

2nd Annual Chair Stakeholder Advisory Meeting

Feedback report from the CIHR Chair in ASD
Treatment and Care Research November 7th, 2014

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Dr. Jonathan Weiss, Associate Professor (Psychology) and Chair in Autism Spectrum Disorders Treatment and Care Research

On November 7th, 2014

Dr. Jonathan Weiss, the Canadian Institutes of Health Research Chair in Autism Spectrum Disorders (ASD) Treatment and Care Research, hosted the second annual Chair Stakeholder Advisory Meeting. Sixty-five members of the ASD community from across Canada attended, from 34 organizations. This included representatives from non-profit organizations, service providers, and government agencies, as well as researchers, self-advocates, and parents of individuals with ASD (see last page for the list of organizations). The primary objective of this meeting was to inform the community of stakeholders about past, ongoing and new research projects, and to develop an understanding of how to further work with communities and stakeholders to foster impactful research. For more information on the Chair in ASD Treatment and Care research, please visit www.asdmentalhealth.ca.

What was covered in the Chair project reports?

Operation Regulation: Preliminary findings from an emotion regulation intervention for youth with ASD – Dr. Kendra Thomson

In the morning, Dr. Kendra Thomson (Brock University) discussed the Secret Agent Society: Operation Regulation (SAS:OR) – a CBT intervention targeting emotion regulation difficulties in youth with ASD. She spoke about the development and design of the SAS:OR program, provided detail about the content and structure of each session, and gave examples of topics that the intervention covers, such as emotion awareness, relaxation and coping skills. Dr. Thompson also presented promising preliminary results on SAS:OR and personal accounts from parents and children who have participated in the program. The next steps for SAS:OR will be to continue to assess the efficacy of the program, and examine the potential for training community agencies to deliver the intervention in order to study its effectiveness in real-world settings.

Autism in Canada: Results from the National Autism Needs Assessment Survey – Carly McMorris & Marg Whelan

Following Dr. Thomson's presentation, Marg Whelan (CASDA) spoke about the history and ongoing development of the Canadian Autism Spectrum Disorder Alliance (CASDA; www.asdalliance.org). She outlined CASDA's commitment to the development and implementation of a National ASD Strategy, and to collectively work towards full and equal access of resources for individuals with ASD and their families. Carly McMorris followed by discussing the findings from the National Needs Assessment Survey, which looked at service use, service needs, and barriers to service from the perspectives of caregivers, professionals and adults with ASD across Canada.

Results from Health Care Access in Developmental Disabilities program of research: A look at transition age youth with ASD across Ontario – Dr. Barry Isaacs

Following the morning break, Dr. Barry Isaacs (Surrey Place Centre) presented on the current research initiatives from the Health Care Access in Developmental Disabilities (HCARD; www.porticonetwork.ca/web/hcardd) program. He began by providing background on how HCARD studies ways in which individuals with developmental disabilities use the healthcare system in

Ontario, and the usefulness of being able to study at a population level through administrative data. Dr. Isaacs then went on to explain, more specifically, the issues that transition aged youth with ASD face when accessing healthcare services in Ontario, and importance of understanding the service use in this group.

What did other members of the ASD community cover?

There were also opportunities in the day for other members of the ASD community to share their perspectives and information about some of their projects. We were honoured to hear from the Hon. Jim Munson (Senator), who spoke passionately about the changes he has witnessed in advocating for policies and programs to support people with ASD across the lifespan and across the country. He also reiterated the need for ongoing discourse at local, provincial, and national levels of government. The audience was further inspired by the Hon. Mike Lake (MP, Edmonton-Mill Woods-Beaumont) as he shared his personal experiences of being the father of a child with ASD. He discussed strategies to foster greater awareness of ASD in Canada, sharing the media outreach strategies he has used.

Community for Brain Development – Dr. Dan Goldowitz

After the first group discussions, Dr. Dan Goldowitz (NeuroDevNet; www.neurodevnet.ca/) discussed the Community for Brain Development. His presentation overviewed its inaugural meeting in Ottawa on October 6, 2014 where 3 areas of importance were discussed in terms of action items for the group to work together on. These included: increasing the number of individuals working in developmental neuroscience by improving training opportunities in this field, expanding policy engagement and advocacy, and the use of knowledge translation. He concluded by emphasizing the importance of approaching policymakers at the Federal level with a 'unified voice' which was accomplished via the Community for Brain Development's participation in NeuroDevNet's "Day on the Hill" on October 7, 2014. Their 'ask' was for 5 more cross-sector research Chairs in the area of neurodevelopmental disorders.

Community Works Initiative – Esther Rhee

Finally, Esther Rhee (Autism Speaks Canada; www.autismspeaks.ca) presented on CommunityWorks Canada and provided details on the development of the program, the elaborate program structure, and the nation-wide implementation plan. CommunityWorks is a program that will contribute to volunteer and employment opportunities for Canadian youth and adults with ASD. Through work and mentoring, participants will gain valuable experience, training and coaching to be prepared for full-time employment.

What recommendations emerged from the group discussion?

In the morning, stakeholders engaged in group discussions where they were asked to provide recommendations for the future direction of the Chair's research, collaborations, and knowledge mobilization activities. The following themes emerged from the discussions:

Strengths of the Chair's research:

- Large amount of research on a wide range of topics published in the last year
- Teambuilding and collaboration across a broad range of sectors
- Excellent research collaborations, knowledge mobilization, and dissemination

Recommended topics for future research:

- Studying needs and services for adults and the aging population with ASD
- Intervention programs based on research for individuals with ASD
- Exploring the impact of sport and being active for people with ASD

Recommendations for collaborations:

- Promote collaboration among agencies, so as to improve the integration of services and allow for smoother transitions
- Connect with rural and smaller communities through community-based agencies
- Canada-wide collaborations involving researchers from various universities across the country, including the North

Strengths of the Chair's knowledge mobilization over the last year:

- Accessibility of information (e.g., Open Access articles, YorkSpace)
- Knowledge translation (e.g., Research Snapshots)
- Outreach presentations about research

Recommendations for knowledge mobilization:

- Expand out from current Toronto-centric and Ontario-centric audiences, and aim to reach a larger, more diverse group of stakeholders across Canada
- Further increase the accessibility of information by making publications available through Autism networks
- Evaluate the knowledge mobilization efforts to determine effectiveness

Recommendations for the ASD Mental Health Blog:

- Deliver information in new formats (e.g., webinars) and create additional material
- Translate posts into different languages so they are accessible to a wider audience
- Further promote the blog on social media platforms



Photo: Anneliese Foetz,
NeuroDevNet KT Core

What innovative research and interventions emerged from the round table discussion?

In the afternoon, we held a large group discussion to learn about the innovative projects supporting individuals with ASD that are taking place across the country. While not an exhaustive list, below are some examples of the different ways that the ASD community is rising up to meet their needs:

Treatment and Survey for Baby Boomers with ASD

York ASD Partnership: Mental health partnerships including sponsored mental health training (York Region)

Social pragmatics program: Engaging peer mentors (Autism Speaks)

JUMP: Math program for kids with ASD

The Realize Community Potential Program: Targets families and professionals, information sharing (Autism Ontario)

Technology for people with ASD (Magnus Mode)

ASD Primary Health Care Tool to help guide health care delivery for people with ASD

Redefinition of model of care at the Centre for Addiction and Mental Health, shifting to home and community interventions

Taming the Bull: Exercise program to target health and wellbeing (ISAND)

Wearable technology (Holland Bloorview and Surrey Place Centre)

Interactive parent training sessions (Centre for Behaviour Health Sciences at Mackenzie Health and Simcoe County District School Board)

Ontario Working Group on Mental Health, Adults, and ASD: One day training, educational resources (Geneva Centre)

Summer day support program for adults with ASD and behaviour challenges in a sport facility (Geneva Centre and Abilities Centre)

Ontario Partnership for Adults with Aspergers and Autism: Collaborative working group

Autism Treatment Network (ATN): Collaboration with 14 sites across North America (Autism Speaks)

Anxiety meter (Holland Bloorview)

Incredible Flexible You: Preschool program for Theory of Mind and Emotion Regulation

MindUp: Mindfulness and social-emotional learning curriculum for schools (The Hawn Foundation)

Sebastian Project: CBT program to target and alleviate core symptoms of autism (Semel Institute)

Playground Therapy: Training pro-social school children to support less able peers (including those with ASD) in play and social interaction

DELSIA: Provides funding to make science work for families (Autism Speaks)

My Life As An Epic Win!: Parent coaching and skill building (Autism Speaks Canada, Autism Ontario)

Providing physical activity based support for ASD youth transitioning into adulthood (Child Development Institute)

"What's so Funny?" Improvisation program; social learning through performance art (Autism-Aspergers Friendship Community)

Kids with ASD work together with without ASD to learn music compositions (Good Buddies Blues Band)

Employment Focus Program: Community and social skills café to open (Geneva Centre)

What was the feedback from participants?

At the end of the day, we asked attendees to submit feedback forms to help us improve our next meeting. Overall, the day was a success. Based on the 46 submitted forms, we learned that attendees most enjoyed learning about recent research and information, networking with a wide range of individuals in the ASD community, the location of the event, and the group and roundtable discussions. The main areas for improvement included ensuring there is enough time to complete all group discussions and providing clearer instructions for the discussions and feedback forms.

Attendees rated the overview of the chair progress ($M = 3.8$ out of 4, $SD = 0.5$), the project reports ($M = 3.7$ out of 4, $SD = 0.5$), and the round table discussion about innovative field work ($M = 3.5$ out of 4, $SD = 0.7$) as very useful in informing the community of stakeholders about past, ongoing and new research projects.

- **98% rated the overview of the chair progress and the project reports as useful**

Attendees rated the group discussion on the evaluation of the chair ($M = 3.5$ out of 4, $SD = 0.7$) and the review of past target areas and identification of future priorities ($M = 3.5$ out of 4, $SD = 0.7$) as very useful.

- **93% believed the discussions to be useful, and 89% felt that the review and identification was useful**

Overall, attendees agreed that the meeting provided an opportunity to give feedback on many topics, including research topics ($M = 2.8$ out of 3, $SD = 0.4$), engaging people with ASD and their families in research ($M = 2.6$ out of 3, $SD = 0.6$), how to best inform stakeholders about research outcomes ($M = 2.6$ out of 3, $SD = 0.6$), the direction and accomplishments of the Chair to date ($M = 2.8$ out of 3, $SD = 0.4$) and future directions ($M = 2.6$ out of 3, $SD = 0.5$).

- **82% of participants felt they had sufficient opportunity to give feedback about the directions and accomplishments of the Chair**

The majority of attendees said they had a better understanding of the goals and plans for the Chair in ASD Treatment and Care Research following the day ($M = 2.8$ out of 3, $SD = 0.5$).

- **37 out of 44 participants said that they had a better understanding of the goals and plans of the Chair**



Photo: Anneliese Poetz,
NeuroDevNet KT Core

In closing – What are the next steps?

This stakeholder event was one of many opportunities to engage with the Chair in a meaningful way to inform how research can address treatment and care of people with ASD and their families in Canada. We are actively developing research projects to focus on the priority areas described above, including collaborations with service providers. We look forward to updating you on our progress over the next few months. In the meantime, please visit and subscribe to the ASD Mental Health blog to stay up to date on current research in the ASD field. Posts also include editorials on salient topics, updates about local events, interviews with innovative ASD researchers, and more. Visit the ASD Mental Health Blog at www.asdmentalhealth.blog.yorku.ca

A sincere thanks to all those who attended the second ASD Stakeholder Advisory Meeting. We hope it was an informative and enjoyable day, and that the chance to network and provide input on ASD research was as worthwhile a day for you as it was for us. A special thanks to our presenters and to Neil Walker for facilitating the day. Further thanks to Carly Albaumb for her coordination of the day and the added support by Dr. Anneliese Poetz and Isaac Coplan from the NeuroDevNet KT Core. If you have any questions, please contact Carly Albaumb at calbaum@yorku.ca.

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Stakeholder organizations: Abe Gold Learning & Research Centre, Abilities Centre, Aspergers Society of Ontario, Autism Canada Foundation, Autism Ontario, Autism Society Canada, Autism Speaks Canada, Blue Hills Child and Family Centre, Brock University, Centre for Addiction and Mental Health, Canadian Institute of Health Research, Conestoga College, Canadian Autism Spectrum Disorders Alliance, Geneva Centre for Autism, Holland Bloorview Kids Rehabilitation Hospital, Integrated Autism Consulting, Integrated Services for Autism and Neurodevelopmental Disorders, Jake's House for Children with Autism, Kerry's Place Autism Services, Mackenzie Health, Ministry of Child and Youth Services, Ministry of Community and Social Services, Ministry of Education, Miriam Foundation, NeuroDevNet, Redpath Centre, Special Olympics Canada, Stars for Life Foundation for Autism, Surrey Place Centre, Toronto Catholic District School Board, University of Alberta, Woodview Mental Health & Autism Services, York Catholic District School Board, York Region District School Board, York University, as well as 3 parent advocates, 4 self-advocates and 2 members of the Parliament of Canada.



Canada



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AUTISM SPECTRUM DES TROUBLES DU
DISORDERS ALLIANCE SPECTRE AUTISTIQUE

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