WHEN THE PANDEMIC BEGAN well over two years ago, I recall telling my center colleagues that we should keep two words front and center in our minds and actions: Compassion and flexibility. The pandemic placed a strain on our faculty, trainees, and staff, many of whom juggled remote work via Zoom with at-home schooling for their kids. All of us experienced the stress caused by being isolated from our friends, families, and coworkers. It was important to be as flexible as possible to accommodate each person’s unique situation.

Compassion and flexibility were also essential in meeting the needs of children and adults on the autism spectrum, many of whom had their daily routines and services severely disrupted by the pandemic. The strain experienced by people on the spectrum and their families has been documented in research conducted at our center and was evident from our day-to-day interactions with families in our clinic and research studies. Our clinicians turned to telehealth to meet the growing need for services, while our research staff donned their masks and face shields and smiled with their eyes as they continued to conduct our research studies. We revamped our clinic procedures to address the growing wait list for services. Remarkably, we were able to reach our research goals and successfully renew our National Institutes of Health (NIH) Autism Center of Excellence program, receiving over $12M in new research funding. I am especially proud of what our center’s faculty, staff and trainees have been able to achieve despite the distinct challenges of the past two years.

Our center’s successes and achievements were only possible because of the many families who were willing to be flexible and continue to partner with us through all the changes. Participants in our studies never fail to make us smile with their ingenuity. In the picture below right, a child used our study materials to creatively show his support for Duke! In this 2022 annual Impact Report, I hope you enjoy reading about our research, clinical services, community advocacy and outreach, and trainees. Thank you, as always, for your partnership and commitment to improving the lives of autistic individuals and their families!

Warm regards,

Geraldine Dawson, PhD
Director, Duke Center for Autism and Brain Development
The team of researchers includes Duke faculty from psychiatry, pediatrics, biostatistics and bioinformatics, computer and electrical engineering, and civil and environmental engineering.

A second project, led by Benjamin Goldstein, PhD, associate professor of biostatistics and bioinformatics, and Gary Maslow, MD, MPH, associate professor of psychiatry and behavioral sciences and co-director of the Division of Child and Family Mental Health & Community Psychiatry, will extend earlier work led by Matthew Engelhard, MD, PhD, which developed an algorithm to screen for autism based on information obtained from an infant’s early medical records. In the newly funded project, the team will use artificial intelligence to analyze a much larger data set with the goal of developing an early detection algorithm that could be used by health systems outside of Duke. The team will examine 260,000 health insurance claims, including those from 6,000 children diagnosed with autism, from birth to 18 months.

That data also will be used to identify the nature of early medical conditions associated with a later diagnosis of autism. Based on the algorithm, a team led by Lauren Franz, MBCNB, MPH, assistant professor of psychiatry and behavioral sciences, will develop support tools to help primary care providers screen and guide patients. The goal is to develop an objective way to alert pediatricians and other providers that an infant has a higher likelihood of autism and then to automatically provide advice for how to link parents with appropriate services for their child.

The third project, led by Kimberly Carpenter, PhD, assistant professor of psychiatry and behavioral sciences, and David Carlson, PhD, assistant professor of civil and environmental engineering, will use artificial intelligence to monitor brain wave activity, which is synchronized with videotaped behavior of three- to six-year-old children diagnosed with autism. The data will be used to identify specific brain networks associated with behaviors characteristic of autism. The team will use this information to validate a brain-based biomarker, or neural signature, that is characteristic of autism which can be used in clinical trials to better understand how therapies influence brain function in autism.

By the Numbers

- $46M total sponsored research funding
- 14 awards, including 7 led by junior faculty as principal investigators
- 19 research studies
- 4,619 participants enrolled across all studies
- > 6,500 individuals enrolled in the Duke Autism Research Registry

Research

Duke Center for Autism Awarded $12M Research Grant to Use Artificial Intelligence to Detect Autism

The Duke Center for Autism and Brain Development has been awarded a $12 million federal grant to develop artificial intelligence tools for detecting autism during infancy and identifying brain-based biomarkers of autism. The grant, from the National Institute of Child Health and Human Development, extends the Duke Autism Center of Excellence research program for an additional 5 years. Geraldine Dawson, PhD, director of the Duke Center for Autism and Brain Development and professor of psychiatry and behavioral sciences, will lead a team of researchers that includes Duke faculty from psychiatry, pediatrics, biostatistics and bioinformatics, computer and electrical engineering, and civil and environmental engineering.

“We are thrilled to receive this award, which allows Duke to remain at the forefront of autism research,” Dawson said. “Our goal is to use advanced computational techniques to develop better methods for autism screening that will reduce known disparities in access to early diagnosis and intervention.”

In a project led by Dawson and Guillermo Sapiro, PhD, professor of electrical and computer engineering, researchers will extend earlier work in which they developed a digital app, deployed on a smart phone or tablet, to videotape young children’s behavior. Artificial intelligence based on computer vision analysis automatically codes the videotapes to identify behavioral characteristics of infants and toddlers who are later diagnosed with autism and track their development. Using a computer, the app can detect differences in the child’s facial expressions, vocalizations, and gaze that are early signs of autism. The new award will extend this work in two ways: First, the team has developed a version of the app that parents can download and use at home. The previous version was administered in the clinic. The goal is to provide access to early detection of autism signs to families who might not be able to travel to a medical center for an assessment, including families from rural locations and those who lack the resources to travel to Duke. Second, in the newly funded study, families will use the app over time to track changes in their child’s development and assess responses to early intervention.

The grant, from the National Institute of Child Health and Human Development, extends the Duke Autism Center of Excellence research program for an additional 5 years.

Duke Center for Autism Director Geraldine Dawson, PhD, will lead a multidisciplinary Autism Center of Excellence (ACE) research team to develop artificial intelligence tools for detecting autism during infancy and identifying brain-based biomarkers of autism. Several team members gathered to kick-off ACE program planning. Pictured left to right: Elizabeth Sturdivant, MS, MD, David Carlson, PhD, Elena Tenenbaum, PhD, Benjamin Goldstein, PhD, Lauren Franz, MBCNB, MPH, Mathias DiMartino, PhD, Maura Sabatoss-Dewto, PhD, Jordan Grapel, MS, Geraldine Dawson, PhD, Lori Reinhart-Mercer, RN, Brian Eicchner, MD, Raghav Swaminathan, Jill Howard, PhD, Moira Rynn, MD.

“We are thrilled to receive this award, which allows Duke to remain at the forefront of autism research. Our goal is to use advanced computational techniques to develop better methods for autism screening that will reduce known disparities in access to early diagnosis and intervention.”

Geraldine Dawson, PhD
Medical Conditions During the First Year of Life
Provide a New Way to Detect Autism Earlier

In research underway at the Duke Center for Autism, investigators are exploring whether information from an infant’s medical record can reliably predict whether the infant will later be diagnosed with autism. The figure shows the number of encounters with healthcare over time (30, 60, 90, 180, 270, and 360 days) among children who later were diagnosed with autism and those who were not. The lines indicate the median number of encounters, and the shading indicates the 25th and 75th percentiles, respectively.

By addressing medical conditions, such as sleep and GI problems, very early in life, it is hoped that children will be better able to benefit from behavioral interventions and have improved quality of life. This innovative work has led to new funding from the National Institutes of Health (NIH). Engelhard recently received an NIH K01 Mentored Research Scientist Career Development Award, which will provide 5 years of support and protected time for a mentored career development experience. His goal is to use analysis of the medical records to develop tools for prediction of autism, ADHD, and other neurodevelopmental conditions, such as language delay, and to explore how to incorporate the prediction algorithms into regular clinical care at Duke.


Duke Center for Autism researchers are studying how co-occurring ADHD symptoms influence patterns of EEG activity and exploring how children’s brain activity patterns are related to their ability to socially interact and communicate with others.

Disentangling the Brain Basis of Autism Versus ADHD

Despite significant advances in understanding the biological basis of autism, clinical trials continue to rely on subjective clinical observation and caregiver report measures as their primary outcome measures. Objective and biologically based markers (“biomarkers”) for diagnosing and assessing response to therapies in autistic individuals are still needed. Electroencephalography (EEG) measures of brain waves offer a promising biomarker that can be reliably collected from children of different ages and cognitive abilities. Despite significant advances in the exploration of EEG as a dependable biomarker, there remains little research on how the presence of co-occurring conditions can impact these EEG biomarkers in young autistic children. This is especially important because up to 60% of autistic individuals also have co-occurring conditions, such as attention-deficit hyperactivity disorder (ADHD). Importantly, although ADHD and autism share many common features and may have shared genetic and neurobiological indicators, previous EEG studies suggest that there are unique patterns of brain activity that differentiate these diagnoses. To explore these differences and to uncover another reliable biomarker for autism, the Duke Center for Autism is working to understand these unique patterns.

Neuroscientist Kimberly Carpenter, PhD, leads a multidisciplinary Duke Center for Autism and Brain Development research team studying how co-occurring ADHD symptoms influence patterns of EEG activity and examining whether variations in levels of social abilities are correlated with individual differences in patterns of EEG. Clarifying the extent to which ADHD symptoms influence underlying brain activity has important implications for addressing differences with identifying reliable brain-based biomarkers in autism, a highly heterogeneous condition.

“As clinical trials seek to demonstrate the effects of various therapies and supports on brain function, it is critical to understand the different patterns of neural activity in autistic individuals with and without co-occurring ADHD.”

Kimberly Carpenter, PhD
Parent Coaching Shows Promise for Autistic Children with ADHD

Study shows telehealth-provided parent coaching improves social and communication skills

A bout half of autistic children also are diagnosed with attention-deficit/hyperactivity disorder (ADHD). Often, they receive their diagnosis later and have more behavior, school functioning, and friendship challenges than autistic children without ADHD. Medications are less effective when autism and ADHD occur together, and no therapies have been proven to support the unique needs of autistic children with ADHD.

“There’s a huge clinical care gap here that needs urgent attention and action,” said Lauren Franz, MBChB, MPH, associate director of the Duke Center for Autism and a child and adolescent psychiatrist.

In a National Institutes of Health (NIH) funded Autism Center of Excellence research study, Franz and her team took important first steps to address the intervention gap by developing novel telehealth-delivered caregiver coaching based on Early Start Denver Model (ESDM) principles adapted for five through 10-year-old autistic children with ADHD. ESDM is a scientifically proven intervention approach that improves communication and cognitive skills in young autistic children. Using this approach, caregivers learn strategies they can use with children during their everyday activities, such as mealtime and playtime, to promote social and communication skills.

Early interventions have been shown to improve communication and cognitive skills in young autistic children. Using the Early Start Denver Model (ESDM), caregivers learn strategies they can use with children during their everyday activities, such as mealtime and playtime, to promote social and communication skills.

“Perhaps most importantly, we adapted the ESDM approach to a telehealth platform. Telehealth is cost-effective and can help therapists better understand each family’s unique context and routines, and with it, we can reach more families who are seeking our help,” said Franz. “Because of how often autism and ADHD overlap, and the increased challenges when they do, it is crucial that children and their caregivers have access to effective supports.”

Franz and Howard offered eight weekly, hour-long telehealth-delivered coaching sessions to 24 caregivers, who gave the coaching high ratings on three validated measures of acceptability, appropriateness, and feasibility. The children participating in the trial showed improvements in their social and communication abilities as well as decreases in ADHD-related challenges. Caregivers also reported decreases in their stress levels. Given these encouraging findings, the team is planning to conduct a larger, randomized trial. If the results of this trial are positive, this research will expand intervention options for school-age autistic children who also have ADHD.

Lauren Franz, MBChB, MPH


Sleep Difficulties Show Up Early in Children with ADHD

S leep disturbances in early childhood are associated with early signs of attention-deficit/hyperactivity disorder (ADHD). Duke Center for Autism researchers have found. In a study funded by the National Institutes of Health (NIH), center researchers studied 646 children over time, and found that toddlers whose parents reported high levels of sleep problems, such as bedtime struggles and nighttime waking, also were more likely to have difficulties in sustaining attention and hyperactivity, which are behaviors related to ADHD. Naomi Davis, PhD, assistant professor of psychiatry and behavioral sciences and a psychologist and researcher at the Duke Center for Autism, led the study.

Families in the study filled out questionnaires about their children’s behavior and development at two time points, first when children were 18-24 months old and again when children were around age three. Davis and her team grouped children based on parent-reported levels of ADHD-related behaviors when they were three years old. The investigators found that those who were deemed “high risk” for ADHD had significantly more parent-reported sleep problems compared to the three-year-olds who were at lower risk for ADHD.

Importantly, the study team noted that these sleep-behavior associations were also true for children over time. Toddler sleep problems were associated with preschool ADHD symptoms, and toddler ADHD symptoms were associated with preschool sleep problems. These associations were found over time, even when the researchers took into account associations between sleep and ADHD in the preschool period.

Researchers have studied naturalistic and stimulant interventions for sleep disorders in children with autism spectrum disorder. Dissemination, and Implementation Subcommittee of the American Academy of Sleep Medicine, Duke Center for Autism Director Geraldine Dawson, PhD, co-author, “Practice guideline: Treatment for insomnia and disrupted sleep behavior in children and adolescents with autism spectrum disorder,” addressing recommendations for autistic children.

For those with ADHD, Davis explains that more research is needed and a holistic approach will work best.

“Put simply, the sleep-behavior association seems to start early and hang together over time,” said Davis. “Because sleep and attention problems seem to be associated over time, we need to work to find strategies that help identify young children who are at risk for both these challenges. Supports and interventions will likely be more effective if a whole-child approach is used — one that starts early and addresses both sleep and behavior challenges together.”

Jessica Lunsford-Avery, PhD, also an assistant professor of psychiatry and behavioral sciences and a co-investigator on the study with Davis, shared some of the research findings in a poster, “Associations between Sleep Problems and ADHD Symptoms in Early Childhood: A Longitudinal, Primary-Care Based Study,” at the Associated Professional Sleep Societies Annual Meeting in June 2022.

“We need to dig deeper into the factors and implications of early sleep and attention problems to create supports and solutions that work for families,” said Davis.
Researchers have designed a digital app that captures an infant’s responses to specially designed movies — including their eye gaze, facial expressions, body movements, and vocalizations. The responses are recorded using the device’s camera and analyzed using artificial intelligence.

Designing New Tools to Detect Early Signs of Autism in Babies

In the United States, the average age of autism diagnosis is four to five years of age, and many children are diagnosed even later. This means that many young children miss out on the opportunity for early behavioral interventions, which have been shown to improve children’s language, cognitive, and social abilities. New research finds that early signs of autism are present much earlier than when a diagnosis is typically made. In fact, for many autistic children, early signs of autism — paying less attention to people, smiling less, failing to turn when their name is called, and using fewer vocalizations — are apparent between six and 12 months of age. The first year of life is a time of rapid brain development when infants are learning about the social world and how to communicate with others. If intervention could begin as soon as early signs appear, perhaps children would have even better outcomes.

Currently, there are no valid screening tools for detecting autism in infants. A Duke Center for Autism and Brain Development team of investigators led by Geraldine Dawson, PhD, and Guillermo Sapiro, PhD, received funding from the National Institute of Mental Health to create and validate an autism screening tool that would be appropriate for infants as young as 6 months of age. They set out to develop a tool that was easy to use by both parents and pediatricians and could accurately and reliably detect early behavioral signs of autism that are seen in infants. To achieve their goal, they designed a digital application (app) that parents can download on their smart phone or tablet at home. The app, which is available in English and Spanish, consists of brief, developmentally appropriate, specially designed movies that are shown to the infant on the parent’s device while sitting on their parent’s lap. The infant’s responses to the movies — including their eye gaze, facial expressions, body movements, and vocalizations — are recorded by the camera in the device and then automatically coded using artificial intelligence and computer vision. Using these methods, the data collected shows whether the child is more interested in the social or non-social elements shown in the movies, and tracks their emotional responses and other behavioral signs of autism. Once the infants are 18–24 months of age, psychologists on the team offer a free diagnostic evaluation to any toddler for whom there is a developmental concern. The research project, called the Sense of Autism in Babies (SOAB) app, which is available in English and Spanish, is being conducted in collaboration with Duke Primary Care providers.

“We have enrolled more than 1,000 infants already, and early results are promising that this novel and scalable approach will offer accurate, reliable screening for autism in infants,” said Brian Eichner, MD, a Duke Primary Care pediatrician and assistant professor of pediatrics. “Our work could lead to an easy-to-use, objective diagnostic tool for doctors and parents, and could mean that kids get access to provided therapies earlier than most do now.”


“Our work could lead to an easy-to-use, objective diagnostic tool for doctors and parents, and could mean that kids get access to provided therapies earlier than most do now.”
Brian Eichner, MD

Do Early Therapies Help Very Young Children with or at High Likelihood for Autism?

I
an analysis of reviews assessing therapeutic or educational interventions for very young autistic children and infants who have higher likelihood of an autism diagnosis, a team of researchers led by Duke Center for Autism Associate Director Lauren Franz, MBChB, MPH, found certain types of interventions can provide benefits. The analysis, “Early intervention for very young children with or at high likelihood for ASD: An overview of reviews,” was published in Developmental Medicine & Child Neurology, May 18, 2022, and covered in multiple news outlets including Science Magazine. In it, researchers found that certain types of interventions — called naturalistic developmental behavioral interventions, developmental interventions, and behavioral interventions — can provide benefits. The researchers pointed out that the field is still in need of larger, high quality studies, and many questions remain to better understand how to best tailor interventions to the unique needs of each child.

“We have a growing evidence base that supports the importance of early intervention and its ability to promote communication skills and help facilitate social interactions and relationships. However, there are limitations to this evidence base, which leaves families with some work to do in order to understand which approach is the best fit for themselves, their child, or their family,” said Franz. In addition to news coverage, study highlights were shared in Developmental Medicine & Child Neurology’s YouTube podcast.


“The Incredible Impact of Early Intervention

Listen to the Autism Weekly podcast with special guest Dr. Lauren Franz

Dr. Lauren Franz, MBChB, Child & Adolescent Psychiatrist and Associate Director, Duke Center for Autism and Brain Development

Duke Center for Autism Associate Director Dr. Lauren Franz joined the Autism Weekly podcast to discuss the center’s research, the power of early interventions, and the need for healthcare access.
Eye Tracking Biomarker Accepted into FDA Biomarkers Qualification Program

To help find a solution, the National Institutes of Health (NIH) has invested $60 million in the Autism Biomarkers Consortium for Clinical Trials (ABC-CT), with the goal of making scientific advancements and finding autism biomarkers that track brain function. Prior to 2022, the ABC-CT, which is led by Yale and includes the Duke Center for Autism, Harvard, UCLA, and the University of Washington, validated a biomarker based on eye-tracking for use in autism clinical trials. The ABC-CT team sought to quantify this difference, and in doing so, potentially develop another biomarker of autism. Nearly 400 children across all ABC-CT sites, ages 6–11, participated in this most recent study, completing clinical assessments and watching several short, fun videos that included social scenes and faces. Scientists compared differences in attention when watching social scenes, specifically looking at the percentage of time participants spent looking at faces compared to the time they spent looking at any other area on the screen. The team published its findings, “The Autism Biomarkers Consortium for Clinical Trials: Evaluation of a battery of candidate eye-tracking biomarkers for use in autism clinical trials,” in Molecular Autism in March 2022.

“The study found that autistic children spent less time looking to the faces across all social scenes compared to their non-autistic peers, and we developed a way to calculate that percentage,” explained Marika Coffman, PhD. "The study found that autistic children spent less time looking to the faces across all social scenes compared to their non-autistic peers, and we developed a way to calculate that percentage." 

Marika Coffman, PhD

Duke Researchers Map Downstream Effects of a Small Genetic Mutation on Brain Function

Although autism has many different causes, science has shown that, in some cases, it is small changes in the structure of proteins that determine how brain cells function and cause challenges in social and communication skills. “We know that mutations of specific genes can contribute to autism, intellectual disability, epilepsy, and other neurodevelopmental diagnoses. Creative science is required to understand how gene mutations lead to these diagnoses,” explains Scott Soderling, PhD, a cell biologist and the George Barth Geller Distinguished Professor for Research in Molecular Biology at Duke University. Soderling leads a team of investigators who have conducted research using gene editing in animal models, new methods to target proteins in specific types of brain cells, and machine learning to uncover the precise biological basis of autism. Their work aims to understand how natural cell responses could be co-opted in ways that could improve social and communication skills for autistic individuals. Their work confirmed that this mutation is one of the causes of autism. Next, the researchers will investigate the connection further, testing whether restoring levels of Scn2a improves brain function that results in increased social and communication skills. Their work could help discover new therapeutic strategies for treating autism and could also be applied to other conditions such as Alzheimer’s Disease, Parkinson’s Disease, depression, and many others.

![The photo shows the experimental setup for a typical eye-tracking study. While the child watches the movie, the child’s gaze is tracked using an invisible infrared light that illuminates the pupil and is used to determine gaze direction.](https://example.com/eye-tracking-study)
Between 2016 and 2020, the number of children ages three to 17 years diagnosed with anxiety grew by 29 percent, and those with depression by 27 percent, according to a US Department of Health and Human Services study published in the *Journal of the American Medical Association: Pediatrics*. Even before the pandemic, research had shown that nearly half of autistic individuals also have anxiety, and many are diagnosed with another mental health issue. The findings suggest concerning changes in child and family well-being after the onset of the COVID-19 pandemic.

“The pandemic has been hard on our children, but for autistic kids, it has been particularly difficult — with the constant changes in routines, structures, and resources,” says Nathan Copeland, MD, MPH, assistant professor of psychiatry and behavioral sciences and a Duke Autism Clinic psychiatrist. In the second year of the global pandemic, Copeland and the clinic’s team of providers, including psychologists, psychiatrists, social workers, and nurses, navigated the exponential surge in need for mental health care services and supports by adapting behavioral health care therapy and evaluations to the Duke telehealth platform.

“COVID, ironically, has made us leave our walls. When patients could no longer come to us, we had to figure out how to go to them. The more we can tear down the walls, the more people and the community can be let in. Our ability to pivot to telehealth has made it easier for some kids to receive care.”

Although telehealth allowed clinic providers to pivot and meet families’ needs, two years later, as Copeland explains, “Things are still not back to the way we were before, and for many stressed families, they just do not feel there is an end in sight.”

In a Duke Health Media Briefing, covered in multiple national news outlets, Copeland and Gary Maslow, MD, MPH, associate professor of psychiatry and pediatrics and co-director of the Division of Child and Family Mental Health & Community Psychiatry, explained the current crisis, calling it the “next wave of the pandemic.”

“The amount of resources we put into fighting COVID, a fraction of that would make a huge difference in making treatment available for those who need it, and for supporting parents and families so they can care for their children,” Maslow said. “There is beginning to be momentum at the federal and state level to do that, and hopefully at the local and community level we can sustain that and really have a robust response to say every child who has a mental health condition needs support.”

Even before the pandemic, research had shown that nearly half of autistic individuals also have anxiety, and many are diagnosed with another mental health issue.

BY THE NUMBERS

- 689 total number of diagnostic evaluations provided (Duke Autism Clinic and research studies)
- Duke Autism Clinic services provided
  - Autism diagnostic and evaluation services
  - Autism intervention and therapies
  - Consultation services
  - Referral services
  - Psychiatric evaluations
  - Medication management
- Comprehensive, coordinated patient care services offered in collaboration with Duke Health
  - Neurology
  - Speech language therapy
  - Eating disorders
  - Primary care
  - Gastroenterology
  - Occupational/Physical therapy
  - Medical genetics

Meeting the Needs of Families During the Pandemic

An autism diagnosis relies heavily on an assessment of social and communication skills. Until 2020, a confident autism diagnosis could be made only in-person, using a play-based assessment tool that measures social communication and the other key indicators of autism, including restricted/limited interests and repetitive behaviors. Not surprisingly, face coverings which mask facial expressions muddle the effectiveness of this approach as a reliable diagnostic tool.

When the COVID pandemic shut down many in-person visits, autism clinicians worldwide considered new options and found solutions for observing young children’s behavior via telehealth. These new methods use standardized activities that are observed and assessed by a trained autism clinician, can be used in a virtual environment and have been shown to reliably diagnose autism in children.

“Right away, we were worried about what the mandatory shutdown of in-person visits would mean for the families who need us and how we were going to make sure our wait list didn’t grow,” said Saritha Vermeer, PhD, a child psychologist with the Duke Autism Clinic. “The switch to telehealth may have been easier for some of our medical colleagues. Meanwhile, we relied on the methods that involved direct interaction with a child or adult — which is an excellent social communication barometer.”

“COVID disrupted this approach, which relied on in-person interactions, so we set aside our traditional thinking and got innovative,” said Tyler Higgs, PhD, also a psychologist at the Duke Autism Clinic.

Using telehealth, Vermeer and Higgs, along with fellow clinic psychologists Jill Howard, PhD, and

Nathan Copeland, MD, MPH

“COVID, ironically, has made us leave our walls. When patients could no longer come to us, we had to figure out how to go to them. The more we can tear down the walls, the more people and the community can be let in. Our ability to pivot to telehealth has made it easier for some kids to receive care.”

Nathan Copeland, MD, MPH

Continued on page 16
and Rachel Aiello, PhD, adjusted the clinic’s typical two-day, in-person autism assessment for younger children to a one-day, telehealth-based assessment and feedback session, saving time and travel for families, and helping to address the months-long waitlist created by the pandemic shutdown. By fall 2021, Duke Autism Clinic diagnosticians were up and running at pre-pandemic levels, assessing toddlers and school-aged children and meeting families to provide feedback on autism diagnoses. The temporary adjustment to offering one-day telehealth assessments and feedback sessions worked well for younger children in other ways, too. “We were able to get an ‘up-close and personal view’ of the child in their own home or familiar setting, where they tend to be much more relaxed. Some families were spared the stress and costs of travel and overnight stays. It seemed even easier for caregivers, other family members, and interpreters to participate, if that is what the family requested,” said Vermeer. “As it turns out, a reliable autism diagnosis can be done extremely effectively and in a way that opens the door to more families that need us,” said Higgs.

NC-PAL Rural Provider Consultation Program Expands as Need for Mental Health Care Increases

More than 70% of autistic children and 35–50% of autistic adults also have at least one mental health diagnosis, a rate much higher than that of the general population (8-20%). Ideally, patients find quality care from a licensed psychiatrist or psychologist trained to care for autistic patients and to assist their families in their support. In predominantly rural states, shortages of trained mental health providers mean access is limited and patients will rely more heavily on their primary care doctors or pediatricians.

In collaboration with the Duke University School of Medicine Department of Psychiatry & Behavioral Sciences and the North Carolina Department of Health and Human Services, Duke Autism Clinic clinicians helped launch the North Carolina Psychiatry Access Line (NC-PAL). The free provider-to-provider consultation service supports primary care providers and pediatricians who have questions about patient behavioral health or medication management. Since its inception, additional funding has helped expand NC-PAL, which now integrates a perinatal consultation program in partnership with The University of North Carolina at Chapel Hill. Nicole Heilbron, PhD, associate director of the Duke Center for Autism, and Gary Maslow, MD, MPH, associate professor of psychiatry and behavioral sciences and co-director of the Division of Child and Family Mental Health & Community Psychiatry, are co-program leaders for NC-PAL. As of fall 2021, NC-PAL had received more than 1,000 pediatric calls and 522 perinatal calls from 617 providers across 48 NC counties. “In national surveys, primary care providers grade themselves as ‘fair’ or ‘poor’ in their expertise of autism, while 30 of North Carolina’s rural counties have no psychiatrist or psychologist to consult. With NC-PAL, we can make connections to bring that expertise to every corner of the state,” said Heilbron.

Community Outreach & Advocacy

Autism Acceptance Month 2022

Rep. Jessica Benham (D-PA), one of only a handful of legislators who self-disclose as autistic, headlined the Duke Center for Autism and Brain Development Autism Acceptance Month program in April 2022. She shared her personal story, explaining how her experiences influence her legislative efforts, especially her work to secure equitable access to high-quality healthcare and public education for autistic people. After her presentation, “Overcoming Stigma, Not Autism: Why Being Autistic Makes Me a Good Legislator,” Duke University students enjoyed a small-group question and answer session with Rep. Benham, at which she shared advice on building self-confidence and self-advocacy skills in a world she said is “built for neurotypical people.”

The center’s “What’s 1 Thing?” Autism Acceptance Month social media campaign sought input from our followers on ways to “make the world more inclusive for neurodiverse people,” “make the workplace more inclusive,” and “help parents of neurodiverse children.” Responses came from all over the world offering practical and life wisdom such as “Educate by example” and “Begin the discussion at home. Accepting children become inclusive adults.”

What’s 1 thing?

“See the person first. We are not all the same. Realize our individuality.”

“Begin the discussion at home. Accepting children become inclusive adults.”

“Educate by example. Show empathy.”

“Be patient. Listen.”

“What’s 1 thing? Expect the best and acknowledge success.”

“In national surveys, primary care providers grade themselves as ‘fair’ or ‘poor’ in their expertise of autism, while 30 of North Carolina’s rural counties have no psychiatrist or psychologist to consult. With NC-PAL, we can make connections to bring that expertise to every corner of the state,” said Heilbron.
Community Outreach & Advocacy

Autism Acceptance Month 2022

Throughout the year, the center responds to requests from news media, and Autism Acceptance Month is no exception. Duke Center for Autism team member Raghav Swaminathan shined in the NC Spectrum News story, “Duke research shows benefits of neurodiversity in the workforce,” highlighting the importance of inclusion in the workplace and explaining the value and dignity that comes from work.

BY THE Numbers

• 7,730 combined followers on Facebook and Twitter
• Facebook followers up 35%
• IG followers up more than 100% doubled
• Twitter followers up nearly 40%

Center Welcomes New Members to its External Advisory Leadership

The Duke Center for Autism and Brain Development benefits from collaborative partnerships with autistic individuals and their families, educators, advocates, business leaders, community stakeholders, and national leaders in autism research. In 2022, we welcomed new members to our two primary external advisory groups, the Autism Center of Excellence (ACE) Advisory Committee and the ACE Community Engagement Advisory Board.

ACE Advisory Committee

The ACE Advisory Committee members serve as advisors to investigators, providing insights across the multiple studies that leverage the ACE award. Most recently, the center welcomed Morénike Giwa Onaiwu, MA, author, advocate, and member of the Interagency Autism Coordinating Committee, to this committee.

ACE Community Engagement Advisory Board

The ACE Community Engagement Advisory Board members provide perspectives and advice to support community-engaged research priorities, increasing the impact of scientific discoveries on the lives of autistic individuals. In 2022, the center welcomed three new members to the board: Kristin Bell, EdD, Executive Director, Exceptional Children’s Department, Durham Public Schools; Kerry Morrison, PhD, parent advocate and District Secondary Coordinator at Vance County, NC, Schools; and Melinda Plue, MSW, LCSW, Director of Advocacy and Chapter Development, The Arc of North Carolina.

Autism Society of NC Walk

The Duke Center for Autism and Brain Development raised approximately $1,000 for the Autism Society of North Carolina’s 2021 Triangle Run/Walk for Autism on a very rainy fall day. Each year, the center’s faculty, staff, and student trainees participate in this ASNC fundraising event and in the Autism Speaks Triangle Walk to support programs and services for autistic people living in North Carolina.

Holiday Greeting Art Gallery & Contest

Congratulations to our 2021 Holiday Greeting Art Gallery Contest winner, Catherine, a nine-year-old artist with autism, epilepsy, and ADHD. Her painting, “Snowman Snow” was featured on our Duke Center for Autism holiday greeting card. More than 35 artists of all ages from around the world submitted art for the Duke Center for Autism Holiday Greeting Art Gallery.

Autism Acceptance Month 2022

The Duke Center for Autism 2021–2022 Speaker Series featured leading investigators, clinicians, advocates, and practitioners sharing the latest in autism research, interventions, policy, and therapies. More than 1,000 people attended these free, virtual one-hour presentations that are open to all those who are interested.

Center Researchers Share Study Findings at INSAR 2022 Annual Meeting

Duke Center for Autism faculty and students presented research study findings to attendees at the International Society of Autism Research (INSAR) 2022 Annual Meeting in May. INSAR, an international scientific organization, convenes the meeting each year to exchange and disseminate scientific progress among autism research scientists and their trainees from around the world. Kimberly Carpenter, PhD, and Jessica Summers, MAT, presented, “The Influence of Co-occurring ADHD on Working Memory Skills in Young Autistic Children.” Marika Coffman, PhD, presented, “The Impact of the COVID-19 Pandemic on Challenging and Adaptive Behaviors in Children Diagnosed with Autism with and without Co-occurring ADHD.”

Happy Holidays

Holiday Greeting Art Gallery & Contest

Congratulations to our 2021 Holiday Greeting Art Gallery Contest winner, Catherine, a nine-year-old artist with autism, epilepsy, and ADHD. Her painting, “Snowman Snow” was featured on our Duke Center for Autism holiday greeting card. More than 35 artists of all ages from around the world submitted art for the Duke Center for Autism Holiday Greeting Art Gallery.

Autism Society of NC Walk

The Duke Center for Autism and Brain Development raised approximately $1,000 for the Autism Society of North Carolina’s 2021 Triangle Run/Walk for Autism on a very rainy fall day. Each year, the center’s faculty, staff, and student trainees participate in this ASNC fundraising event and in the Autism Speaks Triangle Walk to support programs and services for autistic people living in North Carolina.

Center Researchers Share Study Findings at INSAR 2022 Annual Meeting

Duke Center for Autism faculty and students presented research study findings to attendees at the International Society of Autism Research (INSAR) 2022 Annual Meeting in May. INSAR, an international scientific organization, convenes the meeting each year to exchange and disseminate scientific progress among autism research scientists and their trainees from around the world. Kimberly Carpenter, PhD, and Jessica Summers, MAT, presented, “The Influence of Co-occurring ADHD on Working Memory Skills in Young Autistic Children.” Marika Coffman, PhD, presented, “The Impact of the COVID-19 Pandemic on Challenging and Adaptive Behaviors in Children Diagnosed with Autism with and without Co-occurring ADHD.”
Inclusion

A Q&A with Autistic Autism Researchers at the Duke Center for Autism

What is your role at the center? What research projects do you currently have underway?

Brandsen My role at the center is to support initiatives that improve the quality of life for autistic people. One of the research projects that I am currently working on is the Neurodiversity Initiatives Working Group. Our focus is on making the lab a more accommodating place for autistic people. This includes working with other groups in the Duke community to improve how we design our studies, clinical practices, and other programs to take into account things that could be challenging for autistic people and their families.

What led you to pursue autism research?

Brandsen As I began to meet more autistic people, I realized how important it is to have autistic people in science. I wanted to pursue autism research because I think it is crucial to have autistic people involved in the research process. This allows them to have a unique perspective that many others do not possess.

Grapel I primarily work on studies in which we use eye tracking to better understand changes in social development of autistic children. I am also a founding member of the center’s Neurodiversity Initiatives Working Group. Our focus is on making the lab a more accommodating place for autistic people. This includes working with other groups in the Duke community to improve how we design our studies, clinical practices, and other programs to take into account things that could be challenging for autistic people and their families.

What led you to pursue autism research?

Brandsen As I began to meet more autistic children and autistic adults, a pattern emerged very quickly. The overwhelming majority of autistic people reported significant isolation or stigma throughout their lives. Many people had stress related to their autistic identity or isolation or stigma. Hearing these stories gave me a lot of motivation to want to improve quality of life for autistic people. I am excited about the possibility of using research to make the world a little more accessible and less isolating for autistic people. I wanted to pursue research that leaves educators and clinicians better equipped to meet the needs of their autistic students and patients.

Grapel When I was a child, I had a very difficult time making friends. When I was told I was on the autism spectrum, it felt like my life finally made sense. It did not make my problems go away, but at least I understood them better. As I’ve gotten older, it has been very difficult for me to make friends. I have had to come to the conclusion that my challenges come not only from being autistic, but also from how the world treats people with autism. This society I was born into was not built for people like me, so I got into autism research to find ways to change that.

How has your autistic identity affected your approach to your work at the center?

Brandsen I think it has given me a certain amount of understanding of the barriers that autistic people often face in society. Likewise, being a parent of an autistic child with higher support needs has changed my perception of early intervention. I think there can be immense joy in having an autistic child (or any child, of course), and I would love to see a shift in early intervention to focus less on making children “more typical” and to helping children thrive in all of their uniqueness. It has also made me very eager to seek out the perspectives of other autistic people, especially those that are typically under-represented and autistic people with higher support needs.

Grapel Being autistic gives me a unique perspective that many others in the field do not possess. I have been a researcher and care provider, but I have also been the one receiving care. I have an understanding of where our institutions and society need improvements in how they treat persons with autism. This has allowed me to think about our research more in terms of what would actually improve the lives of the people we are treating, rather than just changing their behavior to be less disruptive to the non-autistic community.

“I would love to see a shift in early intervention to focus less on making children ‘more typical’ and to helping children thrive in all of their uniqueness.”

Sam Brandsen, PhD

“BEING AUTISTIC GIVES ME A UNIQUE PERSPECTIVE THAT MANY OTHERS IN THE FIELD DO NOT POSSESS. I HAVE BEEN A RESEARCHER AND CARE PROVIDER, BUT I HAVE ALSO BEEN THE ONE RECEIVING CARE.”

Jordan Grapel, MS

At a Crossroads
Reconsidering the Goals of Autism Early Behavioral Intervention

The neurodiversity perspective is challenging autism researchers and interventionists to reconsider what should be the goals of early intervention, and specifically, whether the goal of intervention should be preventing, or promoting the loss of, an autism diagnosis. Duke Center for Autism Director Geraldine Dawson, PhD, Associate Director Lauren Franz, MBCiB, MPH, and Postdoctoral Associate Sam Brandsen, PhD, shared how autism researchers can take steps to promote neurodiversity-affirming early intervention practices. Read the full JAMA Pediatrics Viewpoint: At a Crossroads—Reconsidering the Goals of Autism Early Behavioral Intervention from a Neurodiversity Perspective, published in JAMA Pediatrics online, July 11, 2022.
Trainee Spotlight: Carla Wall, PhD
The ‘Most Fun Play Partner’ Receives Duke University School of Medicine Postdoctoral Fellow Award

As part of the Duke University School of Medicine Department of Psychiatry & Behavioral Sciences, the Duke Center for Autism supports graduate interns in the Clinical Psychology Doctoral Internship program. Psychology interns have opportunities to blend experiences from both research and clinical areas, providing therapeutic services to autistic individuals, conducting diagnostic evaluations, and participating in community outreach programs.

Carla Wall, PhD, who was named a 2022 Outstanding Postdoc at Duke, first came to Duke as an intern in the child psychology track with a background in autism and neurodevelopmental disabilities and a desire to connect her clinical and research work to it. Now a postdoctoral associate at the Duke Center for Autism, she has trained on the Early Start Denver Model (ESDM), a naturalistic developmental behavioral intervention model for young children that promotes language, social interaction, and learning. ESDM also provides caregiver coaching that teaches parents activities that help improve children's cognitive, social-emotional, adaptive, and language skills.

“ESDM is child-centered and fun. Putting it into action has helped me deepen my understanding of child development. The ‘ESDM mindset’ informs all my work and helps me meet children where they are — as unique individuals with distinctive therapy needs and goals,” says Wall. “My job is essentially to be the most fun play partner I can be for that child. At the same time, I am honing my expertise in specific techniques to engage children, as well as in the science behind why this approach is so effective.”

During her time at the center, Wall has presented to multiple community and state nonprofit groups, such as the North Carolina Parent Teacher Association Special Education Committee, and has also presented to middle school students and teachers celebrating the ‘ESDM mindset’ informs all my work and helps me meet children where they are — as unique individuals with distinctive therapy needs and goals.”

Carla Wall, PhD

Trainee Spotlight: Darby Herkert, BS
Duke University Medical School Student Gets Hands-on Experience with Autistic Families to Prep Her Career in Research

The Duke Center for Autism and Brain Development has supported dozens of undergraduate and graduate students, medical residents, and fellows, providing a unique experience for future researchers and clinicians who hope to improve the lives of autistic people. This year, Duke University School of Medicine student Darby Herkert, BS, joined the center to gain first-hand experiences with autistic children and their families in the Duke Autism Clinic, while also assisting faculty on autism research projects. Herkert has attended the annual conferences of the American Academy of Pediatrics (AAP) and the American Academy of Child and Adolescent Psychiatry (AACAP).

Herkert’s poster, “Determining and Characterizing the Presence of Prior Concerns in Toddlers Who Screen Positive for Autism in Primary Care,” won best poster from a trainee early career researcher for the Council on Early Childhood Session at the AAP National Conference. In her research project, she found that parents’ concerns about their child who is eventually diagnosed with autism begin when their child is just a few months of age. By examining the types of parent and pediatrician concerns documented in a child’s medical record, Herkert found that toddlers diagnosed with autism often have motor, speech, gastrointestinal, and sleep problems early in infancy. After graduating from the Duke University School of Medicine this May, Herkert will attend a psychiatry residency program that allows her to continue her training as a physician-scientist and to work in an academic research clinic setting.

“The center offered me the chance to help design, collect data for, and analyze a project investigating parents and providers who had developmental concerns prior to a positive autism screening,” said Herkert. “I hope to keep contributing to research efforts that help more families get access to the supports and services that meet their individual needs.”
Trainee Spotlight: Billy Carson, MS
Using Computational Tools to Identify Brain Networks that Could Lead to Improvements in Diagnosis and Tracking Progress

Scientists have shown that the brain of an autistic person works differently. Understanding exactly how functions differ — and how they affect social and language skills — is still a big question. Biomedical engineering student Billy Carson, MS, is learning new ways to analyze brain wave electromyocardiogram (EEG) activity to better understand how autism affects brain function. His mentor is David Carlson, PhD, assistant professor in civil and environmental engineering and computer science.

As part of the National Institutes of Health (NIH) Autism Center of Excellence research program, under Carlson’s supervision, Carson’s current research project will examine how brain signals map on different behavior patterns, such as whether a child is able to sustain their attention or gets distracted easily.

“Essentially, Billy and I hope to identify which brain networks are associated with specific characteristics of autism and how these networks are different in autistic children,” explains Carlson. “We expect to get a clearer picture of how brain-wave activity directly affects learning, and social and language development skills. The research could lead to new brain-based biomarkers that could help identify autism or track progress in clinical trials.”

Already, research has shown that machine learning algorithms can identify brain patterns related to differences in brain processing. The team has published research in multiple scientific journals, including Neuropsychologia and Advances in Neural Information Processing Systems. To map the brain networks, Carson will bring sophisticated computational tools to the current project, including machine learning tools that reliably and automatically match patterns and structure in data.

“The signals we pick up while capturing brain-wave activity represent billions of neurons ‘talking’ to one another to process sensory information and respond to stimuli. Machine learning methods are well-suited for the task of picking out the important parts of these recorded brain signals and sifting out unhelpful information that we call noise,” said Carlson. “We can gather and summarize the important information and create a visual of the neurons ‘talking’ to each other, too.”

Uncovering ways to detect autism, which are nonsubjective, biological markers using tools like EEGs, could transform diagnosis and lead to new treatments. This is an important step in understanding autism.

“Determining how the brains of autistic children function could lead us to new interventions and supports for those who need them,” says Babu.

“With it, we can capture data — even miniscule changes in facial movements — that are way beyond the ability for human observation.”

In the past, research on facial expressions usually required manual coding of observations from recorded videos that are often complex and both labor and time intensive for clinicians. These methods are difficult to deploy at scale and universally. As a member of Sapio’s research team, Babu has helped develop advanced computer vision algorithms to capture the distinct, tiny changes in facial movements that are evoked while children watch carefully designed, developmentally appropriate, short, fun movies.

“We are exploring whether these subtle differences in behaviors can help us identify infants as young as six months who are showing early signs of autism. Using these, along with provider and caregiver questionnaires, we have the potential to help more children get earlier diagnosis,” says Babu. “Research has shown that interventions can promote improved language and social skills for life. Our work could help kids get started on these earlier.”

Working with Sapio, Babu has helped to develop an algorithm that relies on capturing the complexity of facial expressions and facial landmark movements, not on “reading” emotions, which are sometimes challenging for autistic children to express. Currently, they are refining the computer vision analysis, focusing on analysis of even more subtle differences in head movements, blink patterns, and attention in autistic toddlers. Babu has published research in the Journal of Child Clinical Psychology and Psychiatry and in IEEE Transactions on Affective Computing. “Our hope is also that these tools will help clinicians monitor behavioral changes so they can more quickly adjust and modify intervention strategies for children needing support,” says Babu.

Pradeep Raj Krishnappa Babu, PhD
Interest in Computer Vision Analysis Leads Him to Duke Researchers Designing Better Diagnostic Tools

After passing the GATE 2012, a rigorous exam in his native India, Pradeep Raj Krishnappa Babu, PhD, jumped at the opportunity to pursue a master’s degree in engineering, where his passion for virtual reality and machine learning began. Later, while participating in an international collaboration experience as a postdoctoral fellow, he visited Duke and met James B. Duke Distinguished Professor of Electrical and Computer Engineering Guillermo Sapio, PhD, who, along with Geraldine Dawson, PhD, leads research using computer vision analysis to create and validate a digital phenotyping tool to screen for autism. Babu had a “lightbulb moment.”

“When I realized that computer vision analysis could be used to help screen for autism or developmental challenges for kids, this awakened a new interest for me,” says Babu. “With it, we can capture data — even miniscule changes in facial movements — that are way beyond the ability for human observation.”

In the past, research on facial expressions usually required manual coding of observations from recorded videos that are often complex and both labor and time intensive for clinicians. These methods are difficult to deploy at scale and universally. As a member of Sapio’s research team, Babu has helped develop advanced computer vision algorithms to capture the distinct, tiny changes in facial movements that are evoked while children watch carefully designed, developmentally appropriate, short, fun movies.

“We are exploring whether these subtle differences in behaviors can help us identify infants as young as six months who are showing early signs of autism. Using these, along with provider and caregiver questionnaires, we have the potential to help more children get earlier diagnosis,” says Babu. “Research has shown that interventions can promote improved language and social skills for life. Our work could help kids get started on these earlier.”

Working with Sapio, Babu has helped to develop an algorithm that relies on capturing the complexity of facial expressions and facial landmark movements, not on “reading” emotions, which are sometimes challenging for autistic children to express. Currently, they are refining the computer vision analysis, focusing on analysis of even more subtle differences in head movements, blink patterns, and attention in autistic toddlers. Babu has published research in the Journal of Child Clinical Psychology and Psychiatry and in IEEE Transactions on Affective Computing. “Our hope is also that these tools will help clinicians monitor behavioral changes so they can more quickly adjust and modify intervention strategies for children needing support,” says Babu.
We wish to express our gratitude to the following agencies, foundations, and individuals who generously supported the work of the Duke Center for Autism this past year:

Department of Defense
National Institutes of Health
• Eunice Kennedy Shriver National Institute of Child Health and Human Development
• National Institute of Environmental Health Sciences
• National Institute of Mental Health
• National Institute of Neurological Disorders and Stroke
• National Institute on Deafness and Other Communication Disorders
New Jersey Governor's Council for Medical Research and Treatment of Autism
Autism Science Foundation
Cord Blood Foundation
New Jersey Governor's Council for Medical Research and Treatment of Autism
Duke Institute for Brain Sciences
Ireland Family Foundation
National Science Foundation
The Marcus Foundation
Simons Foundation
Mr. David O. Andrew
Mrs. Cathy D. Boles
Mr. James Barrett and Dr. Stacey Coulter
Ms. Laura Ann Claburn
Ms. Willy Charlotte M. Cramer
Mr. Paul and Mrs. Sherri DiMarco
Dr. Kristen Dorsey-Leake
Mr. William Florence and Ms. Joy Seppala
Mr. William and Mrs. Carol Kozy
Dr. Sharon Loza
Mr. Michael MacLeay
Mr. Rushabh Modi
Mr. Nick Nickerson / 3,000 Miles for Autism
Mr. Philip A. Mintz
Mr. James Schwab and Mrs. Kimberly Schwab
Dr. Michael Rosen
Mr. Tracey Sheriff
Ms. Jennifer Boscia Smith
Drs. Harry and Andrea Stylli
Ms. Caroline Sullivan
Mrs. Dianne P. Trzyna

WE WELCOME YOUR SUPPORT

By giving to the Duke Center for Autism and Brain Development, you are joining in our mission to help each individual with autism reach his or her fullest potential.

As part of Duke University, the Duke Center for Autism and Brain Development is a 501(c)(3) non-profit organization. The Federal Tax ID number for the program is 56-0532129.

How to contribute:
By secure website: You can make your secure online gift by visiting our website at https://autismcenter.duke.edu and clicking on the Donate button in the top right corner of our homepage. This will take you to a page with a secure link for making donations.

By check: Please make all gifts payable to “Duke University,” with Duke Center for Autism referenced in the “memo” portion of your check, and mail it to:
Duke Health Development and Alumni Affairs
Attn: Ms. Morgan Pope
300 W. Morgan Street, Ste. 1000
Durham, NC 27701