



Duke  CENTER for AUTISM
and BRAIN DEVELOPMENT

2020
IMPACT REPORT

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Dear Friends of the Duke Center for Autism,

We expected 2020 to be an eventful year at the center, and it did not disappoint. In a year of ambitious plans and surprising changes, our team found creative ways to continue our research, clinical services, education and training programs, and community connections.

Center investigators, working in collaboration with scientists across Duke University and internationally, are shedding light on the complex biology of autism and making strides in developing more effective methods for screening and intervention. This year, we shared results of a large clinical trial that evaluated the potential benefit of cell therapy for improving social and communication skills in children with autism. We also continued efforts to understand genetic mutations found in autism, and to identify biomarkers that could make it possible to identify beneficial treatments and track improvements. We believe that this knowledge will lead to new and better treatments.

We are proud to be a National Institutes of Health Autism Center of Excellence. This designation, only given to a handful of universities in the U.S., has provided funding for several investigations aimed at developing improved ways of detecting, diagnosing, and treating children with autism spectrum disorder (ASD) who also have been diagnosed with attention deficit hyperactivity disorder (ADHD). This work is significant because at least half of children and adults with ASD also have ADHD, and we know that children with this combination often receive their diagnosis much later, missing out on the benefits that early interventions can bring.

We recognize that for many families, this year has brought about changes and challenges that have upended lives and made it difficult to access critically needed services and supports. In response, we adapted many of our research studies and our clinical services to a telehealth platform to ensure continuity of vital services and supports to our study participants and our patients, while working with the Duke University School of Medicine to plan to fully reopen when it is safe to do so.

We know that future breakthroughs will come from the next generation of scientists, and we want to set the stage for their success. Our education and training efforts this year supported more than 25 Duke University undergraduates, medical/graduate students, and postdoctoral associates, and reached across the globe and generations to support international mentorship programs.

We advocated to federal leaders for the need for support and accommodations for those with ASD and their families, and we prioritized partnerships that brought needed healthcare services to North Carolina's underserved and rural communities. At the same time, we leveraged our unique relationships with local and student organizations, such as Duke's Neurodiversity Connections, the Duke Nasher and Marbles Museums, and the Duke Institute for Brain Sciences, to offer a wide range of exciting events for families and others in the community.

I know the year ahead will bring its own challenges. I am confident that we will rise to these head-on, supported by our stakeholder community, our generous funders, and Duke University leadership. We remain committed to continuing the work of the center with the goal of improving the lives of those on the autism spectrum and their families. Throughout the year, I hope you will stay connected to us through our website, social media, and our quarterly newsletter, Connections.

Thank you for your continued partnership. Without your support, our work would not be possible. I wish you good health and hope, and look forward to staying connected in the year ahead.

Warm regards,

Dr. Geraldine Dawson

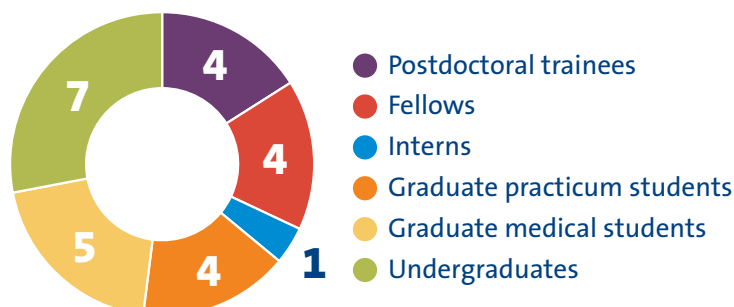
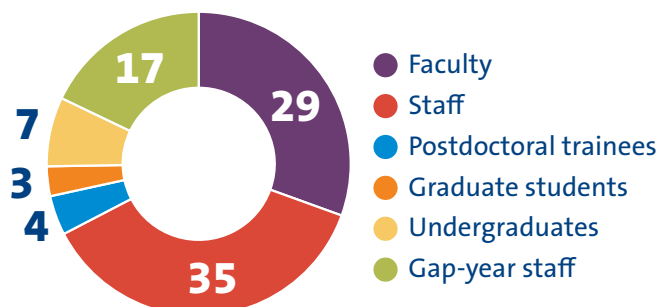
Duke Center for Autism By the Numbers in Fiscal Year 2020

95

Faculty/students/staff
employed full or part time

25

Trainees



Social Media

The Duke Center for Autism reaches a combined total of **5,263** followers on Facebook and Twitter. In 2020, the Center launched its Instagram handle, as well.



Research

- Approx. **\$40 million** in total sponsored autism research funding
- **5,787 individuals enrolled** in Duke Autism Volunteer Research Registry (26% increase from 2019!)
- **13 clinical studies** targeting core ASD symptoms



Clinical Services

- **Diagnostic Evaluations:** 1,074 referrals from Duke providers; 838 patients served through the Duke Autism Clinic; 403 diagnostic evaluations.
- **6 types of clinical intervention services offered to infants through young adults with autism:** parent coaching, early behavioral intervention, social skills training, emotional and behavioral regulation, cognitive-behavioral therapy, and medication management.
- **Services transitioned to telehealth post-pandemic:** Diagnostic evaluations, parent coaching, cognitive-behavioral therapies, and therapeutic consultations and support.



RESEARCH

Clinical Trial Evaluates Cord Blood as a Treatment for Autism

In a study funded by The Marcus Foundation, researchers from the Duke Center for Autism and Brain Development and colleagues from the Duke Department of Pediatrics tested whether a single infusion of a unit of a child's own or donor cord blood could improve social and communication skills in children diagnosed with autism spectrum disorder (ASD). Umbilical cord blood has been FDA approved to treat many conditions.

"Cord blood contains immune modulating cells called monocytes," said Joanne Kurtzberg, M.D., Jerome S. Harris Distinguished Professor of Pediatrics, director of the Marcus Center for Cellular Cures and a pioneer in the use of cord blood treatments. "In the laboratory, these cells calm down a type of brain inflammation that can be seen in children with autism. In this study, we tested whether cord blood infusions would improve social and communication skills in children with autism."



The study examined whether improvements in the child's attention abilities and brain activity were present, as measured by electroencephalographic (EEG) data.

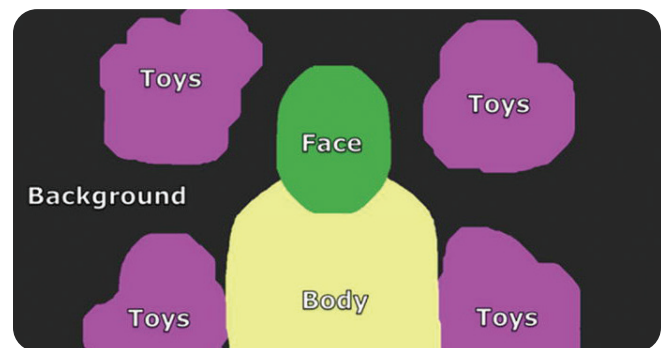
Autism is complex, and strengths and challenges vary from person to person. By definition, children with autism have difficulties with social skills and communication. Approximately 40 percent of children with autism also have an intellectual disability, as defined as an IQ below 70, according to Geraldine Dawson, Ph.D., director of the Duke Center for Autism and Brain Development.

One hundred eighty children with ASD ages two to seven years participated in the randomized, double-blind, placebo-controlled study. Thirty of the children also had intellectual disability. At baseline, children either received an infusion of cord blood that contained the monocyte cells believed to be of therapeutic potential or a placebo infusion.

Children were assessed using validated measures of social skills and communication at their first visit, six months later, and then remotely 12 months later. Clinicians also made clinical judgments about children's improvement. Finally, the study examined whether there were improvements in the children's attention abilities and brain activity, measured via electroencephalographic (EEG) recordings.

Children with ASD tend to have challenges sustaining attention, exhibiting shorter "look durations" to dynamic audiovisual stimuli. Researchers used a unique eye-tracking software to measure look duration and gathered electroencephalogram (EEG) data to measure brain function, while participants watched short videos of actors speaking and interacting with moving toys that made noise.

The EEG testing provided researchers with data on alpha and beta power, measures of brain activity and function. Previous studies have documented reduced alpha power in children with ASD, thought to reflect over-excitation of brain activity.



Researchers used a unique eye-tracking software to measure look duration while study participants watched short videos featuring actors playing with toys. Children with typical development focus their attention on the woman, whereas a child with ASD typically focuses on the toys in the background.

Improvements in Attention and Brain Activity Documented for Some - but More Research is Needed

The study, published online in the May 19, 2020, issue of *The Journal of Pediatrics*, found that a single infusion of cord blood did not improve social or communication skills across the group, as a whole. However, there were positive signs in the subgroup of children with ASD who did not have intellectual impairments: That subgroup of children without disability treated with cord blood showed greater improvement in their communication skills over the six month period, compared to those in the placebo group. Those without an intellectual disability also showed an increased ability to sustain attention, as measured via the eye tracking. This subgroup showed improvements in brain activity, reflected in increased alpha and beta EEG power. This suggests that cord blood might enhance attention to complex, arousing stimuli and improve communication skills in children with ASD without intellectual disability.

More research is needed to determine why the findings in this study are different between those with and without an intellectual disability, and whether the treatment could be altered to be beneficial to more children. “It is unclear whether the lack of a treatment response for children with intellectual disability is due to the short duration of the study, the outcome measures not being sensitive enough to detect change in this subgroup or that the cord blood is actually not an effective treatment for children with autism who also have an intellectual disability,” Dawson said.

“We learned a lot from this initial study,” said Kurtzberg, who co-led the study with Dawson. “In the future, we hope to conduct a trial designed for children with autism who have intellectual disability focusing on outcome measures that can be targeted to test this group of children. We also used lessons learned from this study to design an ongoing study testing other cell therapies in older children with autism without intellectual disability.” ●

Dawson, G., Sun, J.M., Baker, J., Carpenter, K., Compton, S., Deaver, M., Franz, L., Heilbron, N., Herold, B., Horrigan, J., Howard, J., Kosinski, A., Major, S., Murias, M., Page, K., Prasad, V.K., Sabatos-DeVito, M., Sanfilippo, F., Sikich, L., Simmons, R., Song, A., Vermeer, S., Waters-Pick, B., Troy, J., Kurtzberg, J. A Phase II Randomized Clinical Trial of the Safety and Efficacy of Intravenous Umbilical Cord Blood Infusion for Treatment of Children with Autism Spectrum Disorder. *The Journal of Pediatrics*, 2020 Jul;222:164-173.e5.

Illuminating Brain Connections to Unlock New Treatment Strategies

One of the most common questions families ask is “What causes autism?” Just as each person with autism is unique, there is no singular cause of autism – a complex, heterogeneous disorder that manifests itself in a variety of ways and results in diverse challenges and strengths. Autism can occur as the result of a single genetic mutation or combination of genetic and environmental events that influence development.

One of the most strongly linked genetic mutations occurs in the SCN2A gene, responsible for key communications functions in the brain. In fact, mutations in the SCN2A gene can lead to autism or epilepsy, depending upon where the mutation is located within the gene itself. Understanding how this specific genetic mutation affects pathways in the brain can help scientists develop better interventions and, potentially, medications to help treat some of the core symptoms of autism. In a multi-disciplinary collaboration, cell biologist Scott Soderling, Ph.D., neuropsychopharmacologist William Wetsel, Ph.D., and clinical geneticist Yong-hui Jiang, M.D., Ph.D., are pursuing a multi-pronged approach to understand how this small change in the Scn2a gene in mice leads to significant changes in the brain and behavior.



“We are, literally, lighting up the SCN2A protein so we can see exactly what is happening and how its mutation is connected to autism and associated behaviors.”

Scott Soderling, Ph.D.



“It’s like using molecular scissors on the cells. We can cut and paste to edit the DNA chain, essentially crafting the mutation so we can study how it works and create better ways to mitigate its effects.”

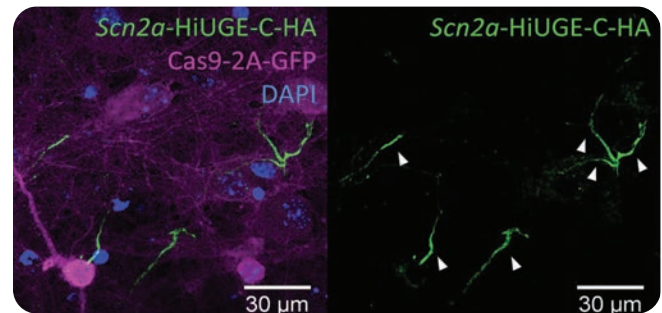
William Wetsel, Ph.D.

“The gene helps facilitate cell-to-cell communication in the brain by regulating sodium channels that let signals into brain cells,” explains Soderling, the George Barth Geller Distinguished Professor for Research in Molecular Biology and chair of the Department of Cell Biology at Duke. “The channels are like portals or tunnels that open the door for key information to flow in and out.” Using a new gene editing approach, called CRISPR (clustered regularly interspaced short palindromic repeats), the team is able to study mice that carry the same *Scn2a* gene mutation. Also, using a unique method they created, the team placed a genetic “tag” on its expressed protein, making it illuminate under a microscope.

“The CRISPR is a gene editing technique that has revolutionized the way we can understand genetic codes,” said Wetsel, associate professor of psychiatry and behavioral sciences and director of the Duke Mouse Behavioral and Neuroendocrine Analysis Core Facility. “It’s like using molecular scissors on the cells. We can cut and paste to edit the DNA chain, essentially crafting the mutation so we can study how it works and create better ways to mitigate its affects.”

Then, using mass spectrometry, the scientists can identify the proteins present in the illuminated cells to learn how the mutation may affect the levels of the *SCN2A* protein—and other relevant proteins—in the cells expressing *SCN2A* in the brain.

Using behavioral analysis tools, the scientists will test mouse behaviors related to speech, social behaviors, and repetitive behaviors. Additional behaviors that may accompany autism—motor responses, seizures, and cognitive performance—will be examined. With the genetic manipulations in the mice, the team is now poised to understand how the *Scn2a* mutation affects the ability to socialize and communicate. Computational methods will be used to predict how the mutation can alter other proteins that are associated with the *SCN2A* protein in neurons. Addressing these key questions will enable the team to design new approaches to modify the mutation in *Scn2a* in ways that can lead to beneficial changes, such as inhibiting seizure activity.



The tagged *Scn2a* is illuminated in green under a microscope.

Adapted from Gao, Y., Hisey, E., Bradshaw, T.W.A., et al. Plug-and-Play Protein Modification Using Homology-Independent Universal Genome Engineering. *Neuron*. 2019;103(4):583-597.e8. doi:10.1016/j.neuron.2019.05.047

“We are, literally, lighting up the *SCN2A* protein so we can see exactly what is happening and how its mutation is connected to autism and associated behaviors. It’s hard to envision how we can help improve outcomes if we can’t first deeply understand how this mutation affects the brain and behavior to begin with,” explains Soderling. “For those with autism who experience significant communication and behavioral challenges, our work could reveal new strategies or new medications that can make an impact.” ●

Gao, Y., Hisey, E., Bradshaw, T.W.A., Erata, E., Brown, W.E., Courtland, J.L., Uezu, A., Xiang, Y., Diao, Y., Soderling, S.H. Plug-and-Play Protein Modification Using Homology-Independent Universal Genome Engineering. *Neuron*. 2019 Aug 21;103(4):583-597.e8.

Harnessing the Power of Machine Learning for Earlier Autism Diagnosis

Adapted from the Duke University School of Medicine Magnify magazine, Dec. 4, 2019, By Jonathan McCall

As its name suggests, autism spectrum disorder (ASD) encompasses a spectrum of possible symptoms and behaviors, ranging from relatively mild difficulties with social interactions in some, to a complete inability to verbalize in others. Persons with ASD have difficulty in interacting with other people and reading social cues. They may become fixated on particular things or interests, or experience an extreme sensitivity to environmental stimuli such as loud noises. But the cues that hint at ASD are not always obvious, especially in younger children, and often emerge in different ways in different people.

ASD affects roughly one in every 54 children in the United States and occurs more often in boys than girls. Although ASD is seen in all races and ethnic groups, children from ethnic and racial minority backgrounds tend to get diagnosed at a later age than white children, and thus often miss out on early intervention. “One of the first indications of autism is that an infant does not pay attention to the social world,” notes Geraldine Dawson, PhD, director of the Duke Center for Autism and Brain Development. “Right after birth, most infants are naturally interested in faces and voices, but infants with autism don’t develop that natural preference.”

Instead, she continues, infants with autism tend to be more drawn to the world of objects. But this dynamic can change the way the brain develops.

“During the infant-toddler period, the brain is rapidly developing – the brain systems that allow us to read facial expressions and understand language develop throughout this time,” says Dawson.

During this period, babies benefit from social interaction and language input from their parents and others around them to fuel that development. “If the babies aren’t paying attention, then they are not getting stimulation to those brain systems.”

Owing to the brain’s inherent malleability—its neuroplasticity—early detection and intervention are critical to improving outcomes in ASD, especially in terms of language and social skills. While this may sound straightforward, early detection can be challenging.

“About 50% of kids [with autism] also have attention deficit hyperactivity disorder, or ADHD,” explains Scott Kollins, Ph.D., who directs the Duke ADHD Program. He notes that the presence of ADHD—which is often marked by difficulty in sustaining focused attention—can mask symptoms of ASD and delay its diagnosis, sometimes for years.

“Early intervention is important no matter what,” Kollins adds, although he emphasizes that it’s even more important in the case of ASD, due to the impact on language and socialization. “It leads to better outcomes across the board.”

Decades of research into ASD and other neurodevelopmental disorders are starting to yield innovative treatments that can make a significant difference in the lives of those affected by them. But clinicians and families are still left with the question of how to obtain an accurate diagnosis as early as possible so that these interventions can do the most good.

The answer to that question, it turns out, may be hiding in plain sight—but it may take the help of artificial intelligence to spot it.



“One of the first indications of autism is that an infant does not pay attention to the social world. Right after birth, most infants are naturally interested in faces and voices, but infants with autism don’t develop that natural preference.”

Geraldine Dawson, Ph.D.

Dawson and Kollins began to explore the possibility of applying modern computational resources to the problem. They knew that the field of machine learning, in which computer algorithms are applied to problems that involve sifting enormous amounts of data in order to find hidden patterns and associations, could offer the tools they needed. Kollins and Dawson assembled a group of researchers at Duke to hunt for associations present in the information contained in patient health records. Working under conditions that ensure data security and strict protections for patient privacy, the team hopes to identify patterns that could help diagnose ASD earlier and potentially open the door to new options for treatment.

“We’ve learned over the last couple of decades that there are a number of early risk factors and risk predictors,” says Dawson. “We believe that these are routinely recorded in the electronic health record – things like birth history, early developmental history, familial risk factors, significant infectious disease involving high fever, feeding difficulties...”



“Early intervention is important no matter what. It leads to better outcomes across the board.”

Scott Kollins, Ph.D.

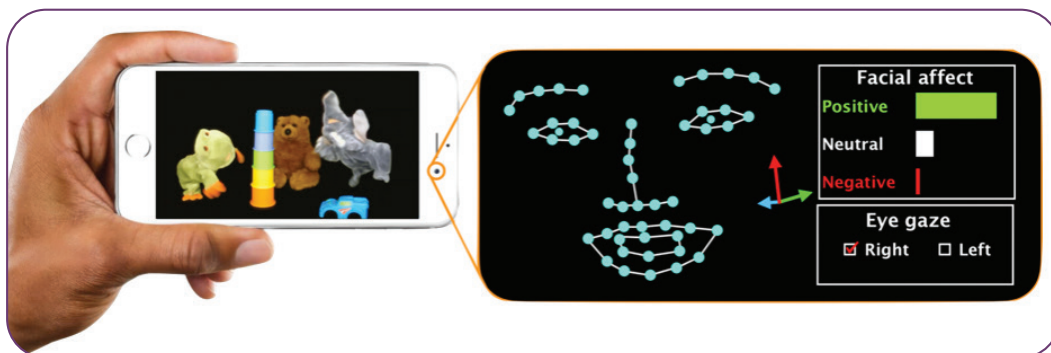
“Premature birth, maternal complications during pregnancy, delayed motor activity...” agrees Kollins, ticking off more of the known risk predictors for ASD. None of these factors in isolation says much about any person’s likelihood of having ASD or ADHD. Put them all together, however, and a sharper picture begins to emerge.

Dawson and Kollins realized that within a child’s medical records was a trove of data already being collected as part of routine health care, data that could be used to develop a risk algorithm.

That algorithm in turn could alert physicians to a child who was at higher risk for developing ASD and/or ADHD, prompting intensified screening and surveillance and helping to get effective interventions to children earlier. It could also alert physicians to be on the lookout for other medical conditions that are often associated with neurodevelopmental disorders, such as eating and sleep difficulties.

With initial support from Duke Forge, Duke’s center for health data science, Dawson and Kollins’ team developed a pilot program to assess whether such an approach could be used to reliably identify children at risk for neurodevelopmental disorders at an early age and provide information that could be used to guide decision-making about intervention and treatment for doctors and parents. The project had the additional goal of reducing racial and ethnic disparities in ASD/ADHD prevention and treatment.

“We’re in the beginning stages,” Kollins explains. “We created a data mart of all individuals since Epic [Duke’s electronic records system] went online and are using those historical data to evaluate whether we can apply a machine learning algorithm to determine which children are likely to develop autism, ADHD, or both.”



In one Center for Autism study, an app designed by Geraldine Dawson, Ph.D. and Guillermo Sapiro, Ph.D., a professor in the Duke University Pratt School of Engineering Department of Electrical and Computer Engineering, detects and measures eye gaze, which could help identify kids who may be at higher risk of ASD.

Dawson notes that in addition to scanning thousands or tens of thousands of medical records for known risk factors, machine learning algorithms are also capable of uncovering previously unknown or unguessed associations lurking in the data—although, as always in machine learning, it’s crucial to be able to discriminate meaningful associations from spurious coincidence. “We have a bigger vision, one of being able to raise a flag in the first year of life that says this is a kid we need to pay attention to,” says Matthew Engelhard, M.D., Ph.D., a Duke Forge research fellow and member of Dawson and Kollins’ team. “If we can raise a flag that gets a substantial number of kids getting diagnosed and treated earlier, then that is success.”

For Dawson, the key metric of success for their project is “being able to empower physicians with more information and advice about how to personalize the care of young patients.” She ticks off multiple positive outcomes that this approach might also enable – reducing racial and ethnic disparities in early diagnosis, increasing surveillance and developing digital tools to improve the accuracy of screening that until now has relied largely on imprecise questionnaires that can also be influenced by literacy barriers and lack of parental knowledge about child development.

The team recently received additional funding from the National Institute of Mental Health to expand their work, and now also includes an expanded group of Duke faculty, including computational scientists Lawrence Carin, Ph.D., Ricardo Henao, Ph.D., and Guillermo Sapiro, Ph.D., and Eliana Perrin, M.D., chief, Division of Primary Care in the Department of Pediatrics.

There are challenges, but Kollins is enthusiastic about “leveraging data science to do some awesome stuff.”

“It’s a huge commitment,” Kollins admits. But he also recalls his early conversations with Dawson as they were first fleshing out their ideas, and remembers clearly what they concluded:

“We can’t *not* do this.” ●

Reimagining Face-To-Face Interventions in a Virtual World

Scientific research has given families, caregivers, and autistic children proven treatments and interventions that are opening doors for new and brighter futures for individuals with ASD. Despite COVID-19, those discoveries must continue.

Through a National Institutes of Health (NIH)-funded, five-year study, an interdisciplinary team of researchers from the Duke Center for Autism and Brain Development and the Duke ADHD Program are studying how co-occurring ADHD symptoms influence the early detection, underlying brain mechanisms, developmental outcomes, and treatment responses in children ages 3-10 years with ASD. A key clinical trial within this Autism Center of Excellence (ACE) study, led by Linmarie Sikich, M.D., associate director of the Center for Autism, evaluates how medication might improve how children respond to a caregiver-delivered behavioral intervention developed by Geraldine Dawson, Ph.D., and Sally Rogers, Ph.D., called the Early Start Denver Model (ESDM). ESDM usually involves meeting in person with caregivers and providing coaching in strategies that promote social interaction and communication with their children.



ESDM behavioral therapy traditionally is used with young children

(i.e., approximately 5 years and younger). However, the Duke ACE study will provide preliminary feasibility data that may inform future research aimed at a wider age range. In order to meet the needs of older and more developmentally advanced participants, ESDM coaching therapy sessions were adapted to include an increased focus on pragmatic language, social skills, and creative play.

With face-to-face coaching out of the question in the COVID-19 pandemic environment, the study researchers were determined that this critical trial within the ACE study would go forward. How do you reimagine a proven, face-to-face therapy tool in a virtual platform?

The ESDM intervention consists of eight, weekly caregiver-child therapy sessions delivered by an ESDM certified coach. Prior to the COVID-19 pandemic, all ACE study caregiver coaching sessions were conducted at the Duke Center for Autism. Sessions involve activities in which the caregiver coach provides live coaching while the caregiver interacts with the child, focusing on ESDM principles and strategies. Session topics include addressing challenging behavior, development of play and language, capturing a child's attention, and establishing joint activity routines.

"I appreciate how quickly the study pivoted from in person to telehealth services and that we were able to complete the study."

**Parent of a daughter
with autism**

In the socially distant COVID-19 world, the study team pivoted to virtual EDSM coaching sessions, using the family's computer, tablet, or phone with a camera, delivered over high-speed Internet.

"We appreciated the opportunity to receive the caregiver coaching intervention. While I was familiar with many of the naturalistic principles of the intervention approach, I still learned many new strategies to build deeper connections with my daughter," explained a mother whose daughter participated in the study.

"Due to COVID restrictions our therapy was converted from face-to-face meetings to telehealth format. I was surprised to find that I preferred the telehealth setting to in-person coaching.



"In particular, groups that have been historically underrepresented in autism research may benefit from increased options for participation beyond in-person involvement. The importance of recruiting diverse samples cannot be overstated."

Jill Howard, Ph.D.

Working from the comfort of our home with Dr. Franz joining remotely made the experience seem more natural, comfortable and easily relatable. That's not to say that the clinic setting wasn't beneficial, but having an in-person observer felt less natural than having a remote coach."

"The benefits of our transition to telehealth caregiver coaching seem to outweigh the challenges and could improve our approach moving forward," explains Jill Howard, Ph.D., a psychologist and a caregiver coach on the Duke ACE study. "First, virtual coaching allows for the potential of reaching patients who may not otherwise be able to access research due to transportation, time, or other barriers.

In particular, groups that have been historically underrepresented in autism research may benefit from increased options for participation beyond in-person involvement. The importance of recruiting diverse samples cannot be overstated."

Some participants, says Howard, have appreciated the opportunity to participate from the comfort of their home, as opposed to the provider's office or clinic setting, which may feel contrived. In the same vein, sessions conducted in the home may facilitate generalization given the use of familiar toys in a familiar environment, and allow for the possibility of addressing "real life" challenges that occur and can be observed during a session.

As one parent explained, "Receiving therapy via telehealth would be preferable regardless of COVID-19 restrictions. The time missed from work was significantly reduced, we didn't have a commute in rush hour traffic, and I didn't have to rush back to pick up another child from afterschool. My time commitment went down from 3 hours to less than 1.5 hours, including room/technology setup. I appreciate how quickly the study pivoted from in person to telehealth services and that we were able to complete the study."

COVID-19 Pandemic Challenges Could Open the Door for More Inclusive Research

COVID-19 has significantly impacted ASD clinical research across the globe. If there is a "silver lining," it's this: Solutions to COVID-related challenges may improve access for all and increase the diversity of participants in clinical research.

A Duke Center for Autism study funded by the National Institutes of Mental Health (NIMH) and based at the University of Cape Town in South Africa aims to assess implementation and clinical outcomes of ESDM-informed caregiver coaching, delivered by non-specialist providers.

Here, too, Duke Center for Autism investigators are transitioning in-person coaching to a hybrid telehealth delivery model. While telehealth is widely recognized as a critical service delivery platform during the pandemic, access to technology and reliable Internet service varies globally. Scientists are pivoting to address disparities in digital access to ensure that study activities continue.

"This pandemic is reaffirming that behavioral interventions need to be adaptable to maximize contextual fit within the service setting and account for preferences of end-users," notes Lauren Franz, MBChB, M.P.H., a child and adolescent psychiatrist in the Department of Psychiatry and Behavioral Sciences and an ACE study investigator.



"I think these studies hold huge potential to inform the development of new intervention approaches that could have broader population-based applicability, and ultimately increase community impact."

Lauren Franz, MBChB, MPH

"We recognize that it is critical that all our study adaptations be documented and we track all our modifications. In fact, I think these studies hold huge potential to inform the development of new intervention approaches that could have broader population-based applicability, and ultimately increase community impact." ●

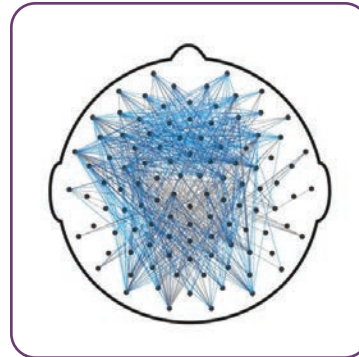
Dawson, G., de Vries, P., Franz, L., and Howard, J. (2020). COVID-19 Pandemic Offers Unique Challenges and Opportunities that Transcend Borders in Commentary: COVID-19 and Autism Research: Perspectives from Around the Globe. *Autism Research*, Jun; 13(6): 844–869.

Autism Biomarkers Could Accelerate Treatment and Testing

In collaboration with investigators at Yale, Harvard, UCLA, and the University of Washington, researchers at the Duke Center for Autism are conducting the Autism Biomarkers Consortium for Clinical Trials (ABC-CT), a longitudinal study of school age children with autism funded by the National Institutes of Health (NIH). The study will establish replicable and quantifiable indices, or “biomarkers,” that can be used to track improvements in brain function and attention that are related to clinical improvement in clinical trials.

Before the ABC-CT began, there were no validated biomarkers for use in clinical trials, only standardized but intrinsically subjective clinician and caregiver/self-report measures. The hope is that these biomarkers – which are based on electroencephalographic (EEG) recordings and eye-tracking measures – will make it easier to determine whether a treatment is working and might make it possible to identify those people most likely to benefit from a particular treatment.

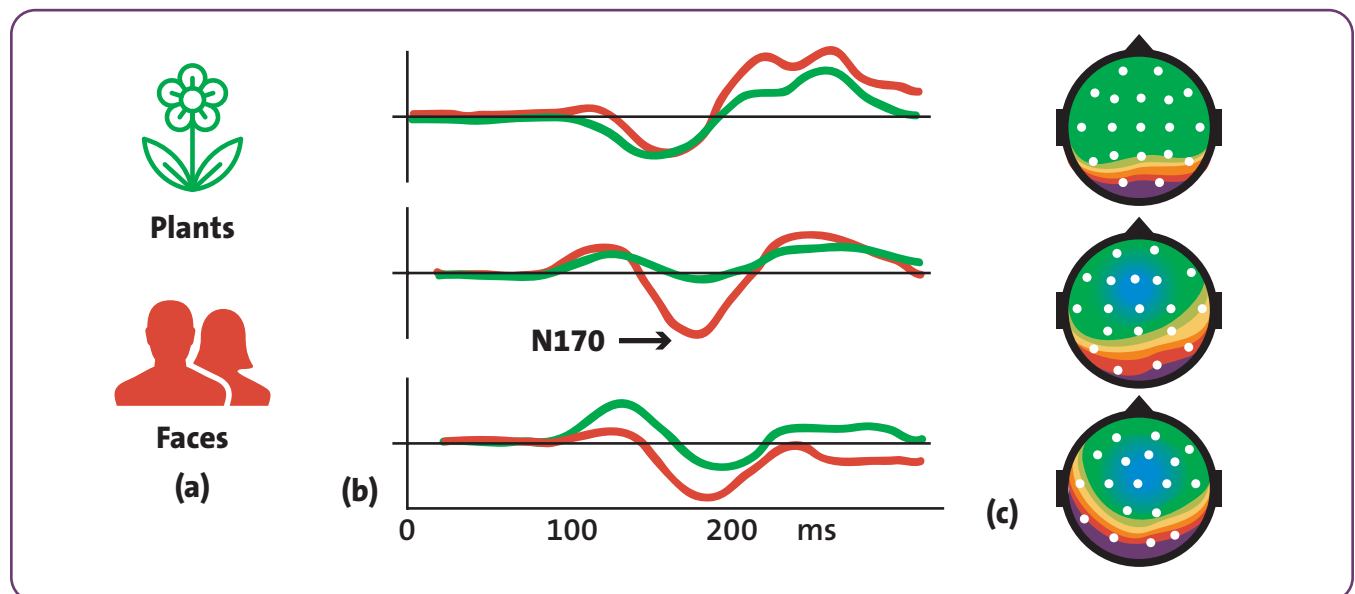
“This is important research because we know that one type of treatment doesn’t help all people with autism,” explained Geraldine Dawson, Ph.D., director of the Duke Center for Autism. “We think we can accelerate development and testing of more effective treatments for autism once we have identified valid biomarkers.”



The hope is that biomarkers – which are based on electroencephalographic (EEG) recordings and eye-tracking measures – will make it easier to determine whether a treatment is working. EEG can measure how the different parts of the brain are connected and coordinated to perform complex functions.

After five years of research, we were extremely pleased that an EEG signature validated by the consortium was accepted into the FDA’s Biomarker Qualification Program in May 2019 and an eye tracking measure was accepted in March 2020.

The EEG measure is the first psychiatric biomarker accepted in the FDA Biomarker Qualification Program. Building on the success of the first five years, the ABC-CT was renewed for another five years of NIH funding. This newly-funded research will follow the original sample of children as they enter teenage years and recruit a new group of preschool age children with autism to study biomarkers in this young sample. All of the information gained and data collected will be available in a research repository to be used by academic and industry researchers conducting autism clinical trials. ●



The N170 is an EEG biomarker that was accepted into the FDA Biomarker Qualification Program. The N170 measures how quickly the brain recognizes that a stimulus is a face rather than an object. The N170 is largest when someone is looking at a face (a) as shown by the middle wave form (b). (c) shows how the brain activity is distributed across the scalp. The N170 is typically slower in individuals with ASD.



CLINICAL



A World-class Team Studies the ASD-ADHD Connection

There is growing evidence that attention-deficit/hyperactivity disorder (ADHD) and autism occur together. In fact, studies show that ADHD – clinically defined by developing unusually high levels of inattention, hyperactivity, and impulsivity – occurs in up to 60 percent of individuals with autism spectrum disorder (ASD) and substantially contributes to poorer outcomes. Even though these two conditions often show up as a pair, few guidelines are on hand to help providers make reliable diagnoses. This is particularly true when it comes to diagnosing ADHD in young children with ASD.

“Symptoms of ADHD are commonly observed in early childhood, and in fact some of the behaviors that are commonly associated with ADHD can be typical for young children,” explains Naomi Davis, Ph.D., an assistant professor in the Department of Psychiatry and Behavioral Sciences and faculty research affiliate with the Duke Center for Autism and Brain Development. “Clinicians need to consider both how ADHD is displayed in young children whose attentional and behavioral self-control are still developing, and how ASD impacts a child’s development, before diagnostic conclusions about co-occurring ASD and ADHD can be reached.”



“Symptoms of ADHD are commonly observed in early childhood, and in fact some of the behaviors that are commonly associated with ADHD can be typical for young children.”

Naomi Davis, Ph.D.

Making reliable diagnoses is critical to ensuring children get needed services and begin interventions as early as possible. However, research about the co-diagnosis of ADHD and ASD is limited because diagnostic guidelines did not allow for the dual diagnosis until 2013. The release of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) that year, allowed clinicians – for the first time – to co-diagnose both disorders.



As part of the NIH-funded ACE study, children are provided comprehensive ASD and ADHD assessments. For some, this includes state-of-the-art technologies that track eye-movement and look duration.

Through a multi-year National Institutes of Health (NIH)-funded Autism Center of Excellence (ACE) study, investigators and clinicians from the Duke Center for Autism and Brain Development and the Duke ADHD Program are collaborating to uncover how ADHD symptoms influence the early detection, brain mechanisms, developmental trajectories, and responses to treatment of young children with ASD. The grant provides funds supporting three inter-related research projects, as well as core services that benefit the entire research project.

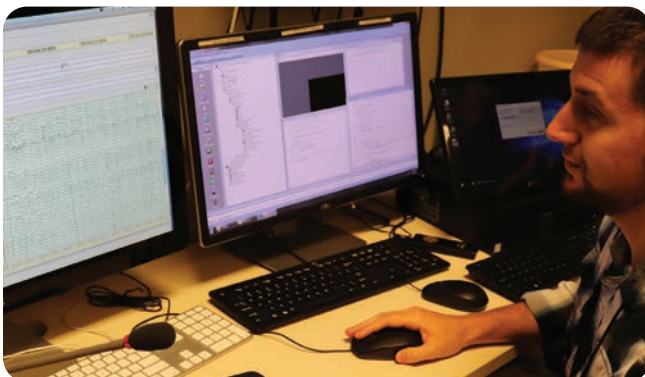
“Both the Duke Center for Autism and the Duke ADHD Program have a history of rigorous research and highly-rated clinical programs,” said Scott Kollins, Ph.D., director of the Duke ADHD Program and co-principal investigator of the ACE study. “We are bringing together a world-class mix of top talent around ASD and ADHD to find better ways to diagnose and intervene so kids get better outcomes.”



“A+ Assessment” is a component of the ACE study that includes a team of clinicians and a study coordinator

whose role is to support recruitment across all ACE study-related activities. The A+ Assessment team provides high-quality, standardized assessments and diagnostic evaluations of participants, and facilitates the experience of families throughout their involvement in the study. The ASD assessment includes a thorough appraisal of the child’s development in multiple domains using “gold-standard” direct assessment, caregiver diagnostic interview, and standardized measures. Best practices for ADHD assessment are used, including interviewing of caregivers for psychiatric concerns, behavioral ratings across multiple settings and contexts, and standardized assessments of cognitive and adaptive functioning.

Because the behaviors associated with ASD and ADHD overlap with those behaviors and symptoms associated with general developmental delay or other psychiatric concerns, the diagnostic process can be complex. The clinicians providing assessments collaborate as a team to consider the child’s developmental and medical history, observed and parent-described symptoms, and developmental skills to arrive at diagnostic conclusions. Drawing on expertise from the entire ACE team of neuroscientists, psychiatrists, psychologists, and pediatricians, the A+ Assessment team has worked to refine the diagnostic process to most effectively help participating families and contribute to the field. As a part of the ACE study, the team plans to disseminate assessment procedures that will inform clinical practice and support providers in their diagnostic work with children.



A world-class mix of top talent around ASD and ADHD is working to find better ways to diagnose and intervene so kids get better outcomes. Here an ACE study investigator reviews electroencephalographic (EEG) data to understand neural mechanisms.

The rapidly evolving challenges associated with the COVID-19 pandemic have caused countless disruptions for families who are seeking diagnostic assessments and support for their children. In response, the A+ Assessment clinicians have been working to adapt clinical practices, including using telehealth, to begin to provide diagnostic assessments while ensuring the safety of staff and families.



“We plan to find answers to something that is poorly understood. I’m optimistic. There’s ample reason to believe our ACE study will make a long-lasting impact.”

Scott Kollins, Ph.D.

“We are hopeful that the pandemic’s silver lining will be what we’ve learned about what’s possible with telehealth,” said Davis. “Some of the changes we made to help families receive evaluations during COVID-19 could mean increased access to care even after this pandemic. We could then facilitate early access to interventions, resources, and family support, promoting long-term developmental outcomes and family functioning.” As telehealth services expand, it will be important to continue seeking and responding to stakeholder feedback in collaborative, family-centered ways.

In the fourth year of the ACE study, which is co-led by Geraldine Dawson, Ph.D., and Kollins, this research leverages the unique combination of expertise in the Duke Center for Autism and Duke ADHD Program to better understand children with co-occurring ASD and ADHD.

“We plan to find answers to something that is poorly understood. I’m optimistic. There’s ample reason to believe our ACE study will make a long-lasting impact,” Kollins said. ●

Associate Director Nicole Heilbron Receives University's Presidential Award



Duke University presented Nicole Heilbron, Ph.D., associate director of the Duke Center for Autism and Brain Development, with its Presidential Award for the 2019-2020 academic year. One of the highest honors for Duke staff and faculty,

the award recognizes individuals and teams who have made extraordinary contributions to the university and health system that demonstrate their commitment to Duke University Core Values of respect, trust, inclusion, diversity and excellence. Heilbron, who is co-director of the Division of Child and Family Mental Health and Community Psychiatry in the Department of Psychiatry and Behavioral Sciences, was recognized for re-envisioning the clinical services offered in the department in order to effectively meet patient needs, provide cost-savings to the system, and maximize the ability of our mental health workforce to meet the needs of patients and families.

"Nicole brings out the best in her colleagues," said Duke Center for Autism Director Geraldine Dawson, Ph.D. "She is talented, dedicated and is keenly focused on making a positive impact in the lives of people with autism. We are fortunate to have her on our leadership team." ●

NC-PAL Partnership Brings Autism Education and Diagnostic Support to Rural Providers

Sixty-five of North Carolina's 100 counties do not have a practicing child psychiatrist, leaving pediatricians and primary care physicians (PCPs) to provide the majority of diagnosis, care, and prescriptions for child psychiatric care. According to a national survey of pediatricians, 65 percent of pediatricians do not feel they have the necessary training to recognize and treat mental health conditions. As a result, it is believed that just one of five children with mental health conditions receives needed services.

In collaboration with Duke University School of Medicine Department of Psychiatry and Behavioral Sciences and the North Carolina Department of Health and Human Services (NCDHHS), the North Carolina - Psychiatry Access Line (NC-PAL) was created to help pediatric health care providers address the diagnoses, medications and psychotherapy interventions for a wide range of behavioral health needs.

In 2018, Duke partnered with the NC Council on Developmental Disabilities to expand NC-PAL services to include assistance with diagnosis and treatment of autism spectrum disorder (ASD) and intellectual and developmental disabilities (IDD). Today, NC-PAL helps hundreds of PCPs across the state to address the complex needs of their patients with ASD, through real-time, one-on-one consultations, educational resources and training, and community support connections.

Additionally, through using NC-PAL as a platform for integrated care, the NC-PAL team was able to partner with NC-START, NC DHHS, The Arc of North Carolina, and the North Carolina Council on Developmental Disabilities to create a Complex Assessment Clinic. This clinic assesses children with complex needs using an interdisciplinary team of a pediatric neurologist and Duke Center for Autism social workers, psychologists, and child psychiatrists. Through these and other programs, the Center is able to further extend its reach throughout the state.



"NC-PAL is one way we bring the expertise, treatments, and services of our Duke Center for Autism to every child in every corner of NC."

Nate Copeland, M.D., M.P.H.

"We want to be a resource that bridges the gap in rural communities," said Nate Copeland, M.D., M.P.H., assistant professor in the Department of Psychiatry and Behavioral sciences and a child psychiatrist at the center. "NC-PAL is one way we bring the expertise, treatments, and services of our Duke Center for Autism to every child in every corner of NC. The feedback from parents has been overwhelmingly positive, who say that the multi-disciplinary team helped them identify new strategies to help their children."

“Additionally, with COVID-19 we’ve adapted,” said Gary Maslow, M.D., M.P.H., a pediatrician and child psychiatrist and co-director of the Division of Child and Family Mental Health and Community Psychiatry. “We offer live, twice weekly video ‘office hours’ to connect providers with psychiatrists and social workers. And, should an NC-PAL call determine that a patient needs to be seen by a psychiatrist, particularly for rural counties, NC-PAL offers one-time video appointments. The complex case assessment work has been adjusted from team-based, in-person evaluations to fully utilizing tele-video services, too. I’m confident we’ll keep finding more ways to reduce barriers in obtaining care for complex patients.”

Since its inception, NC-PAL has achieved high satisfaction rates. More than 60 percent of providers felt “more confident in screening their patients” for behavioral health concerns, and 81 percent felt “more confident in treating pediatric patients” with mental illness.

With that kind of success rate, NC-PAL plans to continue its reach, with the Duke Autism Clinic partnering alongside, making sure to impact high-quality healthcare and services that meet the needs of those with autism. ●

Telehealth Platform Offers New Opportunities for Transforming Clinical Care

The rapidly evolving challenges associated with the COVID-19 pandemic have caused countless disruptions for families who seek diagnostic assessments and support for their children and adolescents who may have autism spectrum disorder (ASD). In response, Duke Center for Autism and Brain Development clinicians, as part of research and clinical services, rallied to adapt clinical practices to the necessary physical distancing constraints of the COVID-19 crisis.



The comfort of one’s home may entail greater significance for individuals with ASD, many of whom experience sensory and social interaction difficulties.

In just weeks, all Duke Autism Clinic providers (spanning disciplines of psychiatry, psychology, and social work) pivoted to telehealth virtual appointments to continue providing needed medication management, individual and family therapy, care coordination, early intervention services, and diagnostic evaluation services to children and families. Telehealth allows families to access video visits from home using a smartphone, computer, or tablet, eliminating the need for transportation to the clinic which has been a barrier to services for some families. Immediate support is available to both providers and patients for any technical difficulties that arise.



“Many caregivers have positively commented about their level of comfort in completing the assessment tasks, convenience and safety with completing the telehealth evaluation in their homes, and their confidence in the diagnostic assessment results.”

Rachel Aiello, Ph.D.

Fortunately, most insurance companies expanded coverage of telehealth services in response to the pandemic, which has generally allowed families to access care at no additional cost beyond what they would normally incur for an in-person visit. Research moved forward as well. Many clinicians who conduct research, such as Rachel Aiello, Ph.D., a psychologist with the Duke Autism Clinic and an investigator with the NIH-funded Duke Autism Center of Excellence/ A+ Study, continued diagnostic assessments using TELE-ASD-PEDS, a tool built for this purpose and under evaluation in an ongoing trial at Vanderbilt University. TELE-ASD-PEDS, in conjunction with extensive clinical interviewing with the caregiver, can allow a trained clinician to make core behavioral observations of infants and toddlers at significant risk for ASD.

Overall, the response to the pivot to telehealth has largely been positive. Tyler Hassenfeldt, Ph.D., a psychologist at the Duke Autism Clinic, reflected on the experience.

“A great benefit of our telehealth evaluations has been the ability to observe our patients in the home setting, which is much more familiar to them than our clinic,” Hassenfeldt said. “It’s been a nice change to interact with parents and children in the place that they are most comfortable, including getting to see them play with their favorite toys and meeting their siblings and pets.”

The comfort of one’s home may entail greater significance for individuals with ASD, many of whom experience sensory and social interaction difficulties. As such, a busy, crowded waiting room, potentially filled with aversive sensory stimuli, may not be the ideal precursor to starting off a medical appointment on a positive note. Instead, a child or adolescent could choose to complete the appointment in his or her favorite chair (or bed, or hammock!), and make use of positive coping tools that might not otherwise be available in the clinic setting, potentially contributing to a more successful and productive session.

Tara Chandrasekhar, M.D., a child and adolescent psychiatrist at the Duke Autism Clinic, noted that her “no-show” rates have dropped considerably, and indicated that it has become much easier for families to access appointments, who sometimes travel a great distance to see her. “However, we have struggled with some of the same things that others have – the technology doesn’t always work well.



With in-person collaboration impossible in the COVID-19 environment, Duke Center for Autism clinicians continued regularly consulting with each other to deliver excellent patient care via telehealth and to ensure continuation of critical research studies.



“Telehealth has given me the ability to watch families in action when they try out different behavioral strategies with their child. I can make suggestions, and we can alter strategies in real time to better fit their child’s needs or the home setting.”

Saritha Vermeer, Ph.D.

Video isn’t always the best way to engage with kids, especially kids on the autism spectrum,” Chandrasekhar noted, adding that “the pandemic is presenting many challenges as kids have experienced disruptions to their routines and services.”

Despite its challenges, the telehealth platform has also offered new opportunities for transforming clinical care. Psychologist Saritha Vermeer, Ph.D., shared, “I like that treatment via telehealth has given me the ability to watch families in action when they try out different behavioral strategies with their child. I can make suggestions, and we can alter strategies in real time to better fit their child’s needs or the home setting.” In this sense, the option of working with families in the home setting conveys advantages that would not otherwise be feasible in the clinic.

Patients requiring in-person appointments, such as urgent needs related to patient safety, are still able to receive these services, even during the pandemic. Certain services and procedures have emerged as relatively more difficult to provide via telehealth, and thus require continued efforts to ensure that families are able to access needed services. Duke Autism Clinic providers remain committed to offering state-of-the-art, high quality, individually tailored care to individuals and families affected by ASD. ●



TRAINING



A Deep Sense of Where I'm Meant to Be

Alarming health disparities exist for people with intellectual and developmental disabilities, who more often experience barriers to routine medical care and services when compared to those without disabilities. The Duke University School of Medicine works to ensure disability-specific curriculum is integrated into its instruction, to ensure students have the knowledge, skills, and attitudes to provide exceptional, compassionate care to patients with autism spectrum disorder (ASD) and other developmental disabilities. Clinicians and faculty at the Duke Center for Autism and Brain Development mentor, support and train medical students, graduate medical education trainees, and postdoctoral trainees throughout the year, as a part of the center's core commitment to educate and inspire the next generation of physicians and scientists.



"Understanding and knowledge aren't only built in the classroom. We give our learners real-life opportunities to help assess and design treatments, and to get to know and understand the challenges faced by the families we serve."

Tara Chandrasekhar, M.D.

"Supporting high-quality, exceptional health care and services for those with autism is only possible with a purposeful commitment to authentic training and mentoring opportunities," said Tara Chandrasekhar, M.D., a child and adolescent psychiatrist at the Duke Center for Autism and Brain Development and program training director for the Duke University Hospital Child and Adolescent Psychiatry Fellowship. "Understanding and knowledge aren't only built in the classroom. We give our learners real-life opportunities to help assess and design treatments, and to get to know and understand the challenges faced by the families we serve."

"As an aspiring child and adolescent psychiatrist in my third year of adult psychiatry residency, I couldn't be more impressed with and grateful for my time at the Duke Center for Autism and Brain Development," explained Michael Sun, M.D., psychiatry resident, Duke University Hospital. "As part of an elective experience, I spent Tuesday mornings working with the most helpful staff, some brilliant mentors including Drs. Chandrasekhar and Vermeer, and of course, the most amazing kids. I learned the ins-and-outs of diagnostic assessments and the 'nuts-and-bolts' of psychopharmacology in managing comorbidities of ASD. I learned how to effectively communicate with parents. I learned the nuances of working with patients with cultural and language barriers. I come away from my experience with a deep and renewed sense that I'm where I'm meant to be. The need is great, but the passion to serve among all the people I've worked with is even greater." ●

Duke Center for Autism Investigator Mentors the Next Generation of Breakthroughs

Advances in the scientific understanding of autism are coming at a rapid pace. To keep the trend going, the field must continually cultivate the next generation of breakthroughs. Knowing that the period of "early career" for scientists (spanning the transition from postdoctoral trainee to a first faculty position) is a high-risk period for attrition in the field, Kimberly Carpenter, Ph.D., assistant professor in the Department of Psychiatry and Behavioral Sciences and investigator on multiple Duke Center for Autism research studies, stepped forward to help.

Research demonstrates that early career faculty who receive strong mentorship early in their careers are more productive and have higher levels of career satisfaction. Although Carpenter's primary role is researching autism and associated conditions, she has a passion for mentoring and has led a number of initiatives both within Duke and internationally to build mentoring programs for early career researchers. In collaboration with a committee of colleagues, she created the Duke Early Career Development Program (ECDP) for the Division of Child and Family Mental Health and Community Psychiatry, which engages more than 30 early career faculty within the division.

Each year the ECDP hosts a number of events such as the Lunch-and-Learn speaking series, ECDP Coffee Hours, in which mid- and senior-level faculty share career trajectory advice in an informal setting, social events, and peer networking events. Even during the COVID-19 shutdown, the ECDP has continued to support early career faculty with virtual social hours and peer networking events to connect and share tips and tricks for balancing the multiple competing demands that the times require.



Although her primary role is researching autism and associated conditions, Kimberly Carpenter, Ph.D., has a passion for mentoring and has led a number of initiatives both within Duke and internationally to build mentoring programs for early career researchers.

In addition to her work at Duke, Carpenter also co-chairs the Early Career Committee (ECC) for the International Society for Autism Research (INSAR). As part of the ECC, Carpenter has taken a leading role in developing a global Mentoring Initiative, a tiered mentorship program in which a senior researcher is paired with an early career researcher who mentors a student/trainee INSAR member. While only two years old, the INSAR ECC Mentoring Initiative has already made major impacts on the careers of early career researchers around the world, serving 46 early career mentees in 14 countries.

That's a lot of breakthroughs in the making. ●

Trainee Spotlight: Postdoctoral Fellow Jaqueline Flowers, Ph.D.



Jackie Flowers was one of the first externs to train at the Duke Center for Autism, while completing her doctoral program in school psychology at the University of North Carolina at Chapel Hill. Today, Flowers is a full-time investigator, providing comprehensive diagnostic evaluations for multiple scientific studies.

Flowers is an important member of a multidisciplinary research team working on the mechanics behind the novel application, Sense to Know, that uses computer vision analysis to automatically assess autism risk behaviors in young infants and toddlers. The unique screening tool uses a series of short movies and games to collect data on a child's gaze, attention, and emotional expressions. Movements are tracked using landmarks on the child's face, including the eyes, eyebrows, nose, and lips. In addition to its potential for screening, the digital tool may help discover new measurable characteristics of autism, called biomarkers, which could be useful in clinical trials. The Sense To Know team is composed of psychiatrists, psychologists, research assistants, and engineers. In her role, Flowers acts as team liaison between the clinical staff, who understand autism symptomology, and the engineering staff, who understand the mechanics of the computer vision analysis.

"I am proud and humbled to be a part of NIH and NIMH studies that have proven essential in the assessment and treatment of autism in our community, both on a local and national level."

Jaqueline Flowers, Ph.D.

"My postdoctoral fellowship has been an incredibly immersive experience," said Flowers. "I am proud and humbled to be a part of NIH and NIMH studies that have proven essential in the assessment and treatment of autism in our community, both on a local and national level." ●

Trainee Spotlight: Medical Student Caroline Leahy, B.A.



Caroline Leahy, a Duke University medical student, spent a year with the Duke Center for Autism and was actively involved in a study that focused on understanding differences in how the brain functions in young children with autism.

“Our research studies take steps toward understanding how patterns of brain activity differ in children with ASD who have executive function difficulties.”

Caroline Leahy, B.A.

She was interested in how difficulties in a set of skills mediated by the frontal lobe, called executive functions, affect children’s ability to pay attention and their brain activity, measured through electroencephalograms (EEG). Deficits in executive function, such as planning ability, are important because they can affect the quality of life and life-long outcomes of people with ASD. Leahy’s research discovered that children with more impaired executive functions had difficulty sustaining their attention and showed a different pattern of brain activity in the frontal region. Fortunately, there are behavioral interventions that can help improve children’s executive function abilities. Leahy’s results suggest that these interventions might also improve children’s ability to sustain their attention, which is important for academic success.

“Our research studies take steps toward understanding how patterns of brain activity differ in children with ASD who have executive function difficulties,” explains Leahy. “The findings corroborate the idea that a clearer understanding of executive functions and their development in ASD can offer insights that could bring on new and better interventions. That’s something I am proud to be a part of. We are working to ensure a future where everybody, regardless of ability, can reach their full potential and enjoy the highest possible quality of life.” ●

Trainees moving on to the next phase of their careers...



Taylor Day, Ph.D.
Postdoctoral Training
Program
Transformative Discovery
in Psychiatry T32 Trainee
University of Pittsburgh



Miranda Foster
Ph.D. Program in
Clinical-Community
Psychology
University of South Carolina



Jordan Hashemi, Ph.D.
Research Scientist
Analysis & Machine
Intelligence Group
BBN Technologies



Adrienne (Anne) Harris, M.A.
Clinical Psychology Doctoral
Internship Program
University of North Carolina
at Chapel Hill



Alexandra Kandah
Ph.D. Program in
Industrial-Organizational
Psychology
University of Central Florida



Yitong Li, Ph.D.
Research Scientist
Apple Inc.



Kevin Ramseur, M.S.
Ph.D. Program
in Clinical Psychology
George Mason University



Addison Welch
Ph.D. Program in
School Psychology
University of Tennessee



COMMUNITY



Researchers Go Virtual with Coaching

Finding solutions to “digital divide” disparities

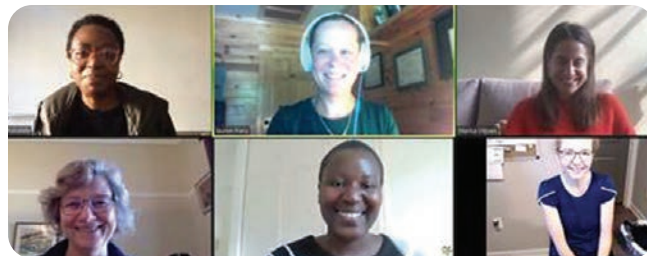
It’s no surprise that the COVID-19 pandemic has significantly impacted autism spectrum disorder (ASD) clinical research and disrupted critically needed access to intervention services for children and families globally. Prior to the pandemic, Duke Center for Autism researchers already were working across the Atlantic Ocean in South Africa, in partnership with the University of Cape Town, to help caregivers in the region, sharing an adapted coaching version of the Early Start Denver Model (ESDM) for implementation by non-ASD specialists. Initial study data are promising, suggesting that caregivers can learn intervention strategies when coached by non-specialists and that the intervention supports growth in child social communication.



Study adaptations for telehealth include telephone-based coaching sessions with resources easily shared via text-based apps

In the face of the COVID-19 pandemic, South Africa implemented one of the strictest lockdowns in the world; and while a phased reopening is underway, children with ASD largely remain cut off from services and support. The University of Cape Town encouraged researchers to switch to a virtual platform, where possible. However, in sub-Saharan Africa the “digital divide” is particularly stark. Fewer than 25% of households own a computer, and even fewer connect to the Internet using high-speed broadband networks.

To find a solution and improve access to telehealth as an option for these families, Duke Center for Autism researchers and colleagues from the University of Cape Town adapted the study, and the sessions and resources, to a hybrid telehealth coaching model using smart phones equipped with pre-paid mobile data.



Despite COVID-19 disruptions, Duke Center for Autism researchers and colleagues from the University of Cape Town continue collaborating to provide an adapted coaching version of the Early Start Denver Model to caregivers in South Africa.

Study adaptations for telehealth include telephone-based coaching sessions with: (1) Joint viewing and supported caregiver reflection of a caregiver-child video recorded by the caregiver on their Smartphone and sent to the coach ahead of the session; (2) Joint review of the session skill that includes simple visuals and words sent to the caregiver via a WhatsApp message software app; and (3) Facilitated discussion of the session skill and caregiver reflection on strategies to practice the skill across daily routines. The adapted study design assumes a gradual lifting of shelter in place orders and incorporates non-inferiority analyses where child social communication and caregiver fidelity outcomes will be compared between in-person and telehealth intervention delivery.

“Identifying feasible solutions to support remote delivery of proven interventions could improve access and care for everyone with ASD, and it has the potential to expand access and inclusion of a greater diversity of participants for future research studies, as well,” said Lauren Franz, MBChB, M.P.H., a Duke Center for Autism child and adolescent psychiatrist and ACE study investigator. ●

de Vries, P., Chambers, C., Dawson-Squibb, J., Franz, L., Harty, H., Schlebusch, L., Viljoen, M. (2020). COVID-19 in Africa – Magnifying Pre-existing Digital and Socio-economic Disparities, but with Glimmers of Hope in Commentary: COVID-19 and Autism Research: Perspectives from Around the Globe. *Autism Research*, Jun; 13(6): 844–869.

Partnership with Marbles Kids Museum Enhances Sensory-friendly Experiences

A child entering the popular Marbles Kids Museum in Raleigh is met with the stimulating combination of brightly-colored open spaces filled with lots of objects, sounds, and play activities. Marbles is an inviting place to learn and develop through play. Imagine, however, what a child with ASD, who is possibly sensitive to bright light, loud noises, or crowds of people, may feel when entering.



Center for Autism team members Miranda Foster, Addison Welch, Margaret McAllister, Dana Ajeen, Hunter Carney, Alex Kandah, and Kevin Ramseur, M.S., collaborated with Marbles Kids Museum to enrich experiences for kids with autism. (Not pictured are Laura Knight and Aidee Leon Lua.)

For some, it can be an overwhelming experience. To enhance the Marbles experience, the Center for Autism partnered with the museum to enrich its sensory-friendly experiences for children with ASD. Center Recruitment and Outreach Coordinator Lori Reinhart-Mercer, RN, and a team of center clinicians and research staff assessed Marbles' interactive exhibits, events, theatre, layout, resources, and digital platforms to make recommendations for more inclusive experiences. Recommendations focused on preparing families prior to visits, providing enriched in-museum experiences, and improving processes to better gather feedback from families.

"The Marbles team shared openly about the areas in which they wanted support," said Margaret McAllister, a center clinical research specialist. "Their focus on learning and building community isn't just policies, but also practices that we saw in action."

Center recommendations such as online ticket sales, "cool down kits," and website enhancements will enrich resources the museum already has in place – such as noise canceling headphones, maps with moveable stickers to plan one's visit, and sensory-friendly nights.

"The value of these improvements will be immeasurable, and I am eager to see them in place," said Janine Eash, community engagement specialist at Marbles Museum. "The partnership between Marbles Kids Museum and the Duke Center for Autism and Brain Development will have a direct impact on more families to engage in creating lifelong, playful memories." ●

Duke Center for Autism Partners with Nasher Museum

The Duke Center for Autism, in collaboration with Duke's Nasher Museum of Art, hosted a sensory-friendly morning at the museum in October 2019. Designed to welcome young people on the autism spectrum, the event celebrated Nasher's exhibition, "Art for a New Understanding: Native Voices, 1950s to Now" and included hands-on arts and crafts activities, gallery exploration and live entertainment with Native American musician and storyteller Ryan Dial-Stanley of the Lumbee Tribe. Dozens of families attended the sensory-friendly morning, which featured sensory "cool down" spaces, behavioral support from Duke Center for Autism staff, lowered lighting and sound, and safe exploration of contemporary art. ●



Families at the Sensory-friendly Morning at Duke's Nasher Museum

Autism Goes to College

In February 2020, the Duke University community enjoyed a screening of “Autism Goes to College” at the Griffith Theater in the Bryan Center on Duke’s campus. The film shares the stories and insights of five students on the autism spectrum and their experiences as undergraduate students. The event, which included a live panel discussion with Duke students on the autism spectrum and professionals, was presented by Duke Neurodiversity Connections, a group founded in 2016 by Duke Center for Autism Psychiatrist Tara Chandrasekhar, M.D., with the aim of raising awareness of neurodiversity on campus and supporting Duke’s neurodiverse students. ●

The Hitchhikers Robotics Group and Duke Center for Autism Host First Robotics Workshop for Youth on the Autism Spectrum

More than 35 children and their families gathered at the Duke Institute for Brain Sciences (DIBS) “Cube” on August 10, 2019, to participate in a Robotics Workshop co-sponsored by the Duke Center for Autism and the Duke University School of Medicine Department of Psychiatry and Behavioral Sciences.



Participants and two of the robots at the Robotics Workshop event

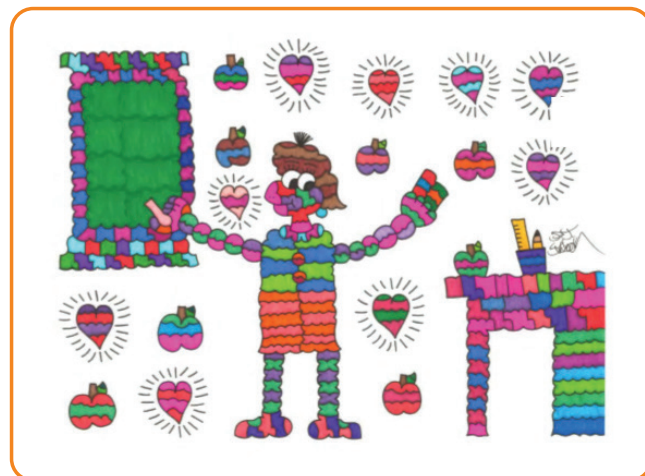
The activities were led by The Hitchhikers robotics group in partnership with Duke Center for Autism and Duke Psychiatry staff. Tyler Hassenfeldt, Ph.D., a psychologist at the Duke Autism Clinic, led the planning for the event, working collaboratively with Department of Psychiatry and Behavioral Sciences colleague, Jashi Abhirajan, and her son Akshar Shrivats, who is a member of The Hitchhikers. Participants took part in three unique workshop stations that gave them the opportunity to build with Legos, play with robots, and learn programming. ●

Art Gallery Shares World View through Eyes of Those with ASD and ADHD

When the Duke Center for Autism and the Duke ADHD Program invited children of all ages to share their unique perspectives on the pandemic, dozens responded. Today, the center’s online COVID-19 Art Gallery shares artwork from artists of all ages, who tapped into their creative talents to share unique responses to, “What makes you happy, sad, or angry?” during this challenging time. Submissions, from simple drawings to more complex paintings, continue to arrive, sharing visuals that express accomplishments, concerns, and fears. Visit the gallery on the Duke Center for Autism website to view and submit artwork. ●



“Untitled #1”



“Teacher Friend”



Members of the Duke Center for Autism during a staff retreat, Oct. 29, 2019.

Thank You

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With your gift to the Duke Center for Autism and Brain Development, you join 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.

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