#### Four female faculty members in the Department of Psychology study and treat Autism Spectrum Disorder

Photos by Steve Wood.

Autism Spectrum Disorder (ASD) is the term that is used to describe a wide range of developmental disorders, now including Autistic Syndrome and Asperger's Syndrome, and diagnosis rates have risen steadily in the U.S. since researchers first began monitoring ASD nearly 20 years ago.

In their 2014 report, The Centers for Disease Control and Prevention (CDC) estimated that 1 in 68 children in the U.S. have autism, with a gender breakdown of 1 in 42 for boys and 1 in 189 for girls—or about five boys for every girl. That is a 30 percent increase over the prior report from 2008 and more than double the 2000 rate of 1 in 150.

Although many people worry about an "epidemic" of autism, the increase in rates may be attributed to our growing awareness of autism as well as changes to the criteria used to diagnose ASD. Regardless, it is a reality for many Alabama families who are motivated to find the right care for their children.

Several faculty members in the <u>Department of Psychology</u> study child and adolescent developmental disabilities, including Autism Spectrum Disorder. And four of those faculty members happen to be female: Dr. Kristi Guest, Dr. Maria Hopkins, Dr. Sarah O'Kelley, and Dr. Laura Stoppelbein. While they all have different concentrations, they have many years of experience in the field. Their profiles offer fascinating insights into their work, the ASD interdisciplinary research platform at UAB, and what they have learned about the disorder over the course of their careers.

#### Dr. Sarah O'Kelley, Assistant Professor

- Director of the Autism Spectrum Disorders (ASD) clinic at UAB Civitan-Sparks Clinics
- Training Director of UAB Maternal and Child Health Leadership Education in Neurodevelopmental and Related Disabilities (LEND)
- Associate Director for Training for the UAB University Center for Excellence in Developmental Disabilities (UCEDD)

• Secondary appointment, Department of Pediatrics, UAB School of Medicine



#### When and why did you come to UAB?

I came to UAB in Fall 2005 after matching as a clinical psychology predoctoral intern in the UAB Psychology Internship Consortium, and my primary placement was at Civitan-Sparks Clinics. This internship was my top choice because of the unique exposure to broad clinical services with individuals with developmental disabilities, as well as a strong program in Autism Spectrum Disorders. I stayed at Sparks for my postdoctoral fellowship and then was hired as a clinical psychologist in 2009. My faculty appointment in the Department of Psychology came in 2011.

# What kind of research do you do, and how does your research impact our understanding/ treatment of ASD?

I have nearly 20 years of research and clinical experience with individuals with Autism Spectrum Disorder (ASD) and other developmental disabilities. My research interests and areas of expertise include cognitive and behavioral characteristics of individuals with ASD (previous collaborative and independent studies have included evaluating implicit learning, central coherence, and theory-of-mind paradigms), screening and early identification (i.e., evaluating validity of screening tools), sibling and family functioning (i.e., the broader autism characteristics and behavioral difficulties in siblings of children with ASD), group social skills interventions, and issues across the lifespan for individuals with ASD. I actively collaborate with investigators on campus and across the country on funded research projects and co-direct an ASD research group at UAB that involves multiple studies evaluating clinical data on children referred for ASD assessment.

### Do you see patients/work in a clinical setting? If so, what is the purpose of those interactions/ assessments and treatments?

I am a licensed clinical psychologist in Alabama. My clinical responsibilities are within two separate ASD-focused clinics at Civitan-Sparks Clinics, where I complete an average of 75 evaluations per year and supervise or provide services to approximately 15 therapy patients per year (long term, individual or group) in addition to school consultations and technical assistance. I have been specifically requested by families and/or schools to provide independent evaluations and behavioral consultations for children in the public schools. I also established a social skills

program utilizing the Program for the Education and Enrichment of Relational Skills (PEERS®) at Civitan-Sparks Clinics, which was developed at UCLA.

Most of the children and teens I see for evaluation are suspected of having ASD so I, along with our interdisciplinary team, conduct the gold-standard assessments to guide this diagnosis. We provide feedback and recommendations to the family to help them obtain services and identify resources in their home communities, which will support improved skills and behaviors and independence as they grow. Most of the families come from all over the state (and surrounding states), so it is not practical for them to return to us for treatment.

I do work with and supervise trainees providing individual therapy, usually to address anxiety and other emotion regulation and to understand how their symptoms of ASD may be supported best in the home, school, and community settings. The PEERS® program is a group intervention for teens or young adults focused on building and developing social interaction skills that promote closer relationships with same-aged peers and increase the time spent with friends.

### Over the years that you have been researching ASD, what have you learned about the nature of these disorders?

Through my research and clinical work, my understanding of ASD has changed significantly. ASD presents in so many different ways and changes throughout a person's lifespan. Although there can be some symptoms that are very limiting (e.g., never developing speech in some individuals, significant self-injurious behaviors or significant adaptive skills delays), I have come to view ASD as another aspect of diversity, specifically neurodiversity. While there are some things we often identify or describe as "deficits" in ASD, there are many ways that individuals with ASD have advantages over those of us without ASD. This has absolutely changed my approach to working with families over the years.

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# What is happening developmentally in the brain to a child who has a spectrum disorder? Can you describe how their brains may work differently than those of us who don't have an ASD diagnosis?

I often explain to families that the brains of individuals with ASD aren't wrong, they are just wired differently, which leads to the different ways of interpreting and responding to the world. For example, they may use a different area of the brain to think about a specific problem or challenge, and this may take some longer than people without ASD, but the end result is similar or sometimes superior (or faster). Much of the research on brain development suggest a different course and pattern of development that may begin prenatally, that sometimes results in too many or too few neurons in certain parts of the brain, which leads to different functioning.

## What role do stress and anxiety play in the individuals with ASD? What about the impact of stress on families?

Anxiety is a common co-occurrence in individuals with ASD. Some of the repetitive or ritualistic behaviors may have an underlying anxious component, and anxiety has been implicated in many of the difficulties that individuals with ASD experience (e.g., feeding, toileting in young children, social difficulties). In addition, many individuals with ASD also having symptoms that result in a diagnosis of an anxiety disorder (e.g., generalized anxiety, social phobia, specific phobia).

Research has also suggested that families of individuals with ASD experience significant and unique stress, even in comparison to families of individuals with other significant, chronic illnesses. Much of this is due to the misunderstanding of the diagnosis and lack of support and resources for families. There is often a significant financial burden to families, which is compounded when one of the parents feels they have to stop working to provide the care and/or transportation to services their child needs. This is one of the things that the Alabama Regional Autism Networks (RAN), including the one at UAB housed at Civitan-Sparks, is trying to improve for families.

#### What do you anticipate for the future of research and treatment for ASD?

Research will continue to focus on contributions to the development of ASD (e.g., genetics) and how it presents differently across individuals. My hope is that intervention research will continue to identify evidence-based practice for individuals across the lifespan and the full range of the autism spectrum. I do think that this will lead to better acceptance and understanding. Autism awareness has come a long way in the last 10 years or so, but there is still much to do in terms of fully including and accepting individuals with ASD in their home communities, and particularly as they exit school-based services, enter the workforce, and seek to live independently.

### How is UAB uniquely positioned to advance our understanding and treatment of ASD?

UAB has an incredible core of researchers and clinicians who are not only uniquely trained and knowledgeable about the diagnosis but also who are extremely passionate about the population they work with. UAB has great community and state connections that have potential to impact individuals, families, and systems important to improved support, understanding, independence, and satisfaction for all involved.

#### Dr. Maria Hopkins, Associate Professor

- Director of Undergraduate Programs, Department of Psychology
- Faculty Advisor, Psi Chi Psychology Honor Society



#### When and why did you come to UAB?

I have been a faculty member in the department since 2007, although I originally came to UAB as an international exchange student. As one of the largest research institutions in the southeast, UAB was in my list of top schools when I was in Sweden and was exploring colleges in the U.S. UAB provides a world- class education and opportunities for multidisciplinary collaborations not found elsewhere in the state.

## What kind of research do you do? How does your research impact our understanding/ treatment of ASD?

My research is focused on social development in children with Autism Spectrum Disorder (ASD). I am particularly interested in issues of emotion recognition and social cognition, as well as technologies designed to assist children with these difficulties. My early research directly addressed emotional development in children with ASD and other developmental disorders. These projects found that ASD children had difficulties recognizing emotions in others, particularly from the eye region of the face. Given these findings, I collaborated with Drs. Frank Amthor and Fred Biasini in the Department of Psychology and developed a computerized gaming platform designed to teach specific skills such as joint attention, face processing, and facial recognition. We documented the effectiveness of this computer-based intervention for ASD children in a series of studies.

My most recent work involves a social robot for children with autism. The robot, Socially Animated Machine (SAM), is designed to teach social skills such as emotion recognition and identification. Our lab research shows that children with ASD enjoy and are motivated by interventions using technology. This is particularly important for children with ASD who often have difficulty with attention and motivation.

### Over the years that you have been researching ASD, what have you learned about the nature of these disorders?

The increase in reported prevalence and overall awareness has brought about a significant expansion in the field of autism research. We are starting to get a much better picture of what this disorder is and the extent of its complexity. We now know there is not one autism but rather a spectrum of disorders that have different causes and different manifestations.

# What is happening developmentally in the brain to a child who has a spectrum disorder? Can you describe how their brains may work differently than those of us who don't have an ASD diagnosis?

We know that autism is a highly heritable neurodevelopmental disorder. But while research is focusing very heavily on the genetic basis for autism, we have not yet identified either the specific genetic sites or the mechanisms of effect. Imaging studies of people with ASD have found differences in the development of several regions of the brain. Studies suggest that ASD could be a result of disruptions in normal brain growth very early in development. These disruptions may be the result of defects in genes that control brain development and regulate how brain cells communicate with each other.

"Just two decades ago, autism was a mysterious and somewhat obscure disorder, commonly associated with savants. Today, thanks to awareness and advocacy efforts, people have a much better understanding of autism."

# What role do stress and anxiety play in individuals with ASD? What about the impact of stress on families?

Parents of children with ASD score higher on levels of stress than other groups of parents. The daily challenges of caring for the child are endless and affect all aspects of the family's mental health and ability to manage the needs of the child.

#### What do you anticipate for the future of research and treatment for ASD?

The past few years have witnessed breakthroughs in the understanding of ASD. However, the increase in reported prevalence highlight the need for continued efforts to translate research discoveries into effective interventions. Much treatment research is now heading toward understanding the variables that affect treatment response and predictors of treatment outcome, and using this information to help tailor treatments for individual children. This should lead to an overall higher positive treatment response across all children with autism.

Just two decades ago, autism was a mysterious and somewhat obscure disorder, commonly associated with savants. Today, thanks to awareness and advocacy efforts, people have a much better understanding of autism. However, many people still conceptualize autism as a disorder where the child sits in a corner rocking or banging his head. I think recognition and appreciation of the much more common lesser forms of the disorder is still lacking.

There is a need to provide support for individuals with ASD to successfully transition into adulthood and become valued and valuable members of their communities, such as increased vocational and post-secondary educational support for young adults with autism and expanding job opportunities.

### How is UAB uniquely positioned to advance our understanding and treatment of ASD?

As a world-renowned research institution, UAB allows for multidisciplinary collaborations to further enhance our understanding of ASD. In order to understand this multifaceted disorder, we need to engage people across disciplines such as geneticists, molecular scientists, child psychologists, neuroscientists, and brain imaging researchers. We need a comprehensive approach in understanding the complexity of the disorder. There is a remarkable amount of expertise here, which makes UAB uniquely positioned to advance our understanding and treatment of ASD.

#### Dr. Kristi Guest, Assistant Professor

- Disabilities Services Coordinator for the UAB Early Head Start Program
- Research Coordinator for the UAB Civitan-Sparks Clinics and the UAB Leadership Education in Neurodevelopmental and Related Disabilities (LEND)
- Executive Board Member, Central Alabama Early Intervention Council
- Secondary Appointment, Assistant Professor, Department of Neurobiology, UAB School of Medicine



#### When and why did you come to UAB?

I received my Bachelor of Science degree in psychology with a minor in chemistry from UAB, and I remained here to complete my Ph.D. in developmental psychology. My doctoral work involved three years of a psychology trainee fellowship through the Maternal and Child Health Bureau's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) with concentration in the areas of cognitive, adaptive, and behavioral assessments of children. A post-doctoral fellowship at the Civitan International Research Center, Sparks Center for Learning and Developmental Disabilities completed my training.

After a few years as a coordinator and program administrator, I was promoted to assistant professor appointment in the Department of Neurobiology in the School of Medicine in 2003 and then joined the faculty in the Department of Psychology as an assistant professor in 2007.

What kind of research do you do? How does your research impact our understanding/treatment of ASD?

Throughout my career as a developmental psychologist, I have worked as a Co-Investigator on federally-funded projects focused on providing clinical services to multiple vulnerable populations of children, including children and their families living in poverty, children with disabilities, children at risk for Autism Spectrum Disorder (ASD), children at risk for abuse and neglect, and children of adolescent mothers. Overall, the themes of my research within these atrisk populations have been to explore the clinical presentation of children referred for an ASD assessment at the UAB Civitan-Sparks Clinics/LEND program, the effectiveness of screening measures in discerning ASD from other developmental delays or disorders, and the behavioral characteristics and development of individuals with the rare genetic syndrome Pitt-Hopkins Syndrome (PTHS), to differentiate the clinical presentation from that of other developmental disabilities. Research to better understand the clinical presentations and development of individuals with ASD or similar symptoms is important to guide more informed recommendations for needed services and intervention.

"The collaboration among researchers, clinicians, and educators across disciplines, departments, and schools is what uniquely positions UAB to advance our understanding of ASD."

### Do you see patients/work in a clinical setting? If so, what is the purpose of those interactions/ assessments and treatments?

My career passion has been to serve children with disabilities and their families, to form partnerships with families and children to enhance developmental outcomes for children, and to promote the well-being of children and families. My education as a developmental psychologist and my clinical expertise has allowed me to fulfill this aspiration for the last 18 years.

As a clinician, my service is concentrated in providing intensive intervention services for young children and their families who are low-income and service coordination for children with disabilities through the UAB Early Head Start Program as well as providing diagnostic evaluations of children presenting with symptoms of ASD with the UAB Civitan-Sparks Clinics. Civitan-Sparks Clinics are a fundamental part of the University Centers for Excellence in Developmental Disabilities (UCEDD) and the Maternal and Child Health Bureau's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs. Within these programs, my clinical responsibilities include providing intensive and comprehensive intervention services for young children, disability services management, comprehensive health services, program management, clinical diagnostic evaluations, and clinical training and mentorship.

In my clinical roles, ultimately I strive to improve developmental trajectories for children; to increase family knowledge about child development, diagnoses, and recommendations for services for children with disabilities; and to enhance the quality of life of children and families while concurrently providing clinical training for future leaders specializing in serving individuals with disabilities.

### How is UAB uniquely positioned to advance our understanding and treatment of ASD?

The UAB Civitan-Sparks Clinics really exemplify how UAB is positioned to advance the treatment of ASD. Since the UAB Civitan-Sparks Clinics are home to the UCEDD and LEND training programs, a core responsibility that faculty provide through clinic activities is instructing and guiding graduate students and interns in the area of neurodevelopmental disabilities to become future leaders in the field. Our Maternal and Child Health Bureau's LEND role is to impart knowledge in the field of development and disabilities through exemplary clinical service and education. Our clinical mentoring of graduate students on evaluation and diagnosis of ASD as well as research on developmental disabilities through the LEND training program at UAB have the ultimate outcome of building service delivery systems for individuals with neurodevelopmental disabilities by equipping new leaders with clinical competency and leadership abilities. UAB is a comprehensive university that is nationally and internationally respected in regard to our research, education, and clinical programs. UAB consistently ranks in the top 25 nationally with regards to funding from the National Institutes of Health. Additionally, UAB is regularly ranked as one of the best medical schools in the U.S. Within the College of Arts and Sciences in the Department of Psychology, we offer graduate training programs in the areas of Lifespan Developmental Psychology, Medical/Clinical Psychology, and Behavioral Neuroscience; a prominent strength of UAB programs is that they are interdisciplinary and collaborative across departments and schools. This collaboration among researchers, clinicians, and educators across disciplines, departments, and schools is what uniquely positions UAB to advance our understanding of ASD.

#### **UAB Study of Individuals with Pitt-Hopkins Syndrome (PTHS)**

Limited clinical studies of individuals with PTHS have shown most display severe intellectual and developmental disabilities, motor and communication delays, restricted and repetitive movements, and characteristics that appear similar to autism. Due to the overlap in symptoms of individuals with PTHS and those with ASD, and because of UAB's expertise in the clinical diagnosis of individuals with ASD, Drs. O'Kelley and Guest partnered with Drs. Elizabeth Rahn, Andrew Kennedy, and David Sweatt in the School of Medicine to conduct a research study focusing to describe the social, communication, adaptive, developmental, and repetitive behaviors of individuals with PTHS. Currently, 26 families have enrolled in the study and data collection is ongoing. Since PTHS is so rare, it is vitally important that researchers and clinicians understand the behavioral characteristics and development of individuals with this syndrome in order to differentiate from other developmental disabilities and to guide recommendations for intervention. Study data was presented at the Civitan International/Simpson Ramsey Neurodevelopment Symposium and at the International Society for Autism Research conference.

#### Dr. Laura Stoppelbein, Professor

- Clinical Psychologis
- Director of Outpatient Services, Glenwood, Inc.



#### When and why did you come to UAB?

I chose to come to UAB for both professional and personal reasons. Professionally, the Department of Psychology has an excellent reputation. It has both distinguished researchers and attracts undergraduate and graduate students who are high quality and are interested in psychology. On a more personal note, I grew up in Birmingham and was interested and happy to get back home and be close to family.

## What kind of research do you do? How does your research impact our understanding/ treatment of ASD?

My research focuses on stress/coping within families and factors that influence stress/coping as well as the outcomes of ongoing stress. Within the area of Autism Spectrum Disorder (ASD), our recent research has focused on how family functioning, such as parental adjustment and parenting styles, impact children with ASD. It seems that specific types of parenting may have an important role in helping to mitigate the potential anxiety and depression that children and adolescent with ASD often experience. Thus, treatment approaches could help focus on building these parenting strengths.

### Do you see patients/work in a clinical setting? If so, what is the purpose of those interactions/ assessments and treatments?

I see children and adolescents at Glenwood, which is a non-profit organization that provides behavioral health care and educational services for individuals with ASD and severe emotional disturbances. At Glenwood, my role is largely administrative as I oversee the outpatient programming which includes psychologists, nurse practitioners, and master's-level therapists. As a clinician, my primary clinical functions are in the area of early identification and assessment of ASD among children and adolescents.

### Over the years that you have been researching ASD, what have you learned about the nature of these disorders?

Although there are common themes that you see across individuals with ASD (e.g., certain types of symptoms), each person is very unique. If you have seen one kid with ASD, you have only seen one kid with ASD. You can not necessarily generalize the experience of one child or family to another.

## What role do stress and anxiety play in individuals with ASD? What about the impact of stress on families?

Stress/anxiety always tend to exacerbate symptoms. They are more than likely not causal, but can cause significant increase in symptoms when they are present within a child with ASD or within the family. Oftentimes, families of children with ASD feel isolated and lack social support because they have limited resources for assistance. Additionally, the stress of having a child also has indirect impacts on things such as a family's ability to attend church, or their ability to maintain gainful full time employment (if they are frequently being called to come get their child from school or daycare).

#### What do you anticipate for the future of research and treatment for ASD?

I think that we are making great strides in our understanding of ASD, but we still have a long way to go. We know that there are a multitude of factors that contribute to ASD, and I believe that our continued research will help us sort out which of these factors are most influential. Within society, I think education and understanding are important. Having opportunities for families of typically developing children to help support the family who has a child with ASD would be a great start. That would provide others with both direct experience to the challenges associated with having a child with ASD and offer the families a chance to bond and feel supported.

### How is UAB uniquely positioned to advance our understanding and treatment of ASD?

We have a number of excellent researchers and clinicians in the area of ASD who are employed at UAB. This is true across the basic sciences, applied/social sciences, as well as in the area of clinical practice. I think supporting a collaborative effort across all three areas is a strength that UAB could capitalize on to help us further our knowledge in this area.

#### Service & Outreach