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Our thanks to:
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It’s with pleasure that we offer this snapshot of the activities and events of the Duke Center for Autism and Brain Development during 2016. As the Center continues to grow, we strive to always keep our core mission at the heart of everything we do: To improve the lives of those affected by autism spectrum disorder and related developmental disabilities through research, clinical services, education, and policy.

In our 2016 annual report, we highlight a few of the many research projects being conducted at the Center, which range from basic science to applied research in the clinic. One of the exciting aspects of being part of the Duke community is the opportunity to collaborate with scientists from many different disciplines, including neuroscience, genetics, engineering and computer science, psychiatry, and psychology, to name a few. A strong commitment to this interdisciplinary approach distinguishes Duke and makes it an ideal place to tackle the complex challenge of autism. Funding for this work comes from industry, the federal government, foundations, and individual donors. Each source of support is crucial for allowing us to explore new approaches to diagnosing and treating autism, with the goal of helping each person with autism reach his or her full potential.

At the same time that we push the boundaries of science, we continue to expand and enhance our ability to provide compassionate, patient-centered clinical care at Duke. We are grateful for the ongoing support of Duke Health in helping our Center improve in our ability to meet the needs of families in Durham and the broader community. Our Center is part of the broader system of clinical care offered to over 3,000 patients with autism at Duke each year, which includes primary care providers and a wide range of subspecialty clinicians. We recognize that patients with autism and their families have diverse needs that change across the lifespan. We are striving to provide coordinated care across the many providers that are often part of any given person’s care at Duke.

A key part of our mission is training the next generation of scientists and clinicians. We feature a few of the many trainees that are involved in the labs and clinics every day at the Center. Their energy, new ideas, optimism, and commitment are a constant source of inspiration and hope for the future. I hope you enjoy reading about their stories and accomplishments.

Finally, we are pleased to tell you about some of the events that have allowed us to partner and simply have fun with people in the community from all walks of life, including persons on the autism spectrum, families, educators, athletes, and policy makers. This year, we were thrilled to have partnered with the Duke Fuqua School of Business on the Autism at Work Program offered by SAP. The MBA students involved in this project will be our future business leaders, and it’s gratifying to know that their experience at Duke will hopefully inspire them to change the way we structure our businesses to take advantage of the remarkable talents of those on the autism spectrum.

As you read through this year’s annual report, if you have a question or thought you would like to share, I'd love to hear from you. I can be reached at geraldine.dawson@duke.edu. Enjoy!

Warm regards,

Geraldine Dawson, PhD
Director
Yong-hui Jiang, MD, PhD, is a man on a mission. Propelled to investigate the possible genes linked to autism, this geneticist, neurobiologist, and pediatrician is seeking answers to how genetic differences can influence the functioning of the brain, a question that parents of children diagnosed with autism spectrum disorder (ASD) often ask him in his clinic at the Duke Children’s Hospital & Health Center.

Funded by Autism Speaks and the National Institutes of Health, Dr. Jiang is studying a gene that carries the code for a family of scaffolding proteins in the brain, known as the SHANK proteins. Dr. Jiang’s research specifically focuses on the SHANK3 form of this gene that has been associated with autism. He conducts his studies in mice in his autism research laboratory at Duke.

Advanced genetic technology has enabled him to create mouse models with genetic mutations in the SHANK3 gene. Says Dr. Jiang: “Using these mouse models, we have found that these mice have similar autism-like behaviors seen in humans that support the validity of using these mice to study human SHANK3 causing ASD.”

Interestingly, genetic information is conserved across species and is somewhat similar in humans and mice. According to Dr. Jiang, genetic studies have shown that the SHANK3 gene can be implicated in up to 2% of individuals with autism.

“We have a long-standing research interest in modeling human genetic disorders in mice. We are at the forefront of modeling SHANK3 causing ASD in mice. Our lab has generated two different lines of SHANK3 mutant mice and these models have been well received in the research community,” says Dr. Jiang, who began this investigation in 2008.
An important goal is to develop and extensively test new medicines first in the animal model before they can be used in humans.

Dr. Jiang found that modulating SHANK 3 proteins in the synapses of neurons disrupts certain molecular pathways in the brain and results in autism-like behaviors, including social deficits and repetitive behaviors.
Dr. Jiang works with an interdisciplinary team at Duke that includes William Wetsel, PhD, Kafui Dzirasa, MD, PhD, Henry Yin, PhD, Allen Song, PhD, Linmarie Sikich, MD, Ru-Rong Ji, PhD, and Geraldine Dawson, PhD. The research aims to understand why this gene has a mutation or is missing altogether in some individuals to cause autism. From the mouse model, Dr. Jiang hopes to glean a treasure trove of information that can lead to a better understanding of the biological basis of autism as well as identifying potential targets for new medical treatments.

Dr. Jiang found that modulating SHANK 3 proteins in the synapses of neurons disrupts certain molecular pathways in the brain and results in autism-like behaviors, including social deficits and repetitive behaviors. He is now working to enhance the function of these receptors with new drugs that correct these autistic behaviors.

“The knowledge gained by the pathophysiology of (autism in) mice is translatable to humans to a certain degree,” says Dr. Jiang. More importantly, the discovery of a drug that can correct the autism-like behavior in mice points to a possible future use of this drug in human ASD, he adds.

Currently, there are no FDA-approved drugs for this purpose in humans. The ultimate aim is to develop and extensively test new medicines first in the animal model before they can be used in humans. A similar drug has been tested in the treatment of Fragile X syndrome, informs this researcher.

So how would parents know if the SHANK3 gene is responsible for autism in their child?

Nowadays, says Dr. Jiang, a majority of children with suspected or diagnosed autism will receive some form of a genetic evaluation. While a SHANK3 gene deletion can be easily picked up by chromosomal microarray, another technique called whole genome sequencing can reveal more subtle variations in our genome. Chromosomal microarray testing is recommended by the American Academy of Pediatrics and is part of a pediatrician’s exam for autism at Duke. The comprehensive genetics evaluation is necessary because 25% of children with autism have an identifiable genetic cause. Knowledge of the genetic basis of autism in patients can help physicians better provide personalized medical care.

With its intricate interweave between environmental factors and genetics, the fabric of autism continues to perplex. While solutions may seem distant, Dr. Jiang’s research on the SHANK gene is bringing us one step closer to understanding the molecular basis of autism and, hopefully, more effective medical treatments.

Yong-hui Jiang, MD, PhD

Researchers at Duke are investigating whether cord blood can enhance brain function and improve social and communication skills of children with autism.

All parents, undeniably, aspire to see their children reach their full potential. However, for individuals with autism spectrum disorder (ASD), achieving this goal can be a challenge. Autism is characterized by difficulties in communication and social interaction and deficits in language abilities. Could cord blood help children with autism communicate and socially interact with others?

Joanne Kurtzberg, MD, director of the Robertson Clinical and Translational Cell Therapy Program and Geraldine Dawson, PhD, director of the Duke Center for Autism, are leading a program of research exploring whether cord blood can improve outcomes of individuals with autism. Says Dr. Dawson: “People with autism have unique strengths. But when there is a disability that prevents a person from fully utilizing those strengths, then our goal is to help that individual reach his or her potential by reducing the disability.”

According to Dr. Dawson, increasing evidence suggests that autism, in some cases, involves a neuroinflammatory process in the brain. Simply explained, the atypical brain development associated with autism appears to be associated with an unusual immune response in the brain. The immune response itself can affect how the brain develops and functions.

So, why cord blood? What can it do? Sourced from the umbilical cord at birth, cord blood is rich in cells that have the ability to modulate immune responses in the brain. Often banked at the time of birth, cord blood has been used to treat several disorders.

Groundbreaking research by Joanne Kurtzberg, a pediatrician at Duke, has demonstrated how umbilical cord blood can be successfully used to treat a variety of conditions characterized by neuroinflammation, including cerebral palsy. Research, in both animal models and humans, has shown that infusion of cord blood may reduce neuroinflammation and allow synapses in the brain to function appropriately.
Building on this hypothesis, Drs. Kurtzberg and Dawson co-led a path-breaking clinical trial to study the safety and efficacy of using umbilical cord blood to treat symptoms of autism.

The cord blood study was funded by The Marcus Foundation, an Atlanta-based philanthropic organization, as part of its $41 million commitment to support innovative research at Duke. Of this, a sizeable chunk—$26 million—is devoted to autism studies.

In a one-year, open-label clinical trial in 2014, twenty-five children with autism between the ages of two and six years were given an intravenous infusion of their own (autologous) cord blood that had been previously banked. Children in this study had a wide range of functioning in their cognitive ability and severity of autism. Dr. Dawson noted that “the study had two goals. We wanted to determine if an infusion of their own cord blood in young children with autism was safe and, secondly, we wanted to determine if there was any evidence that children were showing some improvement after the infusion.”

Initially, all children were given a baseline diagnostic and cognitive assessment. The second day, they received the cord blood and had an MRI. Day 3 was spent completing several observational and standardized assessments that evaluated their social behavior and language skills. Along with parent reports, standardized language tests and an objective eye-tracking method were used to track the children’s attention to social information. Brain activity was also measured with EEG assessments. The children were followed up for one year.

The results so far have been encouragingly positive for a substantial number of children. Interestingly, the eye-tracking test at twelve months showed improved attention to social information. “What we found in that study is that many children showed significant improvement in their social skills and in their language abilities,” Dr. Dawson informed. These results were published this year in the journal, *Stem Cells Translational Medicine*.  

Encouraged by the first study, researchers at the Center embarked on an ambitious Phase II clinical trial with 165 children in the age range of two to eight years in the fall of 2016. This double-blind, placebo-controlled randomized clinical trial has three arms that will allow researchers to compare results in children who have either received autologous cord blood, donor (allogeneic) cord blood or a placebo. The inclusion of allogeneic cord blood is important because if cord blood therapy is found to be effective in this rigorously controlled trial, it would allow more children with autism to access this potential therapy. The last child will be enrolled in the study by the end of 2017.

Scientists at the Center are hopeful that someday medicines will be available that can enhance neural plasticity in both children and adults with autism. In combination with behavioral therapies, the goal of such treatments is to help each individual with autism reach his or her full potential.

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In a study conducted at Duke, researchers tracked the quality metrics of the autism screening tool called the Modified Checklist for Autism in Toddlers (M-CHAT) at a Duke primary care clinic.
Primary Care Southpoint Clinic in Durham. Jeffrey Baker, MD, PhD, a pediatrician who works at the clinic, and other faculty at the Duke Center for Autism provided mentorship. Her study focused on whether physicians accurately documented screening results in the medical chart and if they had referred the child who screened positive for autism for definitive diagnosis and further treatment.

Through a partnership with Dr. Guillermo Sapiro, professor of electrical and computer engineering at Duke, researchers were able to simplify screening with technology. They introduced a screening form on an iPad and asked parents to fill out the M-CHAT form in a digital format. Available in English or Spanish, the form covered the basic 20 questions and automatically asked any additional questions if necessary. The results were automatically scored for the physician along with advice regarding appropriate next steps. Remarkably, accurate documentation in the medical chart rose from 54% to 92% and appropriate referrals increased from 25% to 85%.

In a follow-up survey after the intervention, physicians who participated in this study said they liked getting an automatic score, informs Ms. Campbell. They felt they were doing more accurate screening and were better able to judge whether a child needed a referral. “It saves time of the physician in scoring and asking additional questions. The score helps them make the decision to refer the child for further evaluation. All they had to do was put that score in their note and we saw a huge difference in the number of kids being referred after a positive screen,” Ms. Campbell adds.

In an effort to make the form easily accessible to parents, its digital version can now be found within Duke MyChart, the patient portal to the electronic medical record. Parents can complete the screening form at home before the clinic visit. Researchers and clinicians at the Duke Center for Autism are hoping to integrate their efforts with the ongoing Duke initiative to make all forms digital.

“Early treatment is important for children to do well and have good outcomes,” says Ms. Campbell. This work was published in the *Journal of Pediatrics*. Ms. Campbell received Alpha Omega Alpha Medical School Honor Society’s Best Presentation of 2017 for her work on this project. For her residency in pediatrics, she will be training at the University of Utah with Paul Carbone, MD, who is a nationally recognized expert on pediatric care for patients with autism. Her training at Duke will have far-reaching effects as she pursues a career devoted to improving the quality of primary care services for individuals with autism.

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Until relatively recently, who would have thought that a hand-held device could be used to screen for autism in children on a global scale, or that automated computer algorithms embedded in the ubiquitous iPhones and iPads could measure social communication behaviors in primary care clinics, as well as in naturalistic settings like schools and homes?

An interdisciplinary team of child psychiatrists, psychologists, pediatricians, engineers and computer scientists at Duke University is collecting data on an easy-to-use iPhone application that could potentially help parents screen and monitor risk for autism in their young children using computer vision technology.

Duke researchers collaborated with Apple to develop an investigational ResearchKit® app, a first-of-its-kind iPhone app that parents and caregivers can download at no cost to identify risk markers for autism in children. The app went live in October 2015 and has since been downloaded by 2,500 people in the US and South Africa.

The easy-to-follow app includes a digital version of the questionnaire called the Modified Checklist for Autism in Toddlers for parents to fill out and three videos that they can show their children. It enables the iPhone camera to record facial expressions and head turns toward their parents as the children watch the videos. Computer vision algorithms detect and track data incorporating multiple facial landmarks, including points around the eyes, nose, and mouth, head position, head orientation, and facial affect. Parents can then send researchers the encoded data with or without the recorded videos.

Researchers are collecting the data with an aim to quantify and analyze gaze patterns and emotions of children so that one day this could be used to screen those at risk for autism. “We can’t provide diagnoses as this is a research study that is designed to develop tools that can identify kids who are at risk for autism,” says neurobiologist Kimberly Carpenter, PhD, who was part of the team.

So far, clinical observation of behavior has always been the gold standard in the screening and evaluation of children at risk for autism. Clinicians look for affective behaviors, such as social smiling, social referencing, pointing, directing facial expressions to others, and orienting to name, when screening and diagnosing autism. However, screening is an involved and lengthy process. Most times, it begins at the pediatrician’s clinic during the well-child check-ups at 18- and 24-months of age. Sometimes, even highly trained clinical observers can miss subtle responses, including a delay in orienting to name, that children with autism often exhibit. Clinical observation can also be subjective and time-consuming. It requires extensive training of the rater and does not capture data from children in their natural settings.

Therefore, innovative researchers at Duke had to think outside the box. The first version of the application was on an iPad and used computer vision technology to precisely quantify attention patterns and emotional expressions in toddlers. The goal is to enable pediatricians to accurately identify risk markers using the tablet before referring a child for a full clinical evaluation, informs Dr. Carpenter.

The iPad-based application was tested at the Duke Children’s Primary Care Southpoint clinic. Electrical and computer engineering professor, Guillermo Sapiro, who was a collaborator in the development of both the ResearchKit® and iPad apps, says: “About four years ago, we decided to see if we could replace the human who typically presents the stimuli by a video, and then we needed a system that would both present the stimuli and record the child’s response. So, the iPad was the ideal tool.” In the iPad study, 104 toddlers between 16-30 months of age with and without autism were shown videos designed to elicit autism risk behaviors during their well-child visits in Duke primary care.

Kathleen Campbell, a fourth-year medical student at Duke, explains the simple process in this study. The child sits comfortably in the parent’s lap facing the tablet and watches short videos for five minutes on the iPad. While the child watches the video clips, the examiner, who stands behind, calls out the child’s name and a front-facing iPad camera records videos of facial reactions to the
Research Highlights

videos. Recordings of the child’s head movements in relation to space are mapped. Orienting to name, turning to look at the parent, and affective behavior, including facial expressions, are also tracked.

The researchers observed that compared to typically developing toddlers, those with autism were less likely to orient to their name and turn to share their emotions with their parents. Further analyses are still underway.

Data from this first study have shown promising results.1 Researchers concluded that the app was able to elicit behaviors and automatically indicate a possible risk for autism. “The overall goal of the app was to see if we can provide an integrated solution where the carefully designed stimuli, the recording, and potentially the analysis (as well as simple questionnaires) are all in one system that can be widely distributed,” adds Dr. Sapiro.

When the final data analysis is complete and results validated, scientists at Duke hope that help in the screening for autism could, one day, be in the palm of your hand, but with a global reach. ●


Duke Center for Autism Collaborates on National Study of Childhood Health

Scientists at the Duke Center for Autism and Brain Development are excited to collaborate with the Duke Clinical Research Institute (DCRI) as part of a $157 million federal research initiative to study the effects of environmental factors on childhood health.

The DCRI received a seven-year grant from the National Institutes of Health, totaling $119 million, to fund the organizational framework for the Environmental Influences on Child Health Outcomes (ECHO) initiative. The award builds the infrastructure and capacity of the ECHO initiative to support longitudinal studies on mothers and children.

“We are certainly honored to be selected as the coordinating center for this important research initiative at the NIH,” said principal investigator Brian Smith, MD, a Duke neonatologist and faculty member of the DCRI. “This builds on a number of our strengths in clinical research, notably in pediatric clinical research, where we have developed specific expertise.”

The research initiative studies factors that impact the health outcomes at the time of birth and into later childhood and adolescence. The study will examine a wide range of factors that could influence risk for autism, allergies and asthma, obesity and nutrition, and pregnancy and childbirth.

The DCRI will also train participating research teams, set up standard procedures, monitor quality controls and maintain communication tools. An Opportunities and Infrastructure Fund will support pilot research studies and encourage junior investigators.

Duke Center for Autism scientists will provide specific expertise in assessing autism and related neurodevelopmental disorders in the study. ●

From Duke University School of Medicine Blog, Thursday, September 22, 2016
Early diagnosis and early intervention have been shown to improve outcomes in individuals with autism.
Clinical Services

“I would want to know that someone was actually listening to me, and heard what was hard for me, and said, ‘Here’s how I can help you.’ ”

Building a patient-centered hub for autism services

Clinical psychologist and associate director of the Duke Center for Autism and Brain Development, Nicole Heilbron, PhD, is aware of the anxiety parents often feel when they bring their child to a hospital for a diagnostic evaluation. Along with her team, she is digging deep to find ways to be responsive and accessible to parents and reduce their stress of figuring out what services to get and where to get them.

In 2016, more than 3,000 patients with an autism spectrum disorder (ASD) diagnosis were seen at Duke. The majority were under 18 years of age. With over 20,000 annual clinical visits, many clinics across the health system serve ASD patients.

Over the past couple of years, Dr. Heilbron has been working with Lin Sikich, MD, a child psychiatrist, and the Center’s director, Geraldine Dawson, PhD, to coordinate clinical services at Duke and align the Center’s clinical program with Duke’s autism research and training programs. The goal was to provide a single portal of access for patients with a possible diagnosis of autism. Its aim—to simplify navigation through all the necessary services autism patients may need within Duke. Adopting a hub and spoke model, the Center aims to improve coordination of autism-related services at Duke. Its patient-centered approach focuses on services from birth through adulthood.

The Center staff provide consultation to other Duke providers with the goal of providing a positive experience for autism patients and their families. “We really wanted to understand where people are seeking services at Duke, and what are the services that aren’t there,” says Dr. Heilbron.

The Center works closely with subspecialties such as medical genetics, neurology, gastroenterology, speech and language pathology, and occupational therapy, as
The goal was to provide a single portal of access for patients with a possible diagnosis of autism. Its aim—to simplify navigation through all the necessary services autism patients may need within Duke. Adopting a hub and spoke model, the Center aims to coordinate autism-related services at Duke.
well as primary care, to coordinate care for patients within the Duke Health system. The Center’s staff also helps with crisis management in the Emergency Department, where a child or adult with autism may seek treatment. A recently established patient line has been quite successful, receiving about 1,000 calls in 2016.

The Center’s Autism Clinic offers a wide range of services, including diagnostic evaluations, cognitive and developmental testing, medication management, individual and family therapy, and assistance with navigating transitions for adolescents. Dr. Lin Sikich and other psychiatrists at the Center can prescribe medications to help alleviate some symptoms, such as anxiety and attention difficulties. The Center has evaluated infants as young as six months of age under the expertise of Dr. Dawson who specializes in early detection of autism. Dr. Jill Lorenzi directs the Center’s early intervention services, which involves coaching parents in techniques they can use at home to promote social and language development.

A dedicated team, including a psychologist and a social worker, meets with the family seeking services. Translators are also available. Typically, families come for two consecutive weeks for two hours per visit, during which, a developmental history, cognitive testing, and other assessments are completed. They are given initial feedback and the next steps are explained. A report is prepared for the family with recommendations for treatment.

“We want to prevent the wrong kids from getting to the wrong place and get the right kids to the right place at the right time,” says Dr. Heilbron. The Center partners closely with providers in the community where many families receive their on-going care. As part of its commitment to coordinated care, the Center is helping families connect with local autism-related resources through a growing referral database. The goal is to help families access care in the community or at Duke. “We are really trying to understand where people are seeking care and what are the services needed so we can help connect families with the services they need,” says Dr. Heilbron.

There is clearly a need to build capacity for services. Plans are afoot to hire more clinical staff to meet capacity needs, while education of a growing number of trainees continues. Training includes a clinical and school psychology practicum and internship and an elective rotation for residents in child psychiatry and general psychiatry. Trainees in pediatrics, neurology, and developmental and pediatric psychiatry also routinely observe the Center’s autism clinicians at work.

Steadily, the Center is expanding its footprint to bring evidence-based care to patients with autism in a family-centered way.
As part of its commitment to coordinated care, the Center is helping families connect with local autism-related resources through a growing referral database. The goal is to help families access care in the community or at Duke. “We are really trying to understand where people are seeking care and what are the services needed so we can help connect families with the services they need,” says Dr. Heilbron.
Training

About 1 percent of the world population has autism. The increase in autism prevalence has spurred urgent efforts to increase capacity for autism services and training of providers.

Developing local solutions for a global problem

Researchers at the Duke Center for Autism are expanding their global reach by helping families gain access to evidence-based treatment of neurodevelopmental disorders, including autism, in sub-Saharan Africa and other low-resource communities.

Leading this effort, Lauren Franz, MBChB, MPH, assistant professor of psychiatry and global health, is examining ways to tackle mental health issues in communities that may not have a healthcare worker. For this determined Duke-trained South African researcher, what began as a project focused on diagnostic assessment of children in the Zulu tribe has moved into action. “If we identify children with autism, I feel there’s a strong ethical obligation to offer services and interventions,” she says emphatically.

Work in these areas is challenging. Diagnostic and training tools are missing in low-resource settings, informs Dr. Franz. She plans to return to her native country twice a year to provide early intervention to children with autism that could potentially improve outcomes in their functioning and family interactions. She also intends to spend the next academic year collecting data working with families in South Africa with the Early Start Denver Model (ESDM) early intervention program.

A certified ESDM therapist and parent coach, Dr. Franz, in 2016, received an early career development award from the National Institute of Mental Health to adapt and implement ESDM interventions for children with autism and their families in South Africa. “The project I am doing in South Africa is to take that model, adapt it, and come up with a training model that works with the local community,” says Dr. Franz.

A comprehensive behavioral early intervention method, ESDM has a strong developmental focus. It is delivered in an interactional play-based manner and aims to attune the adult caregiver to the child’s communication attempts. Strategies like these promote the child’s social, cognitive, and language development. Director of the Duke Center for Autism, Geraldine Dawson, PhD, who collaborated with UC Davis professor, Sally J. Rogers, PhD, to develop this early intervention strategy, notes how this model “is focused on the
A comprehensive behavioral early intervention method, the Early Start Denver Model (ESDM) has a strong developmental focus. It is delivered in an interactional play-based manner and aims to attune the adult caregiver to the child’s communication attempts. Strategies like these promote the child’s social, cognitive, and language development.
relationship between the child and the adult and uses strategies that are fun and motivating for the child." The interaction between the therapist and the child is carried out in a naturalistic setting, she adds.

“As a child psychiatrist, I feel it is a powerful way for parents to feel more connected with their children,” says Dr. Franz, adding how she has “seen a lot of growth in children’s language and non-verbal communication strategies and a decrease in challenging behaviors, such as tantrums.” This early intervention technique can be used in children 12 to 60 months of age. At Duke, parent-coaching in this therapy is offered after a child’s diagnosis and is often seen as a “bridge” before the child can get community-based services or join a preschool.

A fan of applying ESDM interventions with flexibility in diverse settings, Dr. Franz highlights how it can be delivered in multiple ways, including an intensive one-on-one format with a therapist, a parent coaching version, a group-based approach suitable for a preschool setting, and through telehealth that involves remote delivery of the intervention in homes. The ESDM manual has been translated into 15 languages and is used worldwide.

“I think there’s a constant tension between maintaining fidelity as a model and actually delivering the intervention in the way that it’s proven to work and then fitting it with the environment that you are working in.” Dr. Franz believes it’s possible to do that. “The therapists that I have been working with in South Africa have been working in the framework of this model for probably two years now with local materials. They have worked with a parent coaching approach with many different children and families and seen a lot of growth,” she informs.

There is a significant global need to develop scalable, feasible, early interventions for ASD that can be carried out in diverse and low-resource settings. Dr. Franz feels that a caregiver-mediated early intervention model could be the answer to the capacity barrier. She recently published the first review of autism services in sub-Saharan Africa, noting the tremendous gap between need and available services. The review was published in the journal, *Autism Research.*

At the Duke Center for Autism, there is a major push to build local as well as global capacity for its ESDM training program. Dr. Franz brought three practitioners from South Africa to train in the ESDM techniques at a workshop held at Duke in December 2016. Four faculty members at the Center conducted a one-day introductory workshop to familiarize parents and community members along with other Duke providers with the basic ESDM principles. This was followed by a three-day advanced workshop to start the certification process for becoming ESDM therapists. Currently, the rigorous certification process for the first group of therapists is ongoing. Drs. Franz and Dawson will be providing an ESDM workshop in South Africa in the fall.

Meanwhile, the Center is aiming to increase its capacity to provide training in ESDM to the local community. Dr. Dawson added, “Building increased capacity for delivering services in Durham and the surrounding area is necessary to meet the growing needs of the autism community.”

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Dr. Jill Lorenzi is Director of Early Intervention Services
Training undergraduates at Duke to be the next generation of autism experts

A graduating senior in the Duke University Class of 2017, Logan Beyer is committed to doing her part in leveling the playing field so that all children get the opportunity to thrive.

The resolve of this 22-year-old undergraduate student strengthened while growing up with some close family members with different abilities who struggled to reach their potential in a world where, she claims, “systems are not built for people, particularly children, with disabilities.”

At Duke, Ms. Beyer had the opportunity to design her own major to investigate systems that impact child development. “With each class I took I fell more in love with the way that knowledge can be translated into treatments and systems that can help these children become everything they are capable of being,” says Ms. Beyer.

Her activities on campus were defined by her passion. As president of the Duke Special Olympics College Club, she started an inclusive intramural basketball league encouraging students to play alongside individuals with intellectual and developmental disabilities as equal teammates. Off-campus, Ms. Beyer designed a special education program at Plantersville Summer Academy and worked for two years with the Guatemalan organization, Primeros Pasos, to ensure continued funding for health education in the Palajunoj Valley.

A demanding school schedule notwithstanding, this driven student trained at the Duke Center for Autism and Brain Development under the tutelage of Kimberly Carpenter, PhD, a faculty member in the Department of Psychiatry and Behavioral Sciences and Michael Murias, PhD, who directs the Center’s neurophysiology laboratories. Here, she assisted with the start-up, day-to-day functioning, and data analysis on a study that examined whether individuals who have sensory sensitivities, commonly seen among people with autism, are at higher risk for developing anxiety. Most recently, she took the lead in analyzing the brain wave data collected in the study. She wants to understand what is different in the brain that can help explain why some people with autism react strongly to certain sounds and other sensory input. During her time at Duke, Ms. Beyer has successfully completed six independent studies and a summer internship.

“I have loved working here. I came in as a freshman, a young intern who really didn’t know how any of this worked. The mentorship I got here made me not only grow academically in terms of how to formulate research questions but also personally in terms of how to be dedicated and really persistent in trying to find answers to the questions that excite you.”

In 2016, Ms. Beyer received the Harry S. Truman Scholarship, a national award that recognizes college juniors with potential to be a “change agent” in their careers. The award helps cover the graduate education costs of students who intend to make an impact through public service.

After leaving Duke, Ms. Beyer plans to pursue an advanced degree in educational psychology and a medical degree in pediatrics. She plans to advocate for policies that spark the necessary collaboration between social, medical, and educational systems to accomplish the goal so that no child is ever left behind.
“I really enjoy working with kids and adults of all ages with all different personalities, interests, strengths, and difficulties. I think that’s part of what makes my work interesting,” says Caroline Leonczyk, a pre-doctoral clinical psychology intern training at the Duke Center for Autism. Passionate to work with individuals with autism through their lifespan, she is eager to take on opportunities for “endless” learning by getting to do something different every day. “That’s what I love,” says Ms. Leonczyk.

In addition to providing diagnostic assessments and therapy to children and adolescents with autism, Ms. Leonczyk is collaborating with Dr. Jeffrey Baker, pediatrician and professor in the Department of Pediatrics, to conduct a quality improvement project focused on the use of visual supports to improve the experience of children with autism in the primary care setting.

The project was inspired by the need for better tools that will help children with autism prepare for their doctors’ visits. Routine and necessary procedures, such as blood draws and blood pressure, can be scary and uncomfortable—particularly for some children with autism. This can cause so much distress that the family and provider are unable to complete the procedure with the child altogether. Over time this can be a great disadvantage to children, as they are less likely to get the preventative care they need.

“It’s often hard for physicians and nurses to accomplish even simple tasks for a patient with autism, such as taking vital signs or swabbing a throat,” notes Dr. Baker. “This isn’t simply a matter of anxiety about pain. Many parents know that kids with autism often need visual prompts and special preparation when facing strange situations. And when you think about it, it’s hard to imagine a more terrifying situation for a child with autism than a doctor’s office. No one is familiar, you don’t know what will happen next, and your excellent memory reminds you that a needle might appear at any moment.”

“We know from parent reports, clinical experience, and the scientific literature that visual supports can be an effective tool to help individuals with autism, particularly when participating in a new activity or routine,” says Leonczyk. Despite their widespread use in educational and recreational settings tailored to individuals on the autism spectrum, visual supports have not yet been widely integrated in medical settings.

“Our goal is to figure out how to adapt and implement these supports in the primary care setting. We know that there are different considerations in a medical setting than at school, for example. The partnership between the Duke Center for Autism and Duke Children’s Primary Care is ideal for answering this question, as it allows collaboration between medical professionals who are familiar with the difficulties that arise during medical visits, clinicians who specialize in intervention for individuals with autism, and families and children who are the experts on their own experience.”

The pilot project is being completed through the Duke Children’s Primary Care Clinic at Southpoint. Ms. Leonczyk, Dr. Baker, and a team of psychology graduate students created visual supports for medical professionals to use during visits and for families to use at home in advance of subsequent visits. Questionnaires are given to parents, nurses, and physicians for feedback that will allow the team to refine the visual supports as needed. To measure how “successful” visits are, the team will also track how many planned procedures were successfully completed among patients. The project is one of many ways the Duke Center for Autism promotes collaboration between researchers and clinicians. Ms. Leonczyk and Dr. Baker are hopeful that the supports are feasible and helpful so they can introduce them to other Duke clinics.
“We know from parent reports, clinical experience, and the scientific literature that visual supports can be an effective tool to help individuals with autism, particularly when participating in a new activity or routine.”
Community Engagement

“I think each individual brings very different strengths and value. People with autism bring diversity of thought to the conversation. Bringing people who think differently can help you look at and solve problems in your company in new ways.”

Building a sustainable employment model for adults with autism

For people with autism, the path to employment may not, in the future, be a road less traveled. In fact, taking a cue from SAP’s employment efforts and commitment to hiring people on the spectrum, more companies may leverage the unique skills and abilities of people with autism in their core business functions.

On May 21, 2013, as part of its diversity and inclusion strategy, SAP, a software company, announced that people with autism would comprise 1 percent of its workforce. In a collaborative effort, SAP joined forces with experts at the Duke Center for Autism and Brain Development and the Duke Fuqua School of Business to help make their Autism at Work program a success.

Five MBA students from Fuqua in 2016 worked on a 12-week consulting project that systematically explored the value of employing people on the spectrum at SAP. With a strong commitment to the mission of SAP’s Autism at Work program, these enterprising young professionals were driven by personal experiences with those with autism—be it a family member, co-worker or a student.

They worked closely with José Velasco, Head of the SAP Autism at Work Program. Their project enabled them to hone their skills working on benchmarking best practices for employing people with autism. Working in teams, they tackled both the internal analysis of what SAP was doing well, as well as external best practices, including stakeholder and regulatory analysis of the challenges and opportunities of employing people with autism. At the end of the year, José Velasco provided an inspiring lecture at Duke’s Nasher Museum which was attended by Duke students, faculty, and staff and the broader community.

Says one team member, Sarah Faller: “I think each individual brings very different strengths and value. People with autism bring diversity of thought to the conversation. Bringing people who think differently can help you look at and solve problems in your company in new ways.”

Other team members included Abdullah Al-Rashid, Kasey Haas, Adair Clayton, and Pete Bi. All team members concur that in many cases people with autism are excellent at tasks that are very detail oriented and are able to catch errors that people without autism may miss. Besides, people with disabilities are oftentimes “extremely loyal to their place of work and will decrease the turnover of the company,” adds Ms. Faller.

SAP’s efforts are exceptional and trail blazing. The Duke students involved in the project appreciate...
For people with autism, the path to employment may not, in the future, be a road less traveled. In fact, taking a cue from SAP’s employment efforts and commitment to hiring people on the spectrum, more companies are leveraging the unique skills and abilities of people with autism in their core business functions.
In December 2016, Duke Health sponsored a sensory-friendly production of Dr. Seuss’ *The Grinch Who Stole Christmas*, in partnership with the Durham Performing Arts Center, the Duke Center for Autism, and the Autism Society of North Carolina. The production featured “sensory-friendly” variations of the original production and provided a supportive and accepting space for individuals with autism and related disabilities. Duke Center for Autism clinicians provided expert advice on techniques to enhance the production and environment, and many of our staff members volunteered at the event. We all enjoyed this special occasion!

We were excited to provide a tour of the Duke Center for Autism to (right to left): ESPN college basketball analyst and former Duke basketball player, Jay Bilas; NBA and former Duke basketball player, Gerald Henderson; and sports broadcaster and former NBA and Duke basketball player, Grant Hill.
We wish to express our gratitude to the following individuals and foundations who generously supported the work of the Duke Center for Autism in 2016.

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Dr. Rachel Coulter and Mr. James Barrett
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Thank You

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 https://www.gifts.duke.edu and entering “Duke Center for Autism and Brain Development” in the search bar.

By check: Please make all gifts payable to “Duke University,” with Duke Center for Autism (fund code 3916962) referenced in the “memo” portion of your check, and mail it to:

Duke Health Development and Alumni Affairs
710 West Main Street, Suite 200
Durham, NC 27701
Attn: Lynda Heaney

Drs. Andrea and Harry Stylli made a generous donation to the Center that established the Stylli Translational Research Program. This program supports a collaborative project with Progenity, Inc. aimed at identifying early diagnostic biomarkers for autism as well as broader interdisciplinary neuroscience research through the Duke Institute for Brain Sciences and Bass Connections. This award also supports the career development of junior faculty conducting neuroscience research at Duke. Shown in the photo are several Duke faculty whose work is being funded through this award (from left to right): Kimberly Carpenter, PhD, Larry Carin, PhD, Geraldine Dawson, PhD, Drs. Andrea and Harry Stylli, Joanne Kurtzberg, MD, and Allen Song, PhD. Gifts such as this one are allowing scientists at the Center for Autism to conduct exploratory, high risk-high impact research that can ultimately transform the way we diagnose and treat autism.
The Duke Center for Autism is proud to feature artwork by artists with autism. Our report cover art (front: “Forest Flowers”, back: “Cabin at Point Lawrence”) is by Chris Stiles, a self-taught artist. Mr. Stiles started creating picture maps when he was 10 years old and progressed to drawing scenes from the Pacific Northwest where he lives, as well as other places he has visited. His artwork has won awards, and his family shares his work “to highlight the autistic condition and demonstrate that these individuals are often accompanied by a special talent and a fresh way of looking at our surroundings.”