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CLINICAL

Provide state-of-the-art, coordinated, interdisciplinary care that is compassionate and responsive to the needs of each person and family. RESEARCH Conduct ground-breaking research that spans the continuum from discovery to dissemination.

Our Four Part Mission

EDUCATION

Inspire, educate, and train the next generation of researchers and practitioners, both in the U.S. and worldwide. POLICY Partner with the community to impact national and international policy to improve the lives of persons with autism and their families.



hen we established the Duke Center for Autism and Brain Development in 2014, we recognized that research and clinical services go hand in hand. Individuals with autism and their families are our source of inspiration and our partners in research. When families donate their precious time by participating in research, it is important that we address their needs by providing high quality clinical services at Duke. Drawing upon existing clinical services as well as developing new programs, a primary goal has been to create a more coordinated, patientand family-centered autism clinical program at Duke. With a prevalence of 1 in 68, autism represents a major public health challenge. We are committed to addressing this challenge by offering outstanding clinical services while building capacity for services in our community.

Another goal has been to build the infrastructure needed to support state-of-the-art basic and applied autism research at Duke, bringing together scientists from many disciplines to develop better methods for autism diagnosis and treatment. We have also established many opportunities for research and clinical training for learners at all levels at our center, from undergraduate students to junior faculty, thus inspiring the next generation of scientists and clinicians dedicated to improving the lives of those affected by autism. We are excited to share a few of the highlights of our progress thus far.

Warm regards,

Geraldine Dawson, PhD Director Duke Center for Autism and Brain Development

Dedicated to helping each individual with autism realize his or her fullest potential

A child with autism and his mother join Provost Kornbluth (center) and Dr. Dawson at the Center's ribbon-cutting event.



Our Four Part Mission: Research

Dr. Geri Dawson and Dr. Joanne Kurtzberg partner to develop new treatments for autism.



RESEARCH HIGHLIGHTS

The Duke Center for Autism is dedicated to exploring highly novel approaches to the diagnosis and treatment of autism. The Center is conducting several clinical trials that are evaluating innovative treatments for both children and adults with autism.

\$41 Million Awarded to Explore New Treatments for Autism and Other Brain Disorders

Duke Health was awarded \$41 million to support an innovative research program that will evaluate the use of umbilical cord blood cells for treatment of autism, stroke, cerebral palsy and related brain disorders. The award from The Marcus Foundation is funding a five-year project led by Joanne Kurtzberg, MD, chief scientific and medical officer of Duke's Robertson Cell and Translational Therapy Program, and Geraldine Dawson, PhD, director of the Duke Center for Autism and Brain Development.

The project builds upon the groundbreaking work on cord blood treatment by Kurtzberg at Duke and Dawson's expertise in measuring the treatment's potential impact on behavioral and brain function. This research holds the promise of truly transformational discovery, and we are deeply grateful to The Marcus Foundation for making it possible. We hope to develop cell-based therapies that can potentially improve brain function in people with autism for whom there are currently no treatments that address the core symptoms.

NIH-funded Multisite Study Assesses Whether Oxytocin Can Improve Social Functioning in Children and Adolescents with Autism

A large clinical trial led by Lin Sikich, MD, associate director, Duke Center for Autism, is evaluating the effectiveness of daily oxytocin nasal spray for improving social functioning in children and adolescents with autism. The NIH Autism Center of Excellence clinical trial builds upon promising results of an earlier study conducted by Sikich. The current trial involves 300 children with autism, ages 3 to 17 years with all levels of functioning, who are being evaluated at Duke, Harvard, Icahn School of Medicine, the University of Washington, Columbia, and Vanderbilt.



The oxytocin hormone affects social affiliation.

Oxytocin is a naturally occurring hormone which has been shown in previous studies to promote sociability. In a pilot study conducted by Sikich, it was found that children with autism who received oxytocin nasal spray twice daily for two months showed

improvement in their social abilities compared to children who received the inactive nasal spray. Following these promising results, the National Institutes of Health (NIH) awarded \$12.6 million to fund a large national clinical trial. Simon Gregory, PhD, associate professor, Department of Medicine at Duke, is examining whether individuals with certain genetic profiles are more responsive to the treatment.

Duke Joins Partnership in NIH-Funded Initiative to Improve Autism Clinical Trials

Scientists are developing potential novel behavioral and medical treatments for autism at a rapid pace based on knowledge gained in genetic and neuroscience research. However, it has been difficult to determine which treatments really work because current outcome measures are not sufficiently reliable or sensitive to change. Methods for identifying which individuals with autism are most likely to benefit from a specific treatment are also needed. To address these barriers, the NIH has invested in a \$32 million multi-site initiative to develop better outcome measures for autism clinical trials and validate biomarkers that can identify specific subtypes of autism.

Several scientists at the Duke Center for Autism, including Dawson, Sikich, and Michael Murias, PhD, are joining other researchers at Harvard, Yale, UCLA, and the University of Washington in a fouryear project that will help the field as a whole to develop more effective and targeted treatments for individuals with autism.

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Our Four Part Mission: Research

The NIH award is part of a "precision medicine initiative" designed to improve autism clinical trials.



Our Four Part Mission: Research

Our research is exploring new ways of detecting early symptoms of autism in infants and toddlers.



Automated Video Analysis Can Potentially Aid in Measuring Autism Risk Behaviors

In collaboration with Guillermo Sapiro, PhD, and Robert Calderbank, PhD, from the Department of Electrical and Computer Engineering at Duke, Jeffrey Baker, MD, PhD, Geraldine Dawson, PhD, Helen Egger, MD, and a team of Duke students are examining whether early symptoms of autism, such as the failure to respond when a child's name is called, can be measured automatically via computer vision techniques. The study, which is being conducted in Duke primary pediatric care clinics, involves showing toddlers a video on an iPad that is designed to elicit early autism symptoms, such as patterns of facial expression and gaze. The toddler's behavior is recorded by the camera located within the iPad. Early results suggest that the computer algorithm can accurately detect several autism risk behaviors, such as a lack of smiling in response to certain stimuli.

One long term goal of this study is to develop feasible approaches to autism screening that can be easily administered by pediatricians in primary care. Currently, many toddlers who are at risk for autism are not screened because primary care physicians often do not have the knowledge or time to conduct in-depth screening during routine wellchild check-ups. Early detection of autism is important because early intervention has been shown to have a significant impact on long term outcome. Support for this project comes from the Coulter Foundation, the Department of Psychiatry, the Educational and Human Development Initiative, and the Information Initiative at Duke.

Interested in Participating in Research?

Participation in research is an invaluable service to the broader autism community. We are conducting studies appropriate for individuals of all ages, from infants through adults, including individuals with and without autism.

To learn more about our research opportunities, visit <u>http://autismcenter.duke.edu/content/how-participate</u>.

IMPROVING TEAM-BASED CLINICAL CARE FOR AUTISM PATIENTS AT DUKE

As the prevalence of autism has grown rapidly over the past several years, so has the demand for services for autism patients at Duke. Approximately 2,700 autism patients are served annually within the Duke University Health System during approximately 14,000 outpatient visits and 880 hospital stays across nine departments. About 3,000 toddlers are screened for autism in Duke primary care clinics each year. Given that the medical needs of persons with autism involve many disciplines, it is often a challenge to provide coordinated care. To address this challenge, we have created a single portal of entry for patients with autism and are developing processes for promoting patient-centered, coordinated, teambased care.

The Duke Center for Autism offers a wide range of clinical services including diagnostic evaluation, psychiatric evaluation, medication management, parent-coaching, infant-toddler intervention, behavioral management, social skills training, treatment of anxiety and depression, and cognitive behavioral therapy. Leading-edge diagnostic assessments, intensive short-term treatment, and longer-term followup are provided for infants through young adults, and a referral hub provides information about resources and programs that are available at Duke and in the community. Along with providing direct services, clinicians at the Center take responsibility for helping families coordinate care across a wide range of medical subspecialties provided at Duke, which include medical genetics, neurology, gastroenterology, speech-language pathology, and occupational therapy. Our goal is a comprehensive, patientcentered approach that meets the individual needs of each person with autism and his or her family.

Our Four Part Mission: Clinical

Our goal is to provide comprehensive, coordinated, patient-centered care.



Our Four Part Mission: Education

Dr. Franz has dedicated her career to improving access and quality of services for children with disabilities in low resource



TRAINING

The Duke Center for Autism provides research and clinical training for junior faculty, postdoctoral fellows, medical students and residents, graduate students, and undergraduates. Here are some examples of the Center's trainee activities.

Early Career Award Promises to Have Global Impact

Dr. Lauren Franz, assistant professor, Psychiatry and Behavioral Sciences and Global Health, grew up



and received her early medical training in South Africa. Following a year of internship in Namibia, Franz returned to South Africa to work as a community service medical doctor at Manguzi, a hospital on the border of

Mozambique in rural KwaZulu-Natal. Through these experiences, she became aware of the lack of access to services by children with disabilities and their families in South Africa and decided to dedicate her career to improving access and quality of services in diverse and low resource communities.

This year, Dr. Franz received an early career "K" award from the NIH to implement a parent-delivered early intervention for children with autism and their families in South Africa. The ambitious project builds upon earlier work conducted by Franz which involved adapting and translating autism diagnostic and assessment tools for Zulu children in South Africa. She was able to demonstrate that these tools could be used to identify children with autism in the rural areas of South Africa. From there, she began to focus on adapting intervention methods that could be used in a country where children do not have access to trained professionals.

Dr. Franz is currently receiving training at the Duke Center for Autism that will allow her to adapt early intervention programs that were developed by faculty at the Center. She then plans to conduct a controlled trial in South Africa to assess whether the parentdelivered intervention improves children's social and communication skills.

Duke Undergrads Study Music Therapy in Durham Public Schools

A team of Duke undergraduate students spent part of their school year observing students with autism and other developmental disabilities in their classrooms in the Durham Public Schools. Their job was to carefully record the sounds, words, and gestures the students were making while engaging in a music therapy program called Voices Together.

This highly interactive program developed by Yasmine White, a music therapist in the community, uses song and movement to promote communication and social interaction among students with disabilities. Although anecdotal evidence suggested that the therapy improved children's ability to communicate, the therapy had never been rigorously evaluated. Support from Duke's Bass Connections initiative and the Social Science Research Institute allowed several Duke faculty and four undergraduate students to design a study that evaluated the Voices Together program, in partnership with Durham Public Schools. Students met weekly with their faculty mentors to learn how to design and implement the study and spent many hours observing students at school.

The study found that children who participated in the Voices Together program improved their ability to communicate using sounds, gestures, and words. The results prompted a second Bass Connections project being carried out with a new group of Duke undergraduate students which will replicate the study in the Alamance Public Schools.

About Bass Connections

Bass Connections is one of the many ways we engage undergraduate students in autism research at the Center. Launched by a \$50 million gift from Anne and Robert Bass, Bass Connections is a university-wide initiative that brings together faculty and students to explore real-world issues in interdisciplinary research teams. To learn more, visit https://bassconnections.duke.edu/.

Our Four Part Mission: Education

The Voices Together Program promotes communication and social interaction through song and movement.



Our Four Part Mission: Policy

Our collaborations extend beyond the local community to include relationships worldwide, as we seek to extend our impact on both practice and policy. Through our partnership with faculty at Fudan University in Shanghai, China, large scale projects to improve autism screening and early intervention are being conducted in China. Below, Drs. Yong-Hui Jiang, Lin Sikich, and Michael Murias provide a tour of the Duke Center for Autism to faculty from Fudan University.



COMMUNITY ENGAGEMENT

Together with the Duke Institute for Brain Sciences, the Duke Center for Autism has hosted a number of community events, including inspirational speakers and sports clinics for children and adults with autism. These events have been extremely popular and provided opportunities for families, clinicians, and others from the community to become engaged at Duke.

Speakers during April Autism Awareness Month included Ron Suskind, a Pulitzer-prize winning journalist, best-selling author and father of a child with autism, and Tito Mukhopadhyay, a poet and accomplished writer who is nonverbal and autistic. John Elder Robison, a well-known author and adult on the autism spectrum, spoke on the topic of neurodiversity in fall 2014. These events helped connect the community with Duke and inspired many to embrace neurodiversity and reconsider stereotypes about autism.

Equally popular were two sport clinics for children and adolescents with autism: a golf clinic co-sponsored with the Ernie Els Foundation at the Washington Duke Golf Club, and a basketball clinic with Coach Krzyzewski and the Duke Men's Basketball team.



Impact on Policy and Practice

The Duke Center for Autism played a key role in the historic passage of NC Senate Bill 676, which expanded insurance coverage for autism. The new law requires qualifying health benefit plans to provide coverage for intensive behavioral intervention at \$40,000 per year for each individual with autism from time of diagnosis through age 18. Center faculty met with state legislators and staff and wrote a letter outlining the key benefits of such insurance coverage. Governor McCrory thanked the Center at the signing ceremony for its instrumental role in the passage of this important legislation.

WITH HEARTFELT APPRECIATION

We dedicate this report to our generous donors, who help make our work possible.

Foundations

The Bass Family Foundation The Coulter Foundation The Duke Endowment The Els for Autism Foundation The Marcus Foundation The Simons Foundation

Individuals

Sandra Forster Joan and Andrew Frankle Michael E. Hayes Jill Ann Jenkins Harold and Selma Lerner Marianne Loffredo and Jeffrey Hass Helen McNamara Kim and James Schwab Melisa Spoloric Vicki Tananbaum Lisa E. Warren

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 to reach his or her fullest potential.

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 <u>https://www.gifts.duke.edu</u>. Click "Make a Gift" and select "Add an unlisted designation" to enter the fund name (Duke Center for Autism) and fund code (3916962).

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: Duke Center for Autism and Brain Development

Our Donors

Our Leadership

Director	Geraldine Dawson, PhD Professor Departments of Psychiatry, Pediatrics, and Psychology and Neuroscience
Associate Director	Linmarie Sikich, MD Associate Professor Department of Psychiatry and Behavioral Sciences
Director, Translational Research	Yong-Hui Jiang, MD, PhD Associate Professor Department of Medicine Division of Medical Genetics
Director, Autism Clinical Services	Nicole Heilbron, PhD Assistant Professor Department of Psychiatry and Behavioral Sciences
Director, Early Intervention Services	Katherine Davlantis, PhD, LCSW Clinical Associate Department of Psychiatry and Behavioral Sciences
Liaison.	Ieffrey Baker, MD, PhD

Liaison, Duke Pediatric Primary Care Jeffrey Baker, MD, PhD Professor Department of Pediatrics



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> For Clinical Appointments Please call 919-681-7148

For Research Inquiries 888-691-1062 or email <u>autismresearch@dm.duke.edu</u>

The Duke Center for Autism and Brain Development is part of the Duke University School of Medicine's Department of Psychiatry and Behavioral Sciences and the Duke Institute for Brain Sciences, whose mission is to conduct research that transforms our understanding of brain function and translates into innovative solutions for health and society.