



PSYCHOLOGY IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES/ AUTISM SPECTRUM DISORDER

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FROM THE PRESIDENT'S DESK Jason Baker, PhD California State University, Fullerton



As many of us reluctantly adopt the certainty of uncertainty due to the ongoing effects of the pandemic, our members continue to demonstrate exceptional persistence and resilience in their dedication to the populations we serve, supporting our mission of advancing psychological research, professional education, and clinical services that increase quality of life in individuals with IDD/ASD.

Our annual convention is approaching! Despite some unpredictability regarding the format, we were fortunate to have received a large number of submissions this year, reflecting high-quality engagement of our membership. Several of our planned symposia draw upon cross-divisional and interdisciplinary perspectives to address central issues of diversity, inclusion, stakeholder involvement, and evidence-based practice. New events this year include a social hour spearheaded by the *APA committee on Children, Youth, and Families* that will include Divisions 7, 16, 33, 37, 43, 53, and 54, designed to provide opportunities for cross-divisional engagement and networking. Our Division 33 *Early Career Psychologist Committee (ECP)* mentoring event will be co-hosted with our *Diversity, Equity, and Inclusion Committee (DEI)* and will focus on promoting inclusivity in

research and practice. Although APA continues to plan for a primarily in-person conference, with virtual opportunities available, our leadership would like to reiterate our commitment to ensuring the involvement of our members in the capacity that works for them and we encourage members to reach out to our program chairs, Cameron Neece and Rachel Fenning, with any concerns or needs.

We are excited to announce our 2022 Division 33 award winners. Alice Carter will be recognized with the Edgar A. Doll Award for her substantial contributions to the understanding of IDD/ASD throughout her impressive career. The Sarah S. Sparrow Early Career Award will honor Vanessa Bal for her substantial early career contributions to the understanding of IDD/ASD. Dr. Bal will be presenting her work at the upcoming convention, as will our two student award winners Amani Khalil (*"Help-Seeking Barriers for Ethnic Minority Caregivers Accessing Autism Interventions"*) and Emily Jellinek (*"Examining Caregiver Stress and Experiences During Function-Based Treatment for Children with Autism"*). We would also like to recognize President-Elect Cameron Neece for being awarded Fellow status from Division 33 this year in recognition of her outstanding contributions to the field of psychology.

We are grateful to our Division 33 Committee leaders and members for their many contributions. Our *Diversity, Equity, and Inclusion (DEI) Committee* has been extremely successful in outreach efforts, increasing committee membership to 13 Division members who contribute diverse perspectives and abilities, including those who identify with traditionally underrepresented groups as well as

FROM THE PRESIDENT'S DESK

stakeholders. The Committee, in collaboration with Division leadership, has developed a Division 33 DEI statement that is currently under final review by the committee and we hope will be adopted soon. The Committee has also been involved with broad APA efforts, including the APA Disability Mentoring Program, and will be co-sponsoring the ECP mentoring event at the Convention.

Underscoring our commitment to professional leadership, Division 33 is currently working on two sets of professional practice guidelines. Our *Committee on ID and the Criminal Justice System* has submitted a proposal to the APA Board of Professional Affairs (BPA) for the creation of professional practice guidelines for the Diagnosis of Intellectual Disability in Forensic Settings. Earlier this year, the APA Council of Representatives adopted and distributed the APA Guidelines for Assessment and Intervention with Persons with Disabilities. Recognizing the contribution of these materials to the broader population upon which it is focused, our Division leadership felt that the field would benefit from more specific guidelines relating to assessment and intervention for individuals with ASD, given the many unique considerations involved. We are excited to have officially developed the *Task Force for Practice Guidelines for Assessment and Intervention for ASD* as an ad-hoc Division 33 committee, which will be led by Eric Butter, Rachel Fenning, and Vanessa Bal.

Supporting our ongoing goal of promoting scientific communication, we are grateful to Laurel Benjamin and her mentor Cameron Neece for re-launching our official podcast, *ACCESS DIVISION 33*. New and upcoming interviews highlight the work of Drs. Neilson Chan (Division ECP), Laura Lee McIntyre (Past Division President) and Julie Lounds Taylor (Division Member-at-Large). Finally, our Division welcomes two new members to the Executive Committee this year. Bridgette Kelleher will be joining us as our new Member-at-Large, and Micah Mazurek was elected President-Elect-Designate.

Our Division 33 website (www.division33.org) remains the hub for sharing updates on initiatives and disseminating resources relevant to the field. Continue to watch for new podcasts, job postings, and additional resources that can be disseminated to advance our mission. We look forward to connecting with you and to continuing the work of identifying ways to promote change and growth in our field, in service to our mission of increasing quality of life in individuals with IDD/ASD across the life course.

Jason K. Baker, Ph.D.
Division 33 President, 2021-2022
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IDD/ASD Training Program Highlight

The Ohio State University Intellectual and Developmental Disabilities Psychology Doctoral Program



Luc Lecavalier, PhD
Training Director, IDD Program



The Ohio State University's (OSU) Intellectual and Developmental Disabilities (IDD) Psychology Doctoral Program is a unique partnership between the Department of Psychology and the Nisonger Center. In addition to their status as graduate students in the

Department of Psychology, IDD students receive a substantial proportion of their training at the Nisonger Center, a University Center for Excellence in Developmental Disabilities (UEDDD) that is housed within the OSU Wexner Medical Center. Since its inception in the 1980s, the program has graduated more than 75 psychologists working all over the country.

The program is accredited by the Psychological Clinical Science Accreditation System (PCSAS). Its goal is to increase the number of well-trained psychological clinical scientists who actively contribute to the application, dissemination and advancement of knowledge in the psychology of IDD. The program comprises five faculty members and at any time has about 12 graduate students. Its structure has many advantages. As one student put it: *"I chose the IDD program at Ohio State because of the unique opportunity to work with individuals with IDD throughout all years of my training, as well as to have multiple collaborative faculty all focused on IDD"* (L. Becker, 1st year graduate student).

The program is designed to integrate science and practice at all levels of training. All IDD Psychology graduate students complete a one-year fellowship in the Leadership Education in Neurodevelopmental and related Disorders (LEND)

program. All students receive training and provide services in Nisonger clinics as well as in external practicum sites. Research activities are a consistent part of graduate training throughout each student's time in the program, with their research experiences becoming increasingly complex and independent as they move through the program. While the faculty have diverse interests, they all have active research programs focusing on clinically significant problems across the lifespan for people with IDD and their families. Examples include Diagnosis of ID and ASD, co-occurrence of developmental disabilities and psychiatric disorders, health promotion, stakeholder engagement in research, and instrument development. One student commented: *"in addition to the outstanding research on disabilities, the clinical training offered within the program is truly unparalleled. I chose the IDD program because of its' dedication to students, high-quality research, education, and clinical training focused on disabilities."* (D. Adedipe, third year graduate student).

It is the vision of the IDD Psychology graduate program to train the future leaders in the IDD field who will assume leading roles in designing, evaluating, and delivering science-driven models of care for individuals with IDD. Examples of current employers of recent graduates: Nationwide



IDD/ASD Training Program Highlight



Children's Hospital, Northwestern University, Millsaps College, the National Institute of Mental Health, Boston Children's Hospital, and Kennedy Krieger Institute. One recent graduate of the program commented: "*Ohio State's IDD Psychology program was my top choice when applying for graduate school as I was really interested in the opportunity to learn from a group of faculty with a wide range of research interests that spanned the lifespan, and the multiple clinical training experiences available all specific to IDD. Since graduating, I have found having in-depth training in clinical assessment and intervention to be advantageous when applying for jobs and conceptualizing new research lines.*" (Rose Nevill, PhD, University of Virginia).



A special THANK YOU to our Founding Sponsor and Sparrow Award Sponsor, WPS!

See page 15 for more information!

APA Council Report



Vanessa H. Bal, PhD
Rutgers University
Rutgers Center for Adult Autism

2022 Council meeting reflects APA's ongoing efforts to promote diversity, equity and inclusion.

As news of Russia invading Ukraine dominated the headlines, the Council of Representatives convened via Zoom on February 25-26, 2022. Adapted from the [meeting overview](#) provided by APA staff, I have tried to provide a (brief!) overview of topics and outcomes covered. Where available online, I have linked documents for further reading.

As a first-time attendee to this meeting, I was pleased to see APA's ongoing efforts to promote diversity, equity and inclusion include both specific anti-racism activities, but also are reflected across action items. These range from updates to guidelines detailing appropriate assessment, treatment and research practices for different populations to reaffirming support for reproductive rights and commitment to research on poverty and socioeconomic status and removing barriers to membership. While I highlight guidelines for persons with disabilities as an issue of specific relevance to Division 33, I look forward to engaging with all of you to consider the ways in which individuals with IDD and ASD are affected by each of the areas outlined below. I am excited to represent our division and continue previous efforts to ensure that this population is carefully considered and well-represented in APA's work. Please reach out if you would like additional information about any of the points below and I am happy to have feedback to inform my future summaries.

Revised Guidelines for Assessment and Intervention with Persons with Disabilities adopted and prompt discussion of need for Autism-focused guidelines.

The Council voted unanimously to adopt this revised *Guideline*. Last updated in 2011, this is obviously highly relevant to Division 33! While the "APA Guidelines apply to persons with all types of disabilities, including mental health issues, disability issues arising from impairments less known to many psychologists, such as mobility, sensory, communication, and neurological impairments, are emphasized." (draft p.8). As our division representative, I spoke in favor of adopting these important guidelines and commended the task force for managing to address such a broad and diverse group of individuals with differing abilities and disabilities, including those with intellectual disability and autism spectrum disorder. (Though it may be of interest to know that autism is mentioned only four times in 122 pages, not including references). I noted, however, that reviewing this sparked conversation within Division 33 leadership, reminding us of the complexities around professional practice for individuals on the autism spectrum who span a range of abilities and challenges as a group themselves. Considering the latest prevalence of 1 in 44, it is highly likely that children and adults on the spectrum will present to psychologist for mental health care and other supports, yet research tells us that many providers feel inadequately prepared to meet their needs. I know many of us are eager to see a professional practice guideline to inform

APA Council Report

support of people on the autism spectrum developed and look forward to collaborating on moving this forward. You can read the guidelines [here](#).

Audit of current anti-racism activities highlights much is being done, but more coordination is needed. The Council of Representatives received a comprehensive audit of current anti-racism activities by APA, including policies, practices and procedures aimed at stemming racial inequities and promoting equity, diversity and inclusion. This was the next step in a process detailed in a resolution Council passed in October that accompanied an apology for past racist actions and omissions by APA and the discipline of psychology. “We are trying to do something the association has not done before,” APA President Frank C. Worrell, PhD, said in introducing the audit. “Eradicating racism is not an easy thing ... so this will take a lot of hard dialogues.” The report can be viewed [here](#).

APA CEO Arthur C. Evans Jr., PhD, noted that APA is engaged in a wide array of racial equity activities but until now, they had not been coordinated. “Our members and our leaders want us to have impact, not just activity,” he said. “This is an organizational commitment that we’ve made.” The audit opens the door to the next phase of APA’s work in this area: creation of a roadmap of prioritized actions aimed at dismantling racism. Those proposed actions will be presented to the Council in August, as directed in the resolution passed in October 2021. The audit, as well as other updates on APA’s EDI and racial equity work can be found [here](#).

COR rapidly comes together to demonstrate support for Ukrainians and colleagues in the Eastern European region. Very early in the day, emails circulated with an NBI to propose a statement voicing solidarity with the National Psychological Association of Ukraine, the

Ukrainian people, and colleagues in the Eastern European region, as the Ukrainian nation defended itself against military invasion. Within a matter of hours, numerous representatives responded in support as co-sponsors/signers. Read the APA motion on Ukraine conflict [here](#).

Psychology’s Role in Advancing Population Health adopted as APA Policy Statement. The measure calls for working within and across diverse systems to advance population health, which focuses on improving the health, health equity, safety, and well-being of entire populations, including individuals within those populations. The policy also advocates for promoting prevention and early intervention strategies and urges psychologists to enlist and educate a diverse array of community partners. Read the statement [here](#).

Revised National Standards for High School Psychology Curricula emphasize scientific nature of psychology. Last updated in 2011, the standards adopted in 2022 have an increased focus on the scientific underpinnings of the field and the importance of incorporating diversity into understanding mental health. Access the standards and summary of changes [here](#).

Climate Change report is a blueprint for actions that APA and the psychology community can take. COR received the report of the APA Task Force on Climate Change, “Addressing the Climate Crisis: An Action Plan for Psychologists.” The report calls on the discipline of psychology to strengthen its capacity to address climate change and collaborate with other fields and sectors for maximal impact. You can view the report [here](#).

Resolution passed to affirm and build on APA’s history of support for reproductive rights. COR’s discussion of this topic mirrored much of the national conversation, with some strongly opposed, others strongly

APA Council Report

in support and some voicing separation of their personal beliefs from what APA's role in this should be. Ultimately, COR adopted a *Resolution for Reproductive Justice: Affirming Abortion Access*, committing APA to continuing to work for and support reproductive justice. You can view the resolution [here](#).

2022 resolution regarding *Interrogation of Criminal Suspects* reflects recent research.

Updating policy from 2014, the 2022 resolution provides more up-to-date scientific evidence on this topic, especially in light of issues related to false confessions. You can view the resolution [here](#).

Updated policy on *Poverty and Socioeconomic Status* demonstrates APA's continued commitment to researching causes and impacts of poverty.

Updating policy from 2000, the 2022 resolution recommits APA to advocate for culturally sensitive and inclusive research that examines the causes and impact of poverty across the lifespan, including structural racism, economic disparities, and related intersectional issues.

Question regarding felony conviction to be removed from APA membership application.

Proponents of removing the question argued that it was discriminatory, deterred otherwise qualified people from joining the association and needlessly stalled the process of becoming a member. You can view the resolution [here](#).

APA members will be asked to vote on APA Bylaw changes concerning membership. The Council passed motions to request APA membership to vote on two APA Bylaw amendments concerning Membership:

- To update the mission of the Membership Board and related amendments to the Association Rules.
- To request APA membership vote to amend the APA Bylaws to allow associate members voting privileges after one year of associate membership (as compared to five years currently required).

Updates to Guidelines Adopted as APA policy

The Council also adopted *Guidelines for Child Custody Evaluations in Family Law Proceedings*, which promote ethically informed practice in disputes over decision making, parenting time, and access to children when relationships dissolve.

The Council adopted revised *Guidelines for Ethical Conduct in the Care and Use of Nonhuman Animals in Research*, which are widely used in the education and training of psychological scientists. Guidelines can be accessed [here](#).

The Council adopted revised *Guidelines for Ethical Conduct of Behavioral Projects Involving Human Participants by High School Students*. Guidelines can be accessed [here](#).



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Thank you to our Doll Award Sponsor, Pearson!

Division 33 Edgar A. Doll Award 2022

EDGAR A. DOLL AWARD
Sponsored by Pearson Assessments

Award Recipient:

Alice Carter, PhD

For Her Lifetime Achievements in the Area of Intellectual
and Developmental Disabilities

A special thank you to our award sponsor:



Division 33 Sarah S. Sparrow Early Career Research Award 2022

SARAH S. SPARROW EARLY CAREER RESEARCH AWARD
Sponsored by WPS

Award Recipient:

Vanessa Bal, PhD

For Her Substantial Contributions to the Understanding of Intellectual and
Developmental Disabilities as Reflected in Her Published and Presented Works.

A special thank you to our award sponsor:



“Special Topics” Column

Emergency Management and Disaster Response for Individuals with Developmental Disabilities



Lyzi G. Cota
Graduate Student

Damage to our mental health, damage to our physical integrity and disruption of our daily activities are some effects of experiencing an emergency or a disaster; they have become part of the challenges of humanity. Every time we experience an emergency, or a natural disaster, it is noticeable that the usual response is developed for a population *without* special needs. It ends up overlooking individuals with developmental disabilities,

which are some of the most vulnerable groups within our communities when these crises happen.

These developmental disabilities encompass Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), Intellectual Disability (ID), Attention Deficit Hyperactivity Disorder (ADHD), and learning disabilities. As an individual diagnosed with ADHD and epilepsy of the temporal lobe caused by a traumatic brain injury, I have found that during emergencies and disasters, many first responders are not fully aware or remember that some victims may be different in terms of disabilities, which are not physically visible but hidden in our brains.

For the purposes of this piece, an emergency is defined by the Federal Emergency Management (FEMA) as "Any occasion or instance--such as a hurricane, tornado, storm, flood, tidal wave, tsunami, earthquake, volcanic eruption, landslide, mudslide, snowstorm, fire, explosion, nuclear accident, or any other natural or man-made catastrophe--that warrants action to save lives and to protect property, public health, and safety." On the other hand, a Disaster is defined by FEMA as – "An occurrence of a natural catastrophe, technological accident, or Human-caused event that has resulted in severe property damage, deaths, and/or multiple injuries."

Dr. Kevin Kupietz, a teacher at the American Military University for Emergency and Disaster

Management courses and a volunteer firefighter with the Roanoke Rapids (NC) Fire Department, conducted in-depth research on best practices for responding to incidents involving autistic individuals. During the United States Fire Administration's Executive Fire Officer Program research he conducted, he found that statistically, an autistic individual is seven times more prone to require the service of responders versus a non-autistic individual.

Hence, since the number of autistic people is growing, the chance for first responders to encounter an autistic individual during an emergency situation is higher; nevertheless, many responders have no training on how to identify an autistic person and neither know how to accommodate an autistic person's needs to provide an adequate response.

More literature related to emergency response for developmental disabilities is required; however, some reliable organizations work exclusively to address these needs, and most of them specialize in autism.

For instance, The Minnesota Governor's Council on Developmental Disabilities provides useful resources such as "Individuals with Autism Spectrum Disorder and Emergency Planning Resources" which encompass the following:

- 1) Products and services such as a List of Devices, Apps, and Assistive Technology;
- 2) Online resources;
- 3) Video Modeling where the individual watches a video that shows what to do and how to respond to a particular situation, such as an emergency, for instance, a runner, a lost dog, fire and safe place, an injury, or how to listen to the police. Then the individual tries to memorize the situation and refers to the response so that he/she will do the same when that situation arises.
- 4) An autism survival Kit;
- 5) Tech Apps: Autism 5-Point Scale EP;
- 6) Other resources like the Connecticut Guide for Including People with Disabilities in Disaster Preparedness. All of these are valuable resources.

“Special Topics” Column

On the other hand, one part of emergency response and preparedness involves an Emergency Kit, this may include:

1) ID bracelet, and autism or epilepsy alert card for others to identify the condition and behaviors, 2) earplugs or headphones, 3) sunglasses to prevent light sensitivity, 4) small flashlight and regular flash light with extra batteries, 5) an easy to read map and directions of the places to visit during the day, 6) emergency cash, credit cards, home keys, 7) doctor prescribed calming pills that do not cause lethargy, 8) small hand sanitizer gel or sanitizing hand wipes individually wrapped, 9) doctor prescribed anti-allergy pills, 10) chewing gum to avoid verbal tics, 11) cellphone with google maps and a charger, 12) a backpack, 13) emergency contact numbers printed and also stored in the cell phone, 14) food and water for 3 days, if a service dog accompanies the person, 15) a safety object or blanket to provides calmness, 17) portable, battery-operated radio and extra batteries, 18) valuable documents (birth and marriage certificates, insurance, special-needs forms).

The need for Emergency Care for Population with Autism Spectrum Disorder (ASD), Cerebral palsy (CP), Attention deficit hyperactivity disorder (ADHD), Intellectual disabilities (ID), and Learning Disabilities is paramount. Educating first responders about the sensory overload that people with autism and developmental disabilities experience during an evacuation event or a disaster, and training them to communicate properly can effectively address the concerns and needs of this population. Furthermore, it can save time and reduce stress for both sides.

Leischen Stelter, the editor of "Public Safety" from the American Military University, provides commonly cited tendencies about some autistic people in order for first responders to identify possible signs of autism that could pose a treat to the individual's physical safety: an affinity for water, tendency to wander, difficulties with communication skills, high thresholds of pain.

Additionally, there are some key suggestions adapted from the Leischen Stelter recommendations They can be followed by first responders to reduce stress during the emergency or disaster and make it more effective and suitable to people with developmental disabilities in general. First responders can re-adapt them when dealing with developmentally disabled individuals.

1. Working directly with parents or caregivers to minimize the stress and fears of dealing with unfamiliar individuals; this can increase the positive response to instructions.
2. Speaking softly and clearly with patience and remaining calm using calming tones will provide individuals with developmental disabilities plenty of time to process the information and respond. The language must be direct and literal avoiding slang, metaphors, figurative speech or jokes.
3. Minimizing visual and audible stimulation to avoid sensory overload due to loud noises and bright lights. It is recommended to limit the use of flashing lights, colored lights, horns and sirens during an emergency crisis and use only when necessary.
4. Providing headphones or earplugs can bring an autistic person into a more calm state during a loud or chaotic event.
5. Reducing the number of responders to avoid creating stress due to crowds, instead of providing a sense of safety so that the individuals in need have their own space. Additionally, if autistic individuals require to be taken to a shelter, they must be provided with their own safe space; this can be done by arranging chairs, tables or cubicles.
6. Minimize physical contact to avoid stress and anxiety due to human touch, even bandage applications, wound cleaning, hugs, holding hands, shoulder or arm touching may cause anxiety and stress in people with developmental disabilities.

First responders must be aware that physical touch is not helpful without asking for permission first. If done without an explanation, it may result in injuries, people running away or responding with physical aggression towards the first responders or themselves. For necessary physical exams, first responders are encouraged to explain first to the individual what is required and why it needs to be done. It is suggested to start at the extremities and work towards the trunk and the head. Since physical contact causes stress and anxiety, this technique helps first responders gain the trust of individuals with developmental disabilities, especially those with autism. The use of toys for autistic children can provide comfort and help to point out where they suffered any harm or pain, always considering the high pain threshold they possess. In addition, extreme caution must be taken if an autistic person must be restrained

“Special Topics” Column

since they may try to fight due to not understanding the situation; explanations are crucial. Many have underdeveloped chest muscles and could suffer from mechanical asphyxiation if they are held in place too long and unmonitored.

Resources that first responders can adapt for cognitively impaired populations are:

- Risk communication messages
- alerts and announcements with simplified versions and formats
- visual aids (drawings and pictures)
- prewritten messages for potential emergencies and disaster scenarios.

For non-English speakers with developmental disabilities, imagery or a digital dictionary on the cellphone is useful to translate and communicate better and faster without waiting for an official translator.

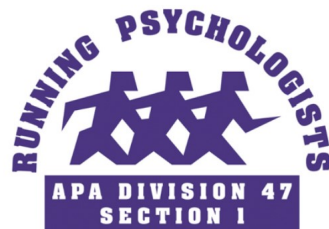
For communication with visually impaired people, online Braille Translators from Braille to Text and Text to Braille can be used.

The active involvement of local, state and federal authorities is critical to raising awareness and training for all first responders. Learning how to address this population can improve their response, reduce risks and casualties, and guard the mental and physical integrity of developmentally disabled people and first responders.

Lyzi G. Cota is a Psychology Graduate Student and MPA Candidate at UNITEC University in Mexico. Lyzi is certified in Emergency Management by FEMA and Crisis Management & Disaster Response by NATO, and is a member of APA Division 33 and the San Diego Psychological Association.



References



[CLICK HERE TO REGISTER](#)

RAY'S RACE

44th Annual Running Psychologists “Ray’s Race” 5k Run & Walk at the American Psychological Association (APA) Convention

Register NOW!! to run and walk with the Running Psychologists in Minneapolis, MN

The 2022 event will be held on Saturday, August 6 at 7 a.m. at Loring Park. This year’s race features picturesque views around Loring Park minutes away from the convention center.

The Annual Ray’s Race is an APA tradition started by former APA President and CEO, Ray Fowler, over 42 years ago! It’s a great opportunity to get some exercise during the convention, network with likeminded colleagues, and see a beautiful part of our host city.

Registration is \$40 for APA Members, Family, & Friends; \$30 for Students. Children 14 and under receive a free entry. The race route is conveniently located near APA hotels and will be a short walk for race participants on the morning of the event!

Announcing:
Nationwide Children's Hospital Toledo
Psychologist Positions

Nationwide Children's Hospital Toledo is currently seeking full-time psychologists to join our team at our new hospital location in Toledo, Ohio.

The ideal candidates for these positions would be interested in providing clinical care to pediatric patients in both the hospital and outpatient clinical settings. The candidates should possess an interest in education, training, and development of new and existing staff members, along with contributing to the overall strategy for the division.

Qualified candidates will possess Ph.D. or Psy.D. degree in clinical, counseling, or school psychology from an accredited university, and Ohio psychology license eligible, accredited psychology internship and relevant post-doctoral training or experience in psychology is highly desirable.

After working collaboratively for more than two years to provide high quality health care to children and their families throughout the region Nationwide Children's Hospital acquired Mercy Health Children's Hospital effective March 1, 2022 and transitioned to [Nationwide Children's – Toledo](#).

Nationwide Children's Hospital – Toledo remains committed to continuing the legacy developed by Mercy Health – Children's Hospital in providing compassionate and quality care close to home. For more information, visit: [NationwideChildrens.org/newsroom/news-releases/2022/03/toledo-announcement](https://www.nationwidechildrens.org/newsroom/news-releases/2022/03/toledo-announcement).

Psychologists in multiple specialties are being recruited including pediatric psychology, pediatric neuropsychology, child clinical psychology, and acute care psychology as well as [neurodevelopmental and autism treatment psychology](#). Specifically, Nationwide Children's Hospital – Toledo will operate two autism diagnostic clinics as well as two autism treatment programs in the region.

These positions may hold program development and leadership opportunities for competitive candidates.

Nationwide Children's Hospital is a nationally recognized pediatric hospital and research center. Consistently named to the *U.S. News & World Report* Honor Roll list of America's top 10 children's hospitals, Nationwide Children's Hospital has more than 1.3 million patient visits annually representing patients from 49 states and 43 countries in addition to providing more than \$260 million in charity care and community benefit services annually. Learn more at [NationwideChildrens.org](https://www.NationwideChildrens.org).

If you or any of your colleagues are interested in applying to or discussing this opportunity, please contact:

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Nationwide Children's is an equal opportunity employer that values diversity. Candidates of diverse backgrounds are encouraged to apply.

**Nationwide Children's Hospital is a
proud sponsor of Division 33.**



Division 33 Student Interview

Gender and Sexual Identity of Autistic Individuals



Interviews conducted by:

Elizabeth Baker, MA, UC Riverside
Ben VanHook, George Mason University



Dr. John F. Strang is a pediatric neuropsychologist at Children's National Hospital who specializes in the assessment and care needs of gender-diverse youth, including those on the autism spectrum. He is

the Director of the Gender and Autism Program, a multidisciplinary clinical program for gender-diverse neurodiverse youth. He is also a specialist in executive function assessment and intervention, and the Director of Research for Children's National's Gender Development Program. We interviewed Dr. Strang to learn more about gender and sexual identity in autistic individuals.

Question 1: Why is it important to consider gender and sexual identity in regard to autism spectrum disorder? Is there a higher prevalence of gender diversity among autistic individuals?

Until recently, the inner experience of autistic people has been largely disregarded by society and researchers. Shockingly, the diagnosis of autism remains an almost fully observational activity, in which clinicians document behaviors and reports of observers, with very little focus on the lived/inner experience of autistic people themselves. Yet, the inner experience of autistic people must be respected: This is a basic human right.

Two aspects of lived experiences for autistic people are their gender and their sexuality. Over the last 15 years, through a series of studies and reports from autism-led community organizations, it has become apparent that many autistic people are

LGBTQ+ and that autism is common among gender diverse/transgender populations (Kallitsounaki & Williams, 2022; The Trevor Project, 2022; Warrier et al., 2020). A recent metaanalysis of studies estimated that autism spectrum disorder is diagnosed in ~11% of gender-diverse individuals (Kallitsounaki & Williams, 2022), far above base rates for autism in the general population.

Question 2: What are some considerations a clinician should keep in mind when providing assessment or therapy to autistic individuals regarding sexual/gender orientation?

Gender and sexuality are very different experiences, and clinicians working with autistic people should understand something about both of them. Gender diversity, the experience of gender identity that differs from sex assigned at birth, may be an abstract concept for some young people. In our research, we have identified that some autistic youth exploring gender may benefit from concrete exemplars of various gender journeys, gender expressions, and outcomes (Strang et al., 2021). For this reason, we invite a range of visitors and role models to join our gender and autism clinical support groups, so autistic youth can interact with and learn from them in a more concrete manner. This can help autistic youth better consider the various options available to them regarding gender, gender expression, identities, and gender-affirming care.

Sexuality is more complex than just who someone is sexually attracted to. There is equally romantic attraction, which can differ from sexual attraction, including among

Division 33 Student Interview

autistic people. Supports for autistic LGBT people are lacking, such as dating, community connectedness, and LGBT autistic health. Sometimes clinicians ignore their autistic clients' gender and/or sexuality, or autistic clients may not automatically know that it is "safe" to talk about such topics with their providers. Creating an affirming space for discussing gender and sexuality, with intentional structure and communication from the clinician, may help facilitate important conversations. Autism clinicians may not be experts in gender and sexuality-related care, so it is important for them to form partnerships with LGBTQ+ specialized providers (Strang, Meagher, et al., 2018).

Question 3: Can you speak as to the importance of community-based participatory research (CBPR) when exploring autism and gender-related issues?

Over the last 15 years, we have seen a range of researcher- and clinician-driven hypotheses about the nature of intersecting autism and gender diversity. Many of these hypotheses have ignored the inner experience and voiced needs of autistic transgender individuals. In working with the autistic transgender community, I have been reminded many times that the societal over-focus on "etiology" of the co-occurrence of autism and gender diversity presents a double standard. Why do we feel the need to try to explain the "why" of the common intersection, instead of focusing on the needs of the many who live at this intersection? We do not put such pressure on gay people to explain the "etiology of being gay." Why is this different for intersectional autism and gender diversity? I think this stems from that common societal bias against the inner experience of autistic people, and we need to work to do better. So much of what I know about the needs of autistic transgender people has come directly from the community itself. There is a great risk in conducting research with this population for misunderstanding and misattribution. Community-based participatory process

research is a way of making sure that research efforts are aligned with what will be useful for autistic transgender people (Strang et al., 2019). And we've heard that research focused on etiology is likely not a community-based priority at this point.

Question 4: How can support be provided to autistic youth who have gender dysphoria or are transgender? How can this be done in states with restrictive policies that limit access to gender-affirming care?

The new [World Professional Association for Transgender Health \(WPATH\) Standards of Care](#) (Version 8) specifically mentions the common intersection of autism and gender diversity. These standards of care call for the inclusion of autism-informed supports for autistic transgender youth so that these young people can equitably access gender evaluations and gender care. This may include the accommodation of providing extra supports for autistic youth to complete evaluations and learn about and consider options. In our own research, we've learned that it is not uncommon for autistic transgender youth to struggle to advocate for their gender-related needs, and this is often related to their communication differences (Strang, Powers, et al., 2018). Further, we've identified that autism-related barriers to gender care are a strong predictor of poorer mental health. Therefore, one of the key interventions autistic transgender youth may benefit from is support around advocating for and navigating gender-related supports and care.

As far as states that restrict gender-affirming care, I know that our gender care communities are struggling and families are experiencing extreme distress. There is a flow of "gender refugees" from these states moving to other parts of the country to access needed care. It worries me so much that life is already complex enough for autistic transgender youth, who have two minoritized identities; now adding the extra strain of state-based

Division 33 Student Interview

restrictions on gender care, we can only imagine how this will impact their gender health over time.

In conclusion, gender identity and sexuality are varied among autistic people. Similarly, autism is more common among people who do not identify with their assigned sex at birth. Clinicians should also consider that autistic people may present their gender identity differently than neurotypical people do. Researchers, including Dr. Strang, are making improvements regarding how best to support

autistic people who identify outside conventional genders. Finally, it is important that autistic transgender youth receive affirming care. Liz and Ben would also like to thank Dr. Strang for taking the time to talk with us about gender identity and autism!



References



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**Friday, 8/5
1-1:50pm**

**Join us
at APA!**

Promoting Inclusivity in Research and Practice in IDD/ASD

APA Division 33 Early Career Professionals Mentoring Event
Co-hosted by the Division's Diversity Equity & Inclusion Subcommittee

Mentoring topics will include:

- Community-based participatory research (CBPR) approaches,
- Inclusivity of underrepresented populations in research, and
- Intersectional perspectives in IDD/ASD research, including experiences from neurodivergent researchers.

Questions?

Contact Division 33 ECP Committee Chair, Sasha Zeedyk: szeedyk@fullerton.edu

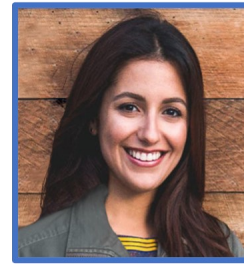


Early Career Psychologist Column

Embracing Autistic Individuals in the Research Process: Two Early Career Professionals Take the Leap and Share What They Learned



Sasha M. Zeedyk, Ph.D.



Yasamin Bolourian, Ph.D.

This research was conducted at California State University, Fullerton.

Autistic adults have been minimally represented in program creation, implementation, and evaluation (Monahan et al., 2021), particularly among social skills programs and interventions, which has several implications. First, nearly all social skills interventions for autistic adults rely heavily on caregiver reports to evaluate their efficacy (Monahan et al., 2021). As such, the opinions and lived experiences of autistic individuals are rarely considered. Second, there is often a mismatch between intervention aims and autistic individuals' priorities (Nicolaidis et al., 2011). Interventions may target change in social behaviors in ways that teach autistic people how to interact in neurotypical ways (Monahan et al., 2021). Thus, many autistic people report feeling pressured to mask aspects of themselves or "camouflage" to navigate social situations (Cage & Troxell-Whitman, 2019; Hull et al., 2017). Qualitative data reveal that autistic adults often engage in camouflaging as a result of being "trained to act normal" (Cage & Troxell-Whitman, 2019). Because of this pressure, many autistic adults who report camouflaging also experience high levels of stress and anxiety (Cage & Troxell-Whitman, 2019; Hull et al., 2017).

Programs that build upon the self-reported priorities of autistic people and limit the

pressure to camouflage their true selves are needed.

Our study, funded by the Organization for Autism Research (OAR), examines the benefits of the Toastmasters public speaking program for autistic young adults, including social communication, self-efficacy, and other transferable skills, in a "no-pressure, supportive" environment (Uttal, 2013). The overall goal of this project is to investigate the participation and feasibility outcomes of the Toastmasters program for autistic young adults. In preparing the grant submission to OAR, we had to ask, "**How are we going to address the lack of autistic representation in this work?**" To start, we researched community-based participatory methods (CBPR) and developed a plan. But, actually doing the work was another story!

We are now six months into our funded work. As two outsiders without the lived experience or shared context of disability and autism, we are continuously learning how to build trust within the community. We write this article to share some practical tips we have learned thus far on how to take the leap to include autistic people and their perspectives in the research process. We hope these suggestions serve as helpful guidance for other early

Early Career Psychologist Column

career professionals (ECPs) interested in employing participatory approaches in their research.

Community-Based Participatory Research (CBPR): A Bit of Context.

Traditionally in autism research studies, academics have held control over decision-making and study design, with members in the autism community providing data only as participants. As the saying “*Nothing about Us without Us*” implies, some argue that autism research has typically been done “on” or “for” autistic individuals, not necessarily “with” them (den Houting et al., 2021; Raymaker & Nicolaidis, 2013). As such, there has been an increase in advocacy efforts focused on including autistic individuals and stakeholders in the research process – i.e., doing research “with” those whom the research is intended to serve (den Houting et al., 2021; Nicolaidis, 2019; Pukki et al., 2022, Stark et al., 2021).

Community-Based Participatory Research (CBPR) is research that includes non-academic community members on the research team (Israel et al., 2005). The origins of participatory approaches to research date back to the mid-twentieth century, and the approach gained popularity in public health programs starting in the 1980s. In addition to strengthening academic-community relationships, this approach ensures the research aims are compatible with community needs, enhances the relevance and application of research results, minimizes potentially harmful or stigmatizing effects of research, and brings together partners with different skills, knowledge, and expertise (Israel et al., 2005; Maccaulay, 2017).

In a true CBPR study, **community members and academics collaborate as equal partners in all parts of the research process** (Israel et al., 2017). Specifically, Israel and colleagues (2017) detailed the following nine principles of CBPR:

- 1) CBPR recognizes community as a unit of identity
- 2) It builds upon a community's strengths

and resources

- 3) It promotes a collaborative, equitable partnership in all research phases
- 4) It facilitates co-learning among all partners
- 5) It incorporates a balance between knowledge generation and research application for shared benefit among all partners
- 6) It attends to local relevance and ecologic perspectives of community problems
- 7) It utilizes iterative processes
- 8) It disseminates results to all partners and involves them in the dissemination process
- 9) It necessitates a commitment to long-term processes and sustainability

Some have specified a continuum or hierarchy when designing studies that include partners in the research process. At the non-CBPR end of the hierarchy, the community is not at all involved in the research process, and academics hold all the decision-making power (i.e., research is being done “to” participants). Moving toward inclusion, research involving consultation, such as focus groups or advisory panels, involves community engagement. However, the researcher still holds most of the power in decision-making (i.e., the research is being done “for” participants). At the “true” CBPR end of the hierarchy, there is authentic inclusion and equal power sharing in all aspects of the research; research is being done “with” partners (den Houting et al., 2021; Nicolaidis, 2022).

Luckily, a few groups conducting this type of research have published resource guides.

The **Academic Autism Spectrum Partnership in Research and Education (AASPIRE)** is based at Portland State University under the leadership of Dr. Christina Nicolaidis. AASPIRE brings the academic and autism community together as equal partners to engage in and develop research that meaningfully benefits the autistic community. Their inclusion resources aim to disseminate what they have learned from conducting CBPR over the last 16 years, including how to include autistic adults as co-

Early Career Psychologist Column

researchers and study participants, how to create accessible study surveys, and example collaboration materials (ASIPRE, 2020). Led by Dr. Stephen Shore and Dr. Teal Benevides, the team at **Autistic Adults and other Stakeholders Engage Together (AASET)** collaborates with the autistic community to identify important topics related to health and healthcare outcomes. In partnership with the project team and autistic community, their developed engagement guide names ways to support meaningful inclusion in the research process (PCORI, 2018). Further, groups of autistic researchers and their allies have been forming over recent years with goals to ensure that autistic perspectives are included in the autism research community. Examples include the **INSAR Autistic Researchers Committee** (INSAR, n.d.) and the **College Autism Network Virtual Association of Scholars** (CANVAS, 2022). Building awareness and connecting with folks in these communities is a first step toward collaborating with autistic partners in research.

Practical tips for getting started. Although we are just beginning our CBPR journey, we have already learned so much. We hope the following tips will help other ECPs considering this approach:

Identify a CBPR methods consultant (just as you would if you were carrying out unfamiliar methodology). After making it through OAR's pre-proposal round, we identified a CBPR expert and asked her to be our methods consultant. In our introductory meeting with her, we shared our experience in qualitative studies, conducting interviews and focus groups with autistic people to identify and shed light on their perspectives. In another study, we also formed an advisory committee of autistic college students, college faculty, and support staff to provide feedback on neurodiversity training modules we developed for professors. We considered all our previous efforts to be participatory research – inclusion, collaboration, and partnered work with the autistic community. Our consultant commended our work before

letting us know that if our proposal was to be called a CBPR research study, we would need to make some major changes to it. And indeed, after meeting with her and much deliberation, we revamped the grant – from changing the title of roles (from “consultant” to “partner”) to increasing the number of partner meetings (i.e., monthly) to allow for regular, ongoing, and collaborative discussions. The latter also meant changing the budget to pay partners for their increased involvement. The lesson: Identify a CBPR methods consultant (one who will give you constructive, unapologetic advice!), meet with them early (i.e., before finalizing and submitting your grant), and be prepared to make changes.

Clearly define the type of study/CBPR method you are employing. As we learned in our initial meeting with our methods consultant, you, too, will need to decide whether your research questions can be addressed through CBPR methods and if you have the capacity to carry out the work. One thing we came to understand was that CBPR researchers will be quick to question something called “CBPR” that should really be labeled “consultation.” Therefore, it is critical to do your homework to truly understand what equal power sharing and partnerships mean. You should not assume that a grant reviewer will not be experienced with these methods, nor should you expect that they will. The lesson: It is critical to define what you mean by CBPR and clearly exemplify how your study does, in fact, meet the CBPR definition.

Consider where and how you will connect with partners and how you will keep them engaged. You will need to have a realistic plan for finding partners. We all are aware that it can be challenging to find research participants. Getting a commitment from autistic individuals and other community stakeholders and retaining individuals is key for a successful CBPR study. In our case, we were already connected with a local non-profit organization; in fact, a long-standing existing program offered through the organization inspired our study. We were able to ask folks we were already connected with to partner

Early Career Psychologist Column

with us. However, even with this pre-established connection, organizing a diverse group of partners to work with us was still more challenging than expected. We also quickly realized that through forming our partnerships, we reduced our potential research sample, as our partners could not serve as both partners and research participants.

Not only is identifying partners important, considering how to keep them engaged is also critical. To ensure that our partners felt valued and respected, we decided to compensate them all equally (including our methods consultant) for their time each month. Given the size of our small grant, we were able to budget for \$100 per hour for them each. Compensating partners this way meant we had to be conservative in other budget areas, a compromise that made sense given our aims. The lesson: Have a concrete plan for finding and fairly compensating your partners.

Make a realistic timeline and expect delays.

Once you start a project, you will likely discover that CBPR takes much more time than many other methods. For example, we have six partners, and only one (our methods consultant) has experience working on research. Thus, the *why* behind research practices should be explained and not assumed to be understood. From these conversations, you may also find that certain aspects of the research process, while mechanical or routine to us, might need changing. Working through an iterative process and making ongoing decisions about your study takes time. Other things that we discovered require additional time include dealing with more paperwork than normal to ensure that partners are appropriately compensated and finding a monthly meeting time that works well with multiple (non-academic) schedules. The lesson: CBPR will take longer than you expect.

Promoting institutional pathways and mechanisms for CBPR studies. Some issues have come up due to the fact that many

academics are not familiar with the CBPR approach. For example, for our funding to be released, we needed to have IRB approval. When we submitted to IRB, we specified that we would submit an interview protocol after collaboratively developing it with our partners. Unfortunately, the IRB pushed back and would not approve our study without a “draft” of the measures. This seemed counterintuitive to our methods, which should involve partners in all aspects of the process, including measurement development. We submitted a draft so that we could move forward, but this meant having to make significant changes after meeting with our partners and applying for an amendment later. The lesson: Don't expect your institution to be familiar with this method of study.

Give yourself space to learn and grow.

As mentioned, early in the grant-writing process, we had to make significant revisions to our plans as we learned more about CBPR. We do not claim to be experts, but rather works in progress. No research study is perfect. The lesson: We just strive to do the best we can while noting limitations along the way, and this would be our advice to anyone carrying out CBPR for the first time.

Six months into our project, and (in addition to some hiccups), we are finding great benefits to the CBPR approach. We know that we will continue to learn a lot and likely be able to expand this list of tips extensively over the next eighteen months of the study. In the meantime, we hope by sharing our own lessons, others will feel comfortable considering the leap to including autistic individuals in the research process. We truly believe that the increased inclusion of autistic individual and stakeholder perspectives in our field will enhance the relevance and application of the research we do.



References



AMERICAN
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APA DIVISION 33: IDD/ASD

CONVENTION PROGRAM: August 4, 5, & 6, 2022

	Thursday	Friday	Saturday
8 am		Division 33 Executive Committee Meeting	Critical Conversation (1hr) Considerations for BIPOC family engagement in early identification and intervention
9 am			Sara Sparrow Early Career Research Award Invited Address
10 am	Critical Conversation (1hr): Community-informed ABA: Incorporating autistic perspectives to maximize benefits and minimize harms *CEUs available for this session	Symposium (1hr) Using a Diversity and Inclusion Program to Close the Gap in Autism Services Health Disparities *CEUs available for this session	
11 am	Lunch / APA Keynote Speakers	Lunch / APA Keynote Speakers	Lunch / APA Keynote Speakers
12 pm			
1 pm	Symposium (2hr): IDD Psychotherapy Research: Current Status and how it can Inform Practice and Treatment Guidelines	ECP Mentoring Event: Promoting inclusivity in research and practice in IDD/ASD	Virtual Poster Session
2 pm		Division 33 Poster Session II: A Focus on ASD	
3 pm	Division 33 Poster Session I	[DIV 25/33] Symposium (2hr): School Experiences, Workplace Accommodations, Mental Health Services and Behavioral Treatment for Autistic and Neurodivergent Individuals	Symposium (2hr): Advancing Culturally Responsive Autism Practices *CEUs available for this session
4 pm	Symposium (1hr): Virtual Delivery of Evidence Based Treatments and Treatment Training for Autism Spectrum Disorder *CEUs available for this session		
5 pm		Division 33 Business Meeting and Presidential Address (Jason Baker)	
6 pm	APA Committee on Children, Youth and Families Social Hour	Division 33 Social Hour	

Division 33 Award Winners

Edgar A. Doll Award (est. 1980)	Sara Sparrow Early Career Research Award (est. 2008)	Jacobson Award (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	Nancy Robinson	
1999	Murray Sidman	
2000	Todd Risley	
2001	Don Routh	
2002	Travis Thompson	
2003	John Borkowski	
2004	Gene P. "Jim" Sackett	
2005	Robert Sprague	
2006	Ann Streissguth	
2007	Douglas K. Detterman	Richard Foxx
2008	Michael Guralnick	Luc Lecavalier
2009	Sara Sparrow	James Mulick
2010	Bruce Baker	Laura Lee McIntyre
2011	Michael Aman	Stephen Greenspan
2012	Ann Kaiser	Anna Esbensen
2013	Steve Warren	Sally Rogers
2014	Wayne Silverman	James McPartland
2015	Laraine Glidden	V. Mark Durand
2016	Michael F. Cataldo	Abby Eisenhower
2017	Leonard Abbeduto	Marc Tassé
2018	Catherine Lord	Cameron L. Neece
2019	Jan Blacher	Eric Butter
2020	Philip W. Davidson	Matthew D. Lerner
2021	Robert Hodapp	Micah Mazurek
2022	Alice Carter	Vanessa Bal

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**Have an idea for a future newsletter? We want to hear from you.
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APA DIVISION 33

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**PSYCHOLOGY IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND
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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.