V PSYCHOLOGY IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES/ AUTISM SPECTRUM DISORDER

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FROM THE PRESIDENT'S DESK Karrie A. Shogren, PhD, Kansas University



These are unprecedented times to be writing my first Presidential update. I want to begin by thanking each and every person that has contributed to efforts

through Division 33 as well as through other research, education, and service activities to address the impacts of the COVID-19 pandemic on our collective work in the IDD/ ASD field. Seeing the rapid creation and sharing of webinars, podcasts, and other COVID-19 resources through our website and listserv has confirmed the importance of Division 33 in enabling professional connections and collaborative activities that. particularly during the pandemic, support our mission of advancing psychological research, professional education, and clinical services that increases the quality of life of individuals with IDD/ASD across the life course. I also want to thank Division 33 members for reaffirming our focus on social justice and our commitment as a Division to identifying actions to address systemic racism and the disparities experienced by people with IDD/ ASD who have intersectional identities. Our **Diversity and Inclusivity Committee** continues its work, and I and the committee welcome engagement and input on how we can enact positive change.

I want to acknowledge everyone who contributed to and enabled Division 33 to pivot and meaningfully participate in the APA 2020 Virtual Convention. Division 33 was proud to contribute five virtual symposia and almost 50 virtual posters focused on IDD/ ASD. Given the quick pivot from in-person to virtual programming necessitated by COVID-19 and the resulting need to learn new technologies and systems we were incredibly proud of the contributions of each of our presenters as well as the conference planning subcommittee. The content from APA 2020 Virtual will remain available on the convention website (<u>https://</u> <u>convention.apa.org/</u>) for the next year for registrants, so people can go back and access this information, enabling ongoing learning about cutting-edge research in IDD/ASD.

We also hosted the Division 33 Business Meeting virtually, concurrent with APA 2020 Virtual in August. Dr. Sigan Hartley's Presidential Address stimulated meaningful dialogue among attendees and we were able to recognize Division Award Winners. Dr. Philip Davidson was our 2020 Edgar A. Doll Award winner and Dr. Matthew Lerner was our 2020 Sara S. Sparrow Early Career Research Award winner. Both award recipients are highly deserving of this honor given their meaningful and sustained contributions to research and practice in IDD/ ASD. We were also incredibly pleased that each of them (as well as our 2019 Edgar A. Doll Award winner, Dr. Jan Blacher) agreed to record their talks, as they could not deliver them in-person, and make them available on our Division 33 website (www.division33.org). This provides a new and exciting opportunity to disseminate

information about cutting-edge research in the field. We also recognized our two student poster award winners, who presented their posters virtually at APA 2020. Eleanora

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FROM THE PRESIDENT'S DESK Karrie A. Shogren, PhD, Kansas University

Sadikova was recognized for her poster titled "Sleep Problems and Symptom Severity in Children with Autism Spectrum Disorder" and Abigail Oldham for her poster titled "Measuring Statistical Learning in Children with ASD using Eye-Tracking." Finally, our Early Career Professionals group participated in an online virtual networking event, bringing together early career psychologists across APA, focusing on "Past, President, and Future ECP Climate Challenges in the Pandemic Era." Check out the ECP tab on our website for additional information about the ongoing work of this group, and opportunities to get involved. Also, stay tuned for ongoing updates about the 2021 APA Convention. President-Elect Dr. Jason Baker and President-Elect Designate, Dr. Camie Neece will be working to develop a strong Division 33 program, and will continue to update Division 33 on plans for APA 2021.

In addition to the initiatives I've already mentioned, there are multiple other longstanding initiatives and committees as well as

new and emerging ad hoc committees to advance the mission of Division 33. Our website is the hub for sharing updates on these initiatives and disseminating resources relevant to the field. We are always seeking new partners to join us. If you are interested in learning more and joining other Division 33 members and affiliates in these important efforts, please reach out to me or any of the leadership. Also, continue to watch for new podcasts and other content that can be disseminated broadly to advance our mission. We look forward to connecting with you and continuing to work to identify ways to address emerging challenges and the resulting opportunities for change and growth in our field, in service to our mission of advancing psychological research, professional education, and clinical services that increases the quality of life of individuals with IDD/ASD across the life course.

Karrie A. Shogren, PhD Division 33 President, 2020-2021 <u>shogren@ku.edu</u>

Plenary Speakers

Department University of Kansas Scientist, Life Span Institute, University of Kansas

Nancy Brady, PhD



April 5-8, 2021





Elizabeth M. Berry-Kravis, MD, PhD Professor, Neurology & Pediatrics Rush University Medical Center

Chair, Speech-Language-Hearing

IDD/ASD Training Program Highlight

University of Kansas Life Span Institute (LSI) Postdoctoral Research Training Program



Matt Mosconi, Ph.D. Director, Life Span Institute Post-Doctoral Program

Steven F. Warren, Ph.D. Co-Director, Life Span Institute Post-Doctoral Program



KU LIFE SPAN INSTITUTE Kansas Center for Autism Research & Training

The University of Kansas Life Span Institute (LSI) Postdoctoral Research Training Program provides two year fellowship support for individuals focused on a career as an independent, externally funded investigator studying autism spectrum (ASD) or related neurodevelopmental disorders (e.g., Fragile X Syndrome, Down Syndrome). Fellows participate in a structured research training program involving separate monthly professional development and research seminars as well as intensive instruction in how to build and support an independent research program. All fellows have the goal of submitting a full external award application (e.g., NIH, IES) by the end of their first year of training, and are well supported in this task by their primary mentor and collaborating faculty. Fellows work closely with one of our core faculty, including Drs. Matthew Mosconi, Steve Warren, Nancy Brady, Karrie Shogren, John Colombo or Brian Boyd, and also are encouraged to seek collaborations with additional faculty as they build towards an independent program of research.

Our postdoctoral research training program was developed through a collaboration of

multiple NIH funded University of Kansas investigators leading studies of ASD, Fragile X Syndrome or related FMR1 gene disorders (e.g., Fragile X-associated Tremor/Ataxia Syndrome, or FXTAS), Down Syndrome, and idiopathic intellectual/developmental disability (IDD). Our goal is to provide support and training opportunities for promising investigators embarking on a critical but often challenging stage in their careers. Fellows work closely with the core faculty member whose expertise matches most closely with their own research goals and background. Fellows also may leverage important clinical and research training opportunities through our Intellectual and Developmental Disabilities Research Center (KIDDRC; U54 HD090216), University Center of Excellence on Developmental Disabilities (UCEDD), and Center for Autism Research and Training. Our faculty collectively have broad expertise that covers multiple different IDD populations, the full span of development, and diverse methodologies that allow for integrative analyses across multiple levels, including behavioral, neurophysiological, and genetic/ molecular. Current projects focus on sensorimotor and neurocognitive development in ASD, neurodegenerative processes associated with Fragile X Tremor-Ataxia Syndrome (FXTAS), language and cognitive development in Fragile X Syndrome, development and behavioral treatment of repetitive behaviors in ASD, mechanisms of

IDD/ASD Training Program Highlight

typical and atypical cognitive development in infancy, and self-determination in adolescents/ adults with IDD and ASD, among others. Fellows are invited to build on these existing programs as they develop new research and methodological skills and build their own line of clinical/translational research.

As part of our goal of helping advance trainees' careers as successful, independent researchers, we provide a forum for intentional conversations about critical professional development skills that often fall by the wayside in traditional mentorship models. For example, as Dr. Kathryn Unruh, a program alum and now current faculty member at KU noted, "the round table discussion format of some of the professional seminar activities allows trainees to learn from a variety of experiences of staff and faculty at all career stages, and to learn through their personal academic journey, including their successes and their failures". Focused seminars on topics from people with disabilities, people of color, such as grant budgeting, managing lab staff, navigating difficult career transions, and communicating research to the general public, provide rich training in areas that often do not receive sufficient attention, and which bear significantly on the success of faculty researchers.

Our program currently is seeking one new postdoctoral research fellow to begin training in Fall, 2021. Upon admission to the program,



fellows will develop an individualized development plan (IDP) with their primary mentor that will include plans for an initial research project, training in professional development skills (e.g., how to set up an independent lab, grant writing, time management, etc.), participation in our autism center and other relevant seminars, and the development of a new funding proposal completed over the first year of training. The majority of the fellow's time will be spent engaged in activities identified in their IDP.

Applicants are welcomed from a range of background training disciplines, including but not limited to clinical psychology, developmental psychology, speech-language, neuroscience, special education, school psychology, and cognitive psychology. Our program also is committed to recruiting trainees from diverse backgrounds. We believe that lack of representation in academia LGBTQI+ people, and others from diverse backgrounds disproportionately hurts the most marginalized people in society. Hence, we strongly encourage applications from people with these identities or who are members of other marginalized communities.

For more information about the fellowship, please contact Matt Mosconi, Ph.D. at mosconi@ku.edu, or go to https:// employment.ku.edu/staff/18017BR. To apply, submit an online application including a cover letter, vitae, professional writing sample (e.g. publication, dissertation), 1-2 page research statement including a description of the primary research interest(s) and potential match with a member or members of our mentoring team, and contact information for three professional references.

Division 33 Student Interview

Social and Racial Injustice in ASD



Interview conducted by: Brianna Gambetti, MS; University of Wisconsin-Madison & Elizabeth Baker, BA; UC Riverside





Dr. Katherine Stavropoulos is an Assistant Professor of Special Education in the Graduate School of Education at UC, Riverside (UCR). She is a licensed clinical psychologist and serves as the Assistant Director of the UCR SEARCH Center, where she is involved in the screening and diagnosis

of children with ASD. Dr. Stavropoulos conducts translational studies to better understand the reward system in ASD, as well as how anxiety contributes to social deficits in ASD. Her work is grounded in improving the lives of people in under-resourced communities, particularly by including underrepresented racial and cultural groups in brain-based research.

Question 1. What current racial and/or cultural disparities exist in the diagnosis and treatment of ASD? Why do such disparities exist?

Unfortunately, we know that Black and Latinx individuals get diagnosed later than White and non-Latinx children. One hypothesized reason for these disparities include lower levels of education and/or income of parents in underserved populations. There is also literature suggesting that Black and Latinx parents report less autism-specific concerns compared to White parents (Donohue et al., 2017; Blacher, Stavropoulos, Bolourian, 2019; Blacher et al., 2014). This might be due to issues in validating ASD-related questionnaires with culturally diverse samples (e.g., if such questionnaires are developed mostly on White participants, they may be less effective for diverse populations). In terms of

issues getting services after receiving a diagnosis, studies indicate that Latinx parents report barriers related to poverty, lower education, limited English proficiency, and lack of ASD awareness (Zuckerman et al., 2014). The consequence of a later diagnosis is later access to services, which has large, negative implications for children. We know that earlier access to services is associated with better outcomes, so delaying services is extremely problematic.

Question 2. In your experience, do parents of different cultures and races express unique concerns about their child?

It's hard to disentangle varying parental concerns between families, particularly when taking into consideration that for some families, there may be less ASD-related knowledge or awareness. This may be compounded by linguistic differences or questionnaires being developed without sufficient consideration for diverse populations. Though knowledge and awareness of ASD "red flags" and risks impact concerns about the child, clinicians and physicians must also use screening questionnaires that are culturally sensitive.

Question 3. What specific disparities can be addressed? How might you address them through your research and clinical practice?

I think gaps in service access can be addressed by making sure that all children diagnosed with ASD have access to free services through healthcare. For families who might not know about what services their children are entitled to, education should be

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Division 33 Student Interview

provided to them so that they know what to ask for, and who to ask. In terms of diagnostic gaps, that is tougher but still do-able, in theory. We need to make sure that there are educational campaigns in underserved BIPOC communities about early signs of ASD. We also need to educate clinicians and doctors about these disparities so that they ask parents culturally sensitive questions about their child's behavior. Additionally, professionals need to look for signs and symptoms of ASD at well-baby visits even if the child doesn't meet on specific screeners (MCHAT, SCQ, etc.). I have anecdotally heard many parents lament not being taken seriously by providers when they express concerns about their children. Sadly, these families were mostly Latinx and spoke Spanish. That suggests we also need to educate providers about the risks of implicit bias.

Question 4. Why are non-White children with ASD diagnosed with Intellectual Disability at a higher rate?

This is a really important point that should be discussed. Updated CDC prevalence reports about ASD just came out in March 2020. The report states that Latinx children have significantly lower prevalence of ASD compared to White/non-Hispanic and Black/ non-Hispanic children. However, even though the prevalence is similar between White and

Black children, Black and Latinx children were significantly more likely to be diagnosed with ID than White children. Also, Black children tended to be diagnosed with ASD at older ages than White children despite having equivalent prevalence rates. Overall, the new 2020 report suggests that non-White children are diagnosed with ID at higher rates than White children. Although the "why" remains unclear, this pattern should be researched. It is probable that this disparity may be related to Question 2 (e.g. that parents from different cultural backgrounds might report different concerns), or the disparity may relate to implicit bias. Either way, we need more research and data on this topic.

Question 5. Does COVID-19 impact disparities for non-White families with ASD/IDD?

Though there is not official data on this yet (to my knowledge), my educated guess is that COVID-19 does impact families of children with ASD/IDD uniquely. We know that COVID-19 disproportionately impacts communities of color, so it would follow that pre-existing disparities would be exacerbated by the COVID pandemic. In fact, one of the theories of *why* COVID disproportionately affects communities of color is that it is simply making disparities more obvious than they were previously.

Psychology in Intellectual and Developmental Disabilities/Autism Spectrum Disorder

You can now join and renew your Division 33 membership online! Just visit: http://www.division33.org/membership/

As always, a very special <u>thank you</u> to Jason Baker for doing such a wonderful job with our website.

Perspectives from ECPs Entering a Nontraditional Job Market: Exploring Alternative Paths and Career Readiness During the COVID-19 Era

Jessie Greenlee, PhD, Emily Hickey, Allison Jobin, & Catie Sanner, PhD

Given the recent impact of COVID-19 on the career trajectory of ECPs, we gathered perspectives and input from current ECPs who were navigating the current job market or transitioning to new academic, clinical, and research positions during this time. While these perspectives do not encapsulate the experiences of every ECP in the field of IDD/ ASD, these perspectives include experiences ranging from tenure-track positions, post-doc trainees, and research scientists. In addition to their specific roles and responsibilities, each have shared their insights on what the pandemic has meant to them and what implications it has had for their careers, research, personal life, and aspirations moving forward. While each Division 33 ECP member interviewed in this piece is incredible in their own right, these professionals also enjoy mentoring students and trainees in both clinical and research aspects, as well as conducting community-partnered research and engaging in collaborative and interdisciplinary research. We hope these experiences will normalize barriers many ECPs are facing

during this time.



Dr. Jessie Greenlee is in her second year as an NIH-funded T32 Postdoctoral Fellow in the Waisman Center's Training Program on Biobehavioral Research on Intellectual and Developmental Disabilities (IDD) at the University of Wisconsin-

Madison. Her research examines inter and intrapersonal determinants of the socioemotional development and mental health in children with IDD

with a particular focus on children with autism spectrum disorder (ASD).

Dr. Emily Hickey is an Assistant Research Scientist at UW-Madison Waisman Center - University Center for



Excellence in Developmental Disabilities (UCEDD), Madison, WI. Her main duties under this role include collaborating with other university and academic staff on research, evaluation, and

dissemination projects.



Dr. Allison Jobin is an Assistant Professor in the Department of Psychology at California State University, San Marcos. She is also an investigator at the Child and Adolescent Services Research Center, as well as a licensed

psychologist and board-certified behavior analyst. Dr. Jobin's research focuses on treatment for children with autism spectrum disorder (ASD) and their families and the effective delivery of evidencebased practices in community settings.

Dr. Catie Sanner is a Postdoctoral Fellow under the supervision of Dr. Cameron Neece in the Loma Linda University Psychology Department, Loma Linda CA. Her role includes the supervision of students in clinical aspects of two NIH funded randomized controlled trials



targeting parenting stress in parents of young children with developmental disabilities.

Q1: What were the most salient factors that influenced your decision to choose your current position and what do you like about it? What are some challenges you are currently facing in your position during this time?

Dr. Hickey: A major factor in choosing my current position was to have protected time to build my independent research career, while also becoming involved in larger research, evaluation, and dissemination efforts within the center. One challenge I am facing in my current research-focused position is how to feel fully oriented to and engaged in ongoing research and evaluation efforts, while also balancing my own independent line of

research. Because I have been fully remote since I began three months ago, I have found it difficult to find my role on the team and to understand the nuances of the expectations. It's easy to feel confused about what's expected and if I'm doing enough. One thing I am very appreciative of is the patience and support of my colleagues. I am also learning how to manage my time and my own expectations of what I can accomplish and when.

Dr. Sanner: One thing that has been really challenging in my current position as a postdoc is to know how to balance and prioritize opportunities and experiences. As a graduate student, varied opportunities and experiences were important while building a diverse and competitive CV, and I often said yes to too much. However, as a post-doc it has been critical to consider and weigh opportunities more heavily that directly align and will move me towards career goals and make me more competitive for funding opportunities and specific jobs. It has often been difficult to balance ongoing research and teaching opportunities, while trying to find time to work towards developing my own independent line of research. Open and ongoing discussions and support with research mentors and other faculty has been extremely helpful in weighing options and hearing about what training experiences were most beneficial when they were in the early stages of developing their own lines of research, and considering various job opportunities.

Q2: The academic job market is stressful in the best of times. Due to hiring freezes, many tenure-track lines were no longer advertised or available. How did you adapt your goals and career aspirations in a time of crisis? What other options did you explore?

Dr. Hickey: I adapted my search criteria to include non-tenure track and non-academic positions. In the end, I feel like the assistant research scientist position was actually a better choice for me personally, as it allows me to focus on my passion for research, disseminating at conferences and in peer reviewed journals, and collaborating on other projects. It was also a nice step following a post-doc position, as I have time to finish manuscripts and other projects while transitioning and developing my own independent line of research. Like other research scientist and research professor positions, because I am still within academia, I also feel like my options remain open should I ever consider a tenure-track position in the future.

Dr. Greenlee: Preparing for the job market this year has been challenging. I have expanded my search to include departments I might not have otherwise considered while also trying to put together options for staying another year at my current institution, albeit in a different position. A byproduct of the limited academic job market has been an increase in conversations around options other than tenure-track jobs and I think that is really useful for students and ECPs. Flexibility has been the key so far - I am trying to keep as many avenues as possible open in hopes that one works out.

If you did get a tenure track position during this time, how is the position different from what you expected? What have been some barriers or new realities during this transition?

Dr. Jobin: I obtained my current position just months before the pandemic impacted us all. I began the position in an almost entirely virtual context, which is expected for the remainder of the academic year. This was certainly unexpected! It has been disappointing to not meet my students and colleagues in person, to experience the life and energy of the college campus, and to benefit from those informal hallway connections and conversations. It's also daunting to launch my research lab in an entirely remote world. However, I have been impressed with the support from my new colleagues and the institution, and the opportunities for training

through virtual means. My institution offered new faculty training in the Summer to prepare for the adjusted semester, as well as many other ongoing training opportunities. Students have shown resilience and grit, and I do feel I've gotten to know them--even online.

Q3: The early stages of any career postgraduate school can be difficult. In general, how has the pandemic impacted your research, clinical work, or career, particularly in the area of developmental disabilities? What have been some drawbacks or silver linings during this time?

Dr. Sanner: As a post-doc, one area of my training that has been significantly impacted by the pandemic has been the more clinical aspects of my training. One goal I had for this year was to obtain research reliability in the ADOS-2. Given that the ADOS-2 cannot be administered reliably with a mask, these trainings and experiences were put on hold indefinitely. I was able to supplement my training in ASD diagnostic measures by attending a virtual clinical training in the ADI-R, as well as finding virtual seminars and trainings focused on ASD research and assessments during a pandemic. Many of these trainings would not have been feasible for me to attend if they had not been virtual, which has been a silver lining. Fewer clinical hours has also afforded me more time to focus on manuscripts and developing my own independent line of research. It's been really important to be flexible and open-minded during this time with an understanding that everyone is trying to adapt given the current pandemic.

Dr. Hickey: Conferences being virtual have also made it difficult to make connections, foster new collaborations, even catch up with old colleagues to support each other in our new roles/jobs as ECPs.

Dr. Greenlee: A silver lining in all this has been the opportunities that have come up via virtual events, training, webinars, etc. that I would not have attended in person due to time or resource constraints. There are a lot of things I miss about in person conferences but some doors have opened with the advent of all virtual spaces, particularly around professional development.

Dr. Jobin: I am definitely having to adjust my expectations around new research projects and student involvement. Starting a new position in a virtual world has also made it more challenging to feel integrated into a new Department and institution, although I recognize growth in my ability to connect with others through alternative avenues--certainly an important professional skill. As we are all experiencing these uncertainties in one way or another, this has led to common ground with my new colleagues and students.

Q4: Thinking about the different types of support that are beneficial to each of us, what type of support mattered to you most during this time? What words of wisdom would you share to other ECPs currently navigating the job market or those who are uncertain of job options after graduate school?

Dr. Hickey: The best piece of advice I can give, and what ultimately led me to my current position, is to spread the word that you are on the job market. Tell everyone; meet up (zoom) with previous and current mentors and colleagues and ask them to spread the word that you're looking for a position, too. Talk to as many people as you can to get insight about what jobs are out there and how you might best prepare yourself to apply to them. That way, when a position does come up, they will be more likely to reach out to you and you'll know whether it is worth putting the time in to apply. Alternatively, if you find an organization that's a perfect fit and they are in a position to hire, it is possible that they might work with you and get creative about crafting a position that is tailored to your experience, expertise, and goals. Additionally, if you're adapting and/or broadening your search criteria to include non-tenure track and non-

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Early Career Psychologist Column

academic positions, many conferences offer workshops and/or panels on job searching of this kind. I would highly recommend attending them, and making connections with any presenters who seem to be in positions that might interest you. Setting up a one-on-one zoom call with them to learn more could be very beneficial, and who knows - they might have other job openings within their organization.

Dr. Greenlee: The best piece of advice I've received is to be flexible but don't try to force yourself into a position that doesn't meet your goals. It is easy to feel overwhelmed by this process and there are times when any option seems like the best option. Keeping the lines of communication open with trusted mentors and advisors is also important - sometimes they can see through the clouds when we are in the middle of the storm. I've also found a network of other ECPs that has been a great source of support and information. We have a writing group once a week and it is a mix of writing and talking about job searches, applications, and troubleshooting new situations.

Dr. Sanner: One piece of advice that I've received is that your first job does not have to be your "dream job" or your job for forever. While it is important that a position aligns with your goals, having a more open mind and some flexibility takes a little bit of pressure off these stressful decisions especially during this time of uncertainty and hiring freezes.

Dr. Jobin: For anyone finding themselves in the position of navigating a new position in these uncertain times, I would recommend reaching out proactively to introduce yourself to those you will be working with, as this will not happen as organically as it would in person. Ask questions of your colleagues, even though it feels you have to be more purposeful when you can't stop by someone's office. Keep in mind, this is a new context for everyone, including for those who are tasked with orienting and supporting you. Leaning on my existing network of peers has been a necessity, in addition to establishing a support network of other new faculty at my new position. This has been critical for real life and professional advice, but also solidarity, levity, and release.

Q6: What recommendations would you give to someone exploring career opportunities or positions (e.g., academic, research, clinical) during this time? What resources would you recommend for those who do not know where to start or have struggled with the disruptions on their path to getting that "dream" job?

Dr. Hickey: It was very helpful to hear from a variety of professionals about their own career trajectories - none of which were completely smooth. There are a lot of paths to get to your "dream" job - and you might learn along the way that there are other options that work even better for you. Considering the current uncertainty, I would encourage flexibility and open-mindedness.

Dr. Greenlee: Professional societies and groups also have online events for students and early career folks about different career options and I would encourage folks to look at groups you may not be affiliated with. I'm finding people are very willing to talk and answer questions.

Dr. Jobin: I would encourage flexibility and openness to unexpected opportunities. You never know what your next decision might lead to down the road. At this last hinge point, a mentor of mine reminded me, "There is no one last great opportunity. You are just making the next choice." Ask your colleagues and mentors about the career landscape in their settings, to learn from the source about the barriers and opportunities.

Q7: What have been some rewarding experiences or memories that you will take from your current experience as an ECP?

Dr. Greenlee: I think working through a pandemic as an ECP has made me appreciate

what I do instead of what I could be (or think I grateful for my fellow ECPs and senior should be) doing. There is a perception in academia that you have to do all the things all series of quick emails or text threads--either at once to be successful and I buy into that a lot less these days. I also think that it's a really exciting time to be an ECP in IDD and ASD research - there can be a steep learning curve when moving into a new position (particularly right now!) but it's also an exciting time to explore new ideas, meet new people and begin to develop your own program of research.

Dr. Jobin: Living through a pandemic has required me to rely on my family and personal and professional support networks, and to be more purposeful with my own self-care. I am

mentors, who have saved me through a with light diversions or much needed guidance or advice. Given my increasingly thinned bandwidth, the pandemic has tightened the alignment of my day-to-day work with my core values. I try to channel this when new opportunities arise. It has also been poignant to experience "work" with my young daughter by my side. We get to see a bit of each others' lives we wouldn't have otherwise experienced. Although challenging for parents and children. I hope this time will also inspire young minds.

Find out more about Early Career Psychology with

Division 33 by visiting http://www.division33.org/



APA DIVISION 33: IDD/ASD

Racial/Ethnic Disparities in Health and Healthcare for Children with Special Needs

Eileen M. Davis, PhD, Rebecca M. Kirchner, MA, & Glenn Flores, MD







University of Miami Miller School of Medicine & Holtz Children's Hospital

It is estimated that racial/ethnic minority children will outnumber White children in America at some point in 2020, and there have been more minority than White births in the US since 2011. The proportion of children with special needs also has increased by 13% over the past decade. Indeed, there are now seven million children with special needs in US public schools, accounting for 14% of public-school students. Students of color are disproportionately overrepresented among children these services are often of poorer quality. Black/ with disabilities: for example, among children 3-21 years old, Black/African-American children are 40% and American Indian/Alaska Native children are 70% more likely than their peers to be provided services under the Individuals with Disabilities Education Act (IDEA). Understanding health and healthcare disparities at the intersection of race/ethnicity and disability is necessary to achieve equity for children with special healthcare needs (CSHCN)

Racial/ethnic disparities in children's health and healthcare in the US are well documented, pervasive, extend across the full healthcare spectrum, and persist over time (Flores, 2010). Despite increased efforts to identify, monitor, and address healthcare disparities for the last two decades (Alegría et al., 2010), minority children remain more likely to be uninsured, have higher rates of unmet healthcare needs, and are less likely to have a usual source of care or to be referred for specialty care (Flores, 2010; Smith et al., 2015). Latino and Black/African-American children account for 53% of all uninsured children in the US, and caregiver unawareness of insurance eligibility, hassles associated with applying for health insurance, and insurance representatives

erroneously informing parents of child ineligibility are associated with uninsurance (US Census Bureau, 2014; Flores et al, 2016). Compared with White children, Asian/Pacific Islander and American Indian/Alaska Native children are more likely to have gone one year or longer since their last physician visit (Flores, Bauchner, Feinstein, & Nguyen, 1999; Shi & Stevens, 2005). When racial/ ethnic minority children do access primary care, African-American and Latino caregivers are more likely to report dissatisfaction with care and difficulties with healthcare access (Ngui & Flores, 2006), which is linked to language barriers and indicators of poor family-centered care (Coker et al, 2010). Minority families of CSHCN are more likely to report that their provider does not listen well, spend enough time with them, or provide adequate information (Coker et al, 2010). Moreover, caregivers of minority children are less likely to receive anticipatory guidance, or to be asked by their provider if they have any concerns regarding their child's development (Guerrero, Rodriguez, & Flores, 2011; Schuster, 2000). Notably, research suggests that this dissatisfaction is reduced when families receive care from providers whose racial/ethnic background is similar to theirs (Saha et al., 1999), and that parents rate healthcare quality as higher overall when providers have high levels of cultural competence (Lieu et. al., 2004). These findings highlight the importance of developing a diverse workforce and training healthcare providers to adequately address the social, cultural, and linguistic needs of families

Lack of access to quality primary care and

Racial/Ethnic Disparities in Health and Healthcare for Children with Special Needs

specialty-care services has important implications for children with intellectual and developmental disabilities, who have been documented to benefit from early detection and linkage to diagnostic services. Notably, although results of the most recent CDC prevalence study found that rates of autism at eight years old were similar for Black/ African-American and White children for the first time, clear diagnostic disparities still remain. Specifically, despite evidence that comorbid intellectual disability is associated with an earlier age of autism assessment and diagnosis, Black/ African-American children, who were more likely to also have an intellectual disability, were less likely to have been evaluated by 36 months (Maenner, 2020). Autism diagnosis rates also continue to be lower in Latino children than White children, which may largely be attributable to stigma, cultural differences in developmental expectations for children, and language barriers (Zuckerman et al., 2014). For instance, caregivers with limited English proficiency (LEP) reported reading, writing, and understanding English as significant barriers to accessing services for their child (Iland et al., 2012), and there are concerns regarding the use by Spanish-speaking LEP families of screening and diagnostic instruments developed in English for a different socio-cultural context (Alonso-Esteban, et al., 2020). Importantly, delays in diagnosis for minority children have compounding effects by delaying access to early-intervention services. Indeed, Spanish-speaking LEP families have been shown to receive significantly fewer hours of intervention services (Amant, Schrager, Peña-Ricardo, Williams, & Vanderbilt, 2018; Nguyen et. al.2016) and have more unmet therapy needs (Zuckerman et al., 2017) than White families.

Given the importance of uninterrupted access to early and intensive intervention services for CSHCN, suspension of community services and school closures related to the COVID-19 pandemic are particularly concerning for this population. Globally, research suggests that parents of children with disabilities have been impacted by the pandemic even more than the general population (Fontanesi et al., 2020). In terms of racial/ethnic disparities, Black/AfricanAmerican and Latino children are five times more likely to die from COVID-19 than White children (COVKID Project, 2020). Although little is known yet about the impact of COVID-19 on assessment and intervention services for minority CSHCN, recent surveys of racially/ethnically diverse families of CSHCN document that most parents report that their child's services decreased after the stay-at-home order went into effect (Neece et al., 2020; Flores et al., 2017).

An urgent healthcare priority is the reduction, and, ultimately, elimination of racial/ethnic disparities in access to timely, high-quality, and culturally sensitive assessment and intervention services, particularly for CSHCN. Identifying and addressing inequities, including those that emerge as a result of the COVID-19 pandemic, will require careful coordination among researchers, community providers and organizations, and the public and private healthcare sectors. Methodologically rigorous research suggests that the use of an enhanced medical-home model can be an effective approach to improving health outcomes and reducing costs for high-risk minority children (Mosquera, Samuels, Flores, 2016). Navigating healthcare systems can be daunting for families of CSHCN, particularly racial/ethnic minority families, who tend to report an increased distrust of the healthcare system, as well as LEP families (especially given that over 67 million people in the US [22%] speak a language other than English at home, and 25.6 million Americans [8%] have LEP). The medical home offers a care-delivery model that coordinates healthcare services in the primary-care setting and can reduce barriers to healthcare access. Additionally, the medical home can directly address the disparities that exist for minority families in receiving specialty care services, which can result in poorer quality of care and adverse outcomes (Flores & Lin, 2013). At the core of the medical-home model are the principles of familycentered care (FCC), which emphasizes shared decision-making between families and providers. The need for FCC is particularly salient for CSHCN, who often require a higher level of specialty services and express high levels of dissatisfaction with providers. FCC highlights the

Racial/Ethnic Disparities in Health and Healthcare for Children with Special Needs

values of 1) adequate time spent with the family; 2) careful listening; 3) sensitivity to family values and beliefs, such as beliefs about developmental and behavioral expectations, views on mental health, and attitudes toward healthcare providers; 4) providing needed information in a manner that is culturally and linguistically appropriate; and 5) involving the family as partners in the child's care. Evidence suggests, however, that rates of accessing a medical home are low among children with intellectual and developmental disabilities in general, and even lower among Black/African-American and Latino children with special needs (23% and 22%, respectively, vs. 31% for Whites; Parish et al., 2013). Moreover, racial/ethnic disparities continue to exist in access to FCC among families of CSHCN, even when adjusting for child health, socioeconomic, and access factors (Coker et al., 2010).

These disparities in FCC access in the context of a medical home can be addressed with the use of cost-effective parent mentors, who are parents who have their own CSHCN and receive training to help other families with CSHCN to address key barriers to children's healthcare through education, linking families to resources, providing peer support, eliminating language barriers, addressing social determinants of health, and empowering parents of at-risk children (Flores et al., 2016). Parent-mentor interventions have been shown to have short- and long-term effectiveness for insuring uninsured children, improving access to a medical home and specialty care, and achieving parental satisfaction (Flores et al, 2016). Under reauthorization of the Continuing Appropriations Act 115-55, organizations are eligible for CMS grants to fund parent mentor programs to address social determinants of health, such as improving education about obtaining and renewing health insurance and guidance on establishing a medical home (U.S. House, 2018).

Another important step in addressing disparities is the development of routine practices for collecting adequate race/ethnicity and language data on all children at all levels (i.e., individual practices, hospitals and healthcare systems, private and public health-insurance providers, and managedcare organizations), with special attention to identifying all racial/ethnic groups, including

multiracial children, as identified by caregivers. Tracking these data systematically can help to better understand, monitor, and target health disparities, including new disparities that may emerge as a result of demographic, economic, and population-health changes, such as the current COVID-19 pandemic. Relatedly, underrepresentation of minority children in health research, because of such issues as lack of validated instruments and unjustified exclusion of LEP families, as well as failure to examine available data by racial/ethnic subgroups, can limit our ability to assess and track progress in racial/ ethnic disparities for CSHCN (Flores et al., 2002; Zamora et al., 2016). Research recruitment and retention efforts must be sensitive to the culturespecific needs of racial/ethnic minority families. Notably, culturally sensitive recruitment strategies are superior to traditional recruitment approaches for successfully involving Latino families in healthcare research, such as through partnering with trusted community organizations, recruitment by bilingual staff, and staff availability to address questions (Zamora et al., 2016). Furthermore, adequately addressing racial/ethnic disparities in access to and quality of care for families of CSHCN must involve rapid-cycle qualityimprovement efforts that assess and revise interventions to ensure that equity is, indeed, achieved and maintained.

In conclusion, by taking the following steps, we can eliminate disparities and achieve equity for CSHCN and their families: 1) routinely collect race/ethnicity data (as self-identified by parent) on all children, and regularly identify, monitor, and target disparities as part of quality-improvement efforts; 2) ensure that every child has health insurance, medical and dental homes, and access to subspecialty care; 3) frame and address disparities as quality-of-care issues; 5) aim for the highest level of cultural competency and a stance of cultural humility that involves families as partners in children's health care; 5) pursue workforce diversity that is more representative of racial/ethnic diversity in the US; and 6) leverage innovative, evidence-based interventions, such as parent mentors, to improve healthcare and health outcomes for CSHCN.

Ψ

2020 APA Student Research Award

Sleep Problems and Symptom Severity in Children with Autism

Eleonora Sadikova, M.Ed., Christina M. Harkins, M.Ed., & Micah O. Mazurek, Ph.D., University of Virginia



Sleep problems are associated with worse developmental, cognitive, and emotional outcomes in children. Up to 80% of children with Autism Spectrum

Eleonora Sadikova, M.Ed

Disorder (ASD) are significantly affected by sleep problems. Sleep disturbances in children with ASD have also been associated with more severe core symptoms of ASD. However, in previous studies of sleep and ASD, symptom severity was measured by the presence of ASD characteristics, rather than the impact of such symptoms on functioning, which may be a more clinically useful measurement of symptom severity. The aim of this study was to examine whether sleep problems are associated with severity (i.e., frequency and functional impact) of specific types of ASD symptoms.

The sample included 606 children (123 female, 483 male, mean age: 9.69 y.o.) diagnosed with ASD, who were enrolled in the Autism Treatment Network Registry Call-Back Study. ASD symptom severity was measured with the Autism Impact Measure (AIM) and its five domains: Repetitive Behavior, Communication, Atypical Behavior, Social Reciprocity, and Peer Interaction. We used the Children's Sleep Habits Questionnaire (CSHQ) total score to measure levels of sleep problems. Associations between sleep problems and specific ASD symptoms were examined through a two-step hierarchical model. Step 1 included parental education, IQ, and age as control variables known to be associated with ASD symptom severity. CSHQ scores were entered in step 2. Separate regression models were tested for the AIM total and each of the five subdomains.

In step 1, parental education (B=-.09, p=.049), IQ (B=-.33, p<.001), and age (B=.02, p=.61) were significant predictors of AIM total score F $(3, 449)=20.61, p < .001, R^2=.11$. Inclusion of CSHQ total score (B=.25, p<.001) at step two resulted in a statistically significant increase in the amount of AIM total score variance explained beyond parental education, IQ, and age F(1,448)=33.07, p<.001, $\Delta R^2 = .17$. Inclusion of CSHQ total score also resulted in statistically significant increases in variance explained beyond the covariates in the Repetitive Behavior, Communication, and Atypical Behavior domains (F(1,467)=40.09, $p < .001, \Delta R^2 = .17; F(1,463) = 9.45, p = .002, \Delta R^2$ =.014; F(1,464)=44.16, p<.001, $\Delta R^2 = .086$, respectively.) By contrast, CSHQ total score did not significantly explain variance in either Social Reciprocity or Peer Interaction domains (F(1,464)=0.37, p=.54; F(1,466) < .001, p=.99,respectively).

Overall, the results indicate sleep problems differentially affect core deficits in ASD. While sleep problems did not predict difficulties with social reciprocity (e.g., shared enjoyment, eye contact) and peer interactions (e.g., social play behavior), they were predictive of speech and communication difficulties and atypical and repetitive behaviors. This may suggest that the effects of sleep disruption on neurocognitive functioning lead to greater effects on effortful language-based skills and behavioral regulation than on core social deficits. Future research should examine causal and directional associations between sleep problems and ASD symptom severity.

2020 APA Student Research Award

Statistical Learning and Its Relation to Language in Young Children with Autism: An Eye-Tracking Study

Abigail Oldham, BA, Abigail Browngoehl, BA, Nancy Raitano Lee, Ph.D, & Giacomo Vivanti, Ph.D. A.J. Drexel Autism Institute at Drexel University



Research has consistently documented language difficulties in autism spectrum disorder (ASD). One plausible yet untested factor contributing to these difficulties is a deficit in statistical learning abilities. Previous research has shown

Abigail Oldham, BA

that statistical learning, the ability to extract statistical regularities, is critical to language development in typical children. Its role in young children with ASD has not been studied due to methodological limitations. To address this gap in research, we created a novel eyetracking task testing statistical learning.

OBJECTIVES: To test the hypothesis that performance in the statistical learning task contributes to variance in verbal language abilities of young children with ASD.

METHODS: A group of 32 children with an ASD diagnosis, ages 25-35 months, was administered an eye-tracking task designed to test statistical learning. Statistical learning was indexed by participants' anticipatory gaze in response to the observation of patterns of events in two conditions. In the deterministic condition, a video-animation showed a sequence of events whereby a ball is descending down a waterfall, is occluded behind a bridge, and then descends down to three stream options, going down the same stream for four trials. In the probabilistic condition, the same scenario was presented, but the ball descended down the same waterfall in three of the four trials, while in one trial it descends down the opposite stream. Anticipatory gaze was computed as the duration of attention to the waterfall stream where the ball descended all the time

(deterministic condition) or most of the time (probabilistic condition) before the ball was seen falling down stream. We examined the association between statistical learning in the two conditions (as indexed by the increase in anticipatory gaze over trials) and verbal ability as indexed by the communication subscales of the Mullen Scales fort Early Learning (MSEL) and Vineland Adaptive Behavior Scales (VABS).

RESULTS: In the deterministic condition, after observing that the ball was consistently descending down the left waterfall in the first two trials, children with ASD were showing anticipatory gaze towards the left waterfall in the following trials (p<.001), thus demonstrating the ability to extract patterns, such as the direction of the ball's path, and anticipate future events. In the probabilistic condition there was no evidence of anticipatory gaze in the direction where the ball was falling in most trials (p=.27). Statistical learning in the deterministic condition, but not in the probabilistic condition, was associated with verbal ability across standardized scores in the MSEL (p=.01) and VABS (p<.05).

CONCLUSIONS: Young children with ASD in this task showed evidence of statistical learning in the deterministic condition, but not in the probabilistic condition. This suggests that children with ASD might be able to learn "what is going to happen next" after observing repetitions of the same event in a deterministic but not in a probabilistic scenario. Children with better performance in the statistical learning task had better language skills, consistent with the prediction that statistical learning contributes to language development in this population.



PARENT TRAINING TO IMPROVE DENTAL CARE

- Primary components: participation enhancement, psychoeducation, behavioral intervention
- 7 core in-person sessions, 4 phone boosters
- Handouts, visual supports, video models, social stories

	Week	Core Sessions			
I	1	Participation Enhancement Intervention, Introduction to			
l		Behavioral Principles and Antecedent Interventions			
	2	Tooth Brushing Psychoeducation, Desensitization, Chaining, and			
l	Behavioral Consequences, Home Dental Support Plan				
I	3	In-Vivo Tooth Brushing, Distraction and Non-Contingent Escape			
	- 4	Home Coaching			
	5	5 Flossing and Diet Psychoeducation			
I	6	6 Dental Visit Preparation, Dental Visit Support Plan			
l	8	Dental Visit Coaching			
26:2	6:24 / 1:07:32				





How Family Perspective Molded the Field of IDD/ASD:

Reflections on the Evolution of a Career

Jan Blacher, Ph.D.

Distinguished Professor University of California, Riverside (UCR) University of California, Los Angeles (UCLA) Director of UCR SEARCH Family Autism Resource Center

> Doll Award, 2019; Address in 2020 APA Division 33





August 6th, 2020 Division 33 – Sparrow Awardee Address APA Annual Convention

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RUBI Parent Training Session 11 Core 7 Supplemental Behavioral Principles (the ABC's) Toileting Prevention Strategies Feeding Daily Schedules Sleep Reinforcement 1 & 2 Time Out · Planned Ignoring Imitation Compliance Training Crisis Management Functional Communication Skills Contingency Contracting Teaching Skills 1 & 2 Generalization & Maintenance



Thank you and congratulations to all of our Division 33 Presenters at this year's virtual APA Conference.

	Edgar A. Doll Award	Sara Sparrow Early Career Research Award (est. 2008)	Jacobson Award		
	(est. 1980)	Research Award (est. 2000)	(est. 2007)		
1981	Sam Kirk				
1982	Gershon Berkson				
1983	Marie S. Crissey				
1984	Sidney Bijou				
1985					
1986	Norman Ellis				
1987	Ed Zigler				
1988	H. Carl Haywood				
1989	Donald MacMillan				
1990	Henry Leland				
1991	Alfred Baumeister				
1992	Earl Butterfield				
1993	Brian Iwata				
1994	Ivar Lovaas				
1995	Stephen Schroeder				
1996	Donald Baer				
1997	Richard Eyman				
1998 1999	Nancy Robinson				
2000	Murray Sidman Todd Risley				
2000	Don Routh				
2001	Travis Thompson				
2002	John Borkowski				
2003	Gene P. "Jim" Sackett				
2004	Robert Sprague				
2005	Ann Streissguth				
2000	Douglas K. Detterman		Richard Foxx		
2007	Michael Guralnick	Luc Lecavalier	Menara Foxx		
			James Mulick		
2009	Sara Sparrow				
2010	Bruce Baker	Laura Lee McIntyre	Storbon Courses		
2011	Michael Aman Ann Kaiser	Anno Fahoraan	Stephen Greenspan		
2012		Anna Esbensen	Solly Degers		
2013 2014	Steve Warren Wayne Silverman	James McPartland	Sally Rogers		
2014	Laraine Masters Glidden	Jailles Wilf'di lidilu	V. Mark Durand		
		Abby Ficorbasser			
2016	Michael F. Cataldo	Abby Eisenhower			
2017	Leonard Abbeduto		Marc Tassé		
2018	Catherine Lord	Cameron L. Neece			
2019			Eric Butter		
2020	Philip W. Davidson	Matthew D. Lerner			

Division 33 Award Winners

The **Edgar A. Doll** Award is a career award that honors an individual for his or her substantial contributions to the understanding of intellectual or developmental disabilities throughout their career. Our deepest gratitude to **Nationwide Children's Hospital** for their sponsorship of this prestigious award and support of Division 33.

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APA DIVISION 33: IDD/ASD

Thank you for reading this edition of the Division 33 Newsletter!

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Psychology in Intellectual and Developmental Disabilities/Autism Spectrum Disorder is an official publication of Division 33 of the American Psychological Association. It is devoted to keeping members informed about the activities of Division 33 and to present news and comment concerning all aspects of service, research, dissemination, and teaching in psychology and IDD/ASD. Brief articles about policy issues in psychology and IDD/ASD, as well as descriptions of service programs and preliminary research summaries are invited. We are especially interested in articles inviting the reaction and comment of colleagues in future issues. Comments and letters will be published as space allows. Manuscripts must conform to APA style and should be submitted via an email attachment. Articles, comments, and announcements should be sent to the current Division 33 President Books, films, videotapes, and other material also may be submitted to the Editor for possible review. Unless stated otherwise, opinions expressed are those of the author and do not necessarily represent official positions of Division 33.