

IASSIDD:Challenging Behaviours and Mental Health (CBMH) Special Interest Group



International Association for
the Scientific Study of Intellectual
and Developmental Disabilities

Welcome and Overview

Welcome to the most recent issue of the challenging behaviour and mental health (CBMH) special interest research group newsletter.

Despite the high prevalence of challenging behaviour and mental health issues among individuals with intellectual and developmental disabilities, there is often a deficit in research on strategies to address this topic. Additionally, access to the evidence-based services that are available to address these concerns is often lacking. The purpose of this SIRG is to address this deficit in the literature through promoting collaborative solutions.

In the nature of encouraging collaborative work, this newsletter is intended as a vehicle for connecting members of the SIRG. In this issue, we present interviews from two of our SIRG members. We hope you find these interviews interesting and that getting to know your colleagues will ignite novel ideas for collaborative efforts that fulfill the mission of our SIRG.

This Issue

Overview of the SIRG **P.1**

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Our Mission

- Provide a focus for the worldwide exchange and dissemination of research, practice, and networking on CBMH.
- Promote integrated research and clinical activities that further our understanding of the relationship between psychological and behavioral wellbeing.
- Encourage the development of cross-national, multi-disciplinary collaboration in research and practice.
- Improve the quality of life and services for people with intellectual disabilities and additional behavioural or mental health needs, their carers, and their families.
- Provide a supportive organizational framework for promoting the work of its members.

Last, we want to provide information on upcoming events and ways for you to get involved in the SIRG! We invite everyone to register and attend the 5th IASSID Asican Pacific Conference in Hyderabad India September 2-5 2020. We will have several presentations on challenging behaviours and mental health, as well as a SIRG meeting where you can meet your peers in this SIRG and discuss initiatives for next year. More information on the event can be found at: <https://iassidd2020.com/>

The Health SIRG is also hosting an event in Toronto in June of 2020. The focus is on raising awareness and increasing knowledge to connect policy and practice to improve the health of individuals with IDD. The health of individuals with IDD often overlaps with topics related to challenging behavior and mental health and this conference may be a great opportunity to collaborate across SIRGs. More information can be found at: <http://www.iassiddhealthsirg2020.com/>

Spotlight on Yasamin

Yasamin was presented with the MENCAP Award by IASSIDD.

Yasamin presented on her dissertation at the IASSIDD Congress in Glasgow, Scotland.

Yasamin and her advisor, Dr. Jan Blacher, recently published a chapter on contributing factors to successful post-school outcomes for emerging adults with IDD in the SAGE Encyclopedia of Intellectual and Developmental Disorders.

Some of Yasamin's and her colleagues' work on faculty training modules about neurodiverse college students was recently shared at the College Inclusion Summit in Nashville, Tennessee, and received very positive feedback! They expect for a pilot of this program to launch next year.

1. CFS; B. Baker & J. Blacher, PIs; 2. J. Blacker, PI; 3. Yasamin would like to acknowledge Dr. Blacker from the University of California Riverside and Dr. Sasha Zeedyk at Cal State University Fullerton for their work and mentorship in this area; 4. Bolourian, Zeedyk, & Blacher, 2018; 5. Zeedyk, Bolourian, & Blacher, 2019



Getting to know the Members

We asked 2 of our members about their research, passions, and lives to bring you a snapshot of your fellow members.

Name: Yasamin Boulourian

Location: Riverside, CA United States

Institution: University of California, Riverside

Position: Postdoctoral Research Fellow

What is your major area of focus in your research and or clinical work?

I am interested in the social, emotional, and behavioral development of youth with intellectual and developmental disabilities (IDD).

In my early research, I evaluated a sample of children with autism spectrum disorder (ASD) from the NICHD-funded "Collaborative Family Study"¹ to study profiles of internalizing and externalizing behaviors. My dissertation expanded on this topic by examining the effects of behavior problems on social development in children with ID or typical development, evaluating trends over 6 time points.

This research is especially interesting to me as these domains are frequently reported by parents and teachers, permeate school and home systems, and are of crucial importance to improving social, academic, and mental health outcomes.

What is the most interesting innovation from your field in the past 5 years?

I am excited to see an increase in research on adults with ASD, and as such, I have engaged and collaborated in a related project, entitled "Autism 101"². It investigates the experiences of neurodiverse college students, as well as knowledge of faculty about IDD³. In-person interviews across campuses revealed that while students with ASD were cognitively capable of performing at or above the academic level of their typically developing peers, other concerns, like anxiety and peer interactions, may impede learning and social outcomes⁴. Also, college students with ASD or ADHD often blend into the student body without being given the attention they need to succeed⁵.

While we continue to gather empirical data from neurodiverse students and their faculty, the ultimate goals of this research is to develop a much-needed curriculum or "toolkit" for university faculty and staff.

What is a project that you are currently excited about?

I am excited about the production of a documentary called *Autism Goes to College*. The film was inspired by the voices of the college students with ASD who participated in our "Autism 101" research. Directed by Erik Linthorst and led by Dr. Blacher, it features five brave and inspiring students – enrolled in college – eager to share their stories and encourage their peers. The film has been screened nationally at film festivals, local theaters and campuses, and has gained international interest. If any members of our SIRG are interested in arranging a screening, I would be happy to help coordinate, or go to:

www.autismgoestocollege.org

If you or someone you know would like to be featured in an upcoming newsletter or have events to announce, please email Mindy Scheithauer (Mindy.Scheithauer@choa.org)

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Spotlight on Yona

Yona serves as the Director of the Azrieli Adult Neurodevelopmental Centre at CAMH

One of Yona's big data projects focused on the disproportionately high health care costs for adults with IDD. It was recently published in the Journal of Intellectual Disabilities Research.¹

Yona's team worked with researchers in Australia to compare methodologies for IDD research across regions and cultures. This work was published in Intellectual and Developmental Disabilities.² Additional resources related to this collaboration can be found at <https://3dn.unsw.edu.au/content/education-resources>

Yona is an adult sibling of an individual with IDD, thus she has the unique perspective of a clinician, researcher, and family member.

In addition to Yona's family, she lives in Canada with her husky puppy, named Juno. Having Junos is a great way for Yona to stay in-tune with podcasts and get in a daily walk.

1. Lunsky, DeOliveira, Wilton, & Wodchis, 2019;
2. Balogh et al., 2019

Name: Yona Lunsky

Location: Toronto, Canada

Institution: U of Toronto; Centre for Addiction & Mental Health

Position: Professor, Dpt of Psychiatry

What is your major area of focus in your research and or clinical work?

I work in a psychiatric hospital with a specialized inpatient and outpatient program for adults with ID. I have always been interested in the intersection of mental health and ID, and over the years I have focused on what happens clinically with this population. I also emphasize the broader health system, studying population level health using administrative health data. Last, I focus on the implementation of changes within the health care system to address existing inequities.

I direct a program called H-CARDD, www.hcardd.ca which brings partners together to understand and address health care gaps in Ontario. More recently, I prioritize work focused on partnerships with people with ID and/or ASD and their families to innovate and develop improved health services.

What is your major area of focus in your research and or clinical work?

I have seen different countries partnering to get at big picture issues using big data. There are many things we have always suspected were concerns but our studies were small and underpowered, or biased because they came from small community or clinical samples.

Administrative data has flaws, but we can easily replicate what is done in one jurisdiction with another by knowing what data we have and asking similar questions. The earlier work in our field focused on physical health, but there is more work being done now focused on mental health, or the intersection between how mental health diagnoses in people with IDD impact other aspects of their health and health care use.

What is your major area of focus in your research and or clinical work?

I have been working closely with parents and now adult siblings, to co-design mental health interventions targeting the caregiver, with a focus on mindfulness. One of the projects is based on Acceptance and Commitment Training, and the intervention itself is quite brief. We are currently training teams of family caregivers and clinicians from across Canada to deliver this intervention. The other project teaches mindfulness skills, but we have shifted from offering it face to face to offering it virtually. We have also begun exploring teaching mindfulness skills virtually to people with IDD.

I love this work because it really gets at ways to offer something useful even in the midst many systemic problems. I think we know enough about the problems but we need to harness our energy to do something positive and I love the teamwork, and everything I can learn from people with disabilities and families.

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