, like a visit from the zoo. For snack time, there is a healthy choice menu. To teach children about a healthy diet, we serve a fresh fruit or vegetable every day and a whole grain snack. Also, through the "Buddy Skills" program, MICC students learn how to be a friend to children with ASD. Visit CARD.KennedyKrieger.org for more information about the MICC classroom.

"MICC is so much more than a traditional early childhood education program," says the parent of a student who attended the class. "In addition to giving my child the opportunity to prepare for kindergarten, MICC helped him learn kindness, patience and compassion. He learned that the world is full of people of all different strengths and challenges, and that everyone is worthy of friendship."

CARD Occupational and Speech-Language Therapists Prepare Youth for Adulthood

By Sarah Welch, MS, OTR/L

The occupational therapists at the Center for Autism and Related Disorders (CARD) are thrilled to share big news with you! CARD's new expansion space (in the new building at 1741 Ashland Avenue) has several specially designed assessment and intervention suites. The largest and most specialized of these is an efficiency apartment, which will be used by occupational therapists and speech-language pathologists at CARD to provide exciting, motivating and authentic interventions that will help youth with ASD build the skills they need for success—now and as adults. What's more, CARD's new space is conveniently located near gift shops, stores and food establishments within and outside Kennedy Krieger Institute (there's even a Starbucks across the street!), which will allow for real-life practice. This expansion will enable us to serve more adolescents with ASD and to continue designing innovative therapeutic and instructional programming.

Our intervention services are offered in individual and group-based formats. Our current Life Skills program is a 12-week treatment that is co-facilitated by an occupational therapist and speech-language pathologist. Over the 12 weeks, adolescents and teens learn the foundation skills necessary to complete skills often needed on a day-to-day basis. The activities in which youth engage are highly motivating and help to build executive function skills (like planning, flexibility and self-organization), practical living skills (such as washing dishes), personal care skills, and so forth. Our Life Skills curriculum will expand soon to provide more in-depth training on topics such as independent living, money management, shopping and meal planning, navigating the community, and technology safety.

In addition to our intervention offerings, we provide comprehensive evaluations for teenagers transitioning to adulthood. These evaluations are focused on assessing key areas of development important for adulthood. During the evaluation, we assess a teen's safety awareness and effectiveness at self-care, completing chores and preparing food. For more information about our occupational therapy services, please call 443-923-7680.



Paving a Clearer Path for Families

By Megan Myatt, MS, CCC-SLP

The Center for Autism and Related Disorders' (CARD) unique diagnostic evaluation process often involves appointments with at least two—and up to five—providers. At the completion of a multidisciplinary team evaluation, families are provided with a great deal of information, including diagnoses, recommendations, referrals, resources and more! While this information is certainly invaluable, families may feel overwhelmed by all the information they receive. In an effort to organize all the new information families will receive during their child's evaluation process, CARD staff members designed the Passport system in 2017.

During their first appointment at CARD, families are given a blue folder containing a single piece of paper in the pocket. On this paper are designated spaces for each team provider to summarize the results of his or her evaluation, along with appropriate recommendations, referrals and additional information. Typically, these providers include a speech-language pathologist, occupational therapist, social worker or care coordinator, and physician or psychologist.

Families keep this folder in a safe place and bring it to all CARD appointments. The CARD professionals and staff members who meet with the family add information about the child's assessments to the folder, as well as helpful resources like handouts and applications for services. When a child has completed his or her evaluation process, parents have a collection of information, organized in a single space, from each professional. They may choose to use their folder of information and resources immediately—to set up appointments, begin therapy, etc.—or they may put the folder aside, referring to it later on, when they are ready to take the next steps.

Families often tell us how helpful the Passport system has been for them. Information from multiple professionals is neatly kept in one place—it's right at parents' fingertips when they have a question or want to share the information with another professional (e.g., their child's pediatrician or teacher). The folder also provides parents with an organized record that serves as a reference as their child gets older. More than 80 percent of families consistently bring their Passport folder to all CARD appointments. The result is improved and streamlined care coordination for families. This reduces family stress and increases the efficiency of the family's visits to CARD. We enjoy seeing families use their Passport folder so effectively!

Kennedy Krieger Institute
Center for Autism and Related Disorders
Team Evaluation Summary

Speech-Language Pathology		Occupational Therapy	
Diagnoses:		Diagnoses:	
Family Next Steps:		Family Next Steps:	
Provider Next Steps:		Provider Next Steps:	
Name:		Name:	
Phone: 443-923-		Phone: 443-923-	
Email: @kennedykrieger.org		Email: @kennedykrieger.org	
Medical/Psychology		Social Work	
Diagnoses:		Diagnoses:	
Family Next Steps:		Family Next Steps:	
Provider Next Steps:		Provider Next Steps:	
Name:		Name:	
Phone: 443-923-		Phone: 443-923-	
Email: @kennedykrieger.org		Email: @kennedykrieger.org	

An example of an evaluation passport

Preschool Anxiety Study By Roma Vasa, MD

Anxiety disorders are experienced by about 40 percent of children with autism spectrum disorder (ASD). Anxiety disorders can cause major disruptions in a child's development, and can make ASD symptoms worse. They can also interfere with a child's academic performance, make it difficult for a child to connect with peers at school, and negatively impact family life. Signs of anxiety in children with ASD include irritability, clinginess, avoidance of activities and sleep difficulties.

Research suggests that some children with ASD experience anxiety during the preschool years (ages 3–5), although very little research has been conducted with children in this age range. Early onset anxiety can lead to future anxiety and depression. Therefore, early detection and treatment of anxiety is important and can improve overall functioning throughout development.

We are launching a new study at the Center for Autism and Related Disorders (CARD) that focuses on studying anxiety in preschool children. We will examine the prevalence of anxiety as well as the different types of anxiety that can occur in young children. Participation in the study will consist of two to three sessions involving a parent and his or her child. We will conduct comprehensive assessments to evaluate anxiety in children with ASD, and to understand some of the possible risk factors that can cause anxiety in preschool-aged children with ASD. We hope this study will help to develop new treatments and improve the lives of children with anxiety and ASD.

Hot off the Press: The Pragmatic Rating Scale - School Age

By Rebecca Landa, PhD, CCC-SLP

Dr. Rebecca Landa's research team has been examining the development of children at high and low risk for autism spectrum disorder (ASD) and other developmental delays from infancy to school-age. At the same time, Dr. Landa has been conducting research to gather data on the effectiveness of a unique tool to assess pragmatic communication in children ages 4 to 18: The Pragmatic Rating Scale—School Age (PRS-SA).

These two lines of research have come together to generate important discoveries that now appear in an article, "Predictors of Pragmatic Communication in School-Age Siblings of Children with ASD and Low-Risk Controls," by Dr. Kathryn Greenslade, Ms. Elizabeth Utter and Dr. Landa. This article can be found in the *Journal of Autism and Developmental Disorders*. Read the full article at: <https://link.springer.com/>

Why Do We Need a Tool Like the PRS-SA?

Pragmatic communication includes language and non-language aspects of communication that impact the social appropriateness of one's communicative behavior. Certain factors—like how well one can follow along with what someone else is saying, how well one can judge what kind of information (and how much) to share with a particular communication partner, and how well one uses language to convey ideas and make them relevant to the situation at hand—are taken into consideration by a clinician when using the PRS-SA.

The PRS-SA enables a clinician to engage in a conversation with a child or teen, and observe and rate 21 different aspects of his or her communication behavior that impact the social appropriateness (pragmatics) of that behavior. There is no other assessment of pragmatic communication like the PRS-SA, yet such an assessment is of utmost importance for a number of reasons. Some of these reasons include the fact that all children with ASD have pragmatic communication difficulties, but these often go undocumented and untreated, and the fact that children without ASD (including some siblings of children with autism who have sub-clinical symptoms) have age-appropriate language skills and IQ, but have difficulties with pragmatic communication.

Without documenting pragmatic communication difficulties using a tool like the PRS-SA, these children and youth often fail to qualify for services. Without therapy to address these pragmatic communication difficulties, children and youth may be at increased risk for bullying and low self-esteem.

What We Found

We found that PRS-SA scores differentiated children with ASD from both children with milder developmental disorders, and children with neurotypical development. In addition, children's social communication behavior at age 14 and 24 months, as well as their expressive language skills at 24 months, predicted their pragmatic communication skills at 8 to 12 years old.

There are two big take-home messages here. Firstly, PRS-SA scores detect even mild pragmatic communication differences. We are continuing to enroll children and youth, with and without developmental challenges, in our study of the PRS-SA. Once we have enough participants, we will be able to identify the cut-off score that signals the need for social communication intervention.

Secondly, If a toddler shows low levels of social initiation at 14 months of age, is late talking, or shows other social communication delays at age 24 months, don't wait: Check in with a speech-language pathologist through your local Infants and Toddlers (birth to age 5) program to see whether early intervention is warranted. Getting off to a strong developmental start pays off later.

New Research Study: Social Communication, Interaction and Play Screener (SCIPS) By Melissa Janssen, MS, Senior Research Coordinator

Early detection of social and communication delays enables children to benefit from intervention while their brains are in a rapid phase of development. Based on our research following the development of hundreds of children, from infancy to school age, we have defined the early indicators of later social and communication delays. Using video from our research assessments of 1- and 2-year-olds who did and did not show early signs of social and communication delay, we developed an exciting, unique video-guided developmental screening tool.



This screener is called the Social, Communication, Interaction and Play Screener (SCIPS). Parents can complete this screener online, using a smart phone, iPad or computer. After logging in, parents watch pairs of videos contrasting children with and without delays. As the videos play, they hear an explanation of the signs of typical development versus risk for delay. These video pairs and the voice-over narration help parents accurately answer screening questions about their child.

Our goal is to make it easier for parents to recognize whether their 1- or 2-year-old could benefit from extra enrichment or even early intervention. While some children with early signs of a delay will ultimately catch up to age-expected developmental milestones, others do not. So, we have adopted a “why wait” philosophy to ensure that parents are equipped to act early and help boost their child’s developmental progress. There is no other screener like the SCIPS.

Our research will show whether the SCIPS is easier for parents to use than other existing screeners, and whether the SCIPS is more accurate than other screeners. To do this, we must enroll at least 200 children ages 12 to 36 months, including children whose parents are concerned about a social or communication delay (or even autism) and parents who have no concerns about their child’s development. Participating parents will complete an online consent form and three online developmental screeners, one of which is the SCIPS. All three screeners can be completed at home. Any information a parent provides about his or her child when completing the screeners is strictly confidential and accessible only to study team members. Within a month after completing the screeners, parent(s) will bring their child to our Child Development Lab for a play-based assessment (parents remain with the child the whole time).

You can help our study by participating or referring families with children in the SCIPS age range (12 to 36 months). Please visit KennedyKrieger.org/VGCR or email REACH@KennedyKrieger.org for more information.

SPARK Aims to Accelerate Autism Research By Bonnie Van Metre, MEd, BCBD, Senior Research Coordinator

The Center for Autism and Related Disorders (CARD) is one of a select group of 21 leading national research institutions chosen by Simons Foundation Autism Research Initiative (SFARI) to participate in a groundbreaking study, the Simons Foundation Powering Autism Research for Knowledge—SPARK for short.



SPARK is an online research initiative designed to speed up research and advance our understanding of autism to help improve lives. This study is sponsored by SFARI and is currently the largest autism study undertaken in the U.S. SPARK is collecting information and DNA for genetic analysis from 50,000 individuals with autism and their families in order to give researchers the information they need to improve treatment and achieve scientific advances as rapidly as possible.

Autism is known to have a strong genetic component. While we know that genetic factors contribute to autism, there is still so much we don’t know. By studying these genes and how they interact with environmental factors, researchers can better understand the causes of autism and link them to the symptoms, skills and challenges of those impacted.

SPARK aims to accelerate autism research by inviting participation from a large and diverse community, with the goal of including individuals with a professional diagnosis of autism and who, collectively, represent the full spectra of age, background, race, geographic location, socioeconomic status and sex. SPARK connects participants to researchers, offering them the opportunity to impact the future of autism research and participate in any of the multiple studies offered through SPARK. Another goal of SPARK is to elicit feedback about living with autism from individuals and parents of children with autism to develop a robust research agenda that is meaningful to them.

At CARD, the SPARK effort is being led by Dr. Ericka Wodka, supervising neuropsychologist at CARD and assistant professor of psychiatry and behavioral sciences at the Johns Hopkins University School of Medicine, and Dr. Rebecca Landa, executive and founding director of CARD. So far, CARD has connected more than 1,700 individuals with autism and their families with the SPARK project. These families receive support during registration and throughout the study. The SPARK research team participates in community events and collaborates with other autism organizations to help inform all families with a family member with autism about this exciting opportunity.

To learn more about SPARK, including how to participate in the study, visit sparkforautism.org/KKI or contact us at SPARKStudy@KennedyKrieger.org or 443-923-7598.

Kennedy Krieger's SYNGAP1 Clinic

By Alyssa Blesson, MGC, CGC, and Constance Smith-Hicks, MD, PhD



Kennedy Krieger Institute launched a multidisciplinary outpatient clinic for individuals with SYNGAP1-related disorder in 2017. SYNGAP1-related disorder is an emerging disorder caused by genetic changes in the SYNGAP1 gene. This gene encodes a protein present at the gaps (synapses) between nerve cells and involved in communication between neurons. The genetic changes (mutations) that cause this disorder disrupt the function of the protein and have a substantial impact on development.

Commonly reported effects of the disorder include, but are not limited to, global developmental delays, intellectual disability, autism spectrum disorder, sensory processing difficulties, disruptive behaviors and epilepsy. The severity and onset of symptoms can vary among individuals, but symptoms generally begin in the first two years of life. Currently, there is no cure or specific treatment for SYNGAP1-related disorder.

To further define and improve the medical management of this disorder, the Kennedy Krieger-Johns Hopkins SYNGAP1 Program was created for individuals with an established diagnosis of SYNGAP1-related disorder. This program has both a clinical and a research component. The clinic employs a multidisciplinary approach to care. The clinical team is comprised of clinicians from the Center for Autism and Related Disorders and the Kennedy Krieger Division of Neuropsychology. Team members have extensive expertise in autism spectrum disorder and include an assistive communication specialist, occupational therapist, genetic counselor, neurologist, neuropsychologist and speech-language pathologist. The research program is geared toward defining the clinical characteristics of the disorder and developing outcome measures and biomarkers.

The SYNGAP1 Family Meet-Up in Baltimore, Maryland, was hosted at Kennedy Krieger in November 2017. This meeting was organized in collaboration with the Bridge the Gap SYNGAP Education and Research Foundation (ERF). Bridge the Gap SYNGAP ERF is a nonprofit organization founded by parents and family members of individuals with SYNGAP1-related disorder, with the mission of raising awareness, providing education and funding research for SYNGAP1-related disorder. The meeting provided families with a platform to interact with and learn from each other, to learn from clinicians and scientists during formal and informal presentations, to enroll in the natural history study/patient registry, and to participate in research evaluations.

As more individuals worldwide with SYNGAP1-related disorder are diagnosed, and our understanding about the disorder advances, the Kennedy Krieger-Johns Hopkins SYNGAP1 Program will continue to serve as a valuable resource for medical management, research and education to advance the care of this patient population. For more information or to schedule an appointment, call **443-923-2778**.

Connecting Language Using Books

By Sharon Conty, MS, CCC-SLP, and Alyson Fagon, MS, CCC-SLP

This past summer, speech-language pathologists Sharon Conty and Alyson Fagon at the Center for Autism and Related Disorders (CARD) offered the center's second annual summer CLUB (Connecting Language Using Books) group. CLUB was created in 2017 as a summer program offering group speech-language therapy to address reading, comprehension and classroom-based social skills.

Two groups—one for children ages 6 to 8, and one for children ages 9 to 11—met one to two times per week for 90 minutes to read modified, age-appropriate chapter books with the assistance of clinicians. Each group consisted of four to six children with similar ages, language abilities and needs. Each group was structured to recreate a small classroom setting while providing language strategies to increase social awareness and understanding of relevant information in text.

CLUB clinicians introduce children to a variety of language strategies and help them practice these strategies to better understand written text and social schemes. Before reading the chapter for the session, the clinicians introduce pertinent vocabulary. In reading the chapter, they focus on understanding emotions, making inferences and predictions, and problem solving. Children are encouraged to use text, visuals and prior knowledge and life experiences to define vocabulary, answer comprehension questions, and solve conflicts that characters encounter in the story.

Clinicians individualize objectives for each child and may address skills such as responding to “Who, What, When, Where and Why?” questions; making logical inferences and predictions; problem solving; and defining vocabulary. They don't address decoding and reading mechanics, because the focus is on story comprehension and meaning-related literacy skills. They do, however, provide and informally address writing content strategies. Children do not need to be able to write on their own to participate in these groups.

To address social skill development, clinicians encourage children to make appropriate greetings, participate in conversations, share opinions and negotiate in group activities. Social goals are clearly identified so children may practice them outside of the sessions. This promotes generalization. Skills addressed may include eye contact and body orientation, maintaining conversations through commenting and asking questions, waiting one's turn in conversation, and using appropriate greetings depending on each child's need. Homework is given at the end of each session and discussed at the beginning the next to promote self-advocacy and conversation skills.

Our summer CLUB groups offer opportunities for learning new skills and having fun! Parents have reported that their children were excited about the group sessions, and that they demonstrated growth, over the course of the summer, in their social skills, and in their abilities to comprehend and explain what they read. We look forward to next summer's CLUB groups and hope to expand our offerings to a wider age range of children. Please watch for information regarding next summer's groups in future newsletters.

Email Fagon@KennedyKrieger.org and Conty@KennedyKrieger.org for more information.