

# 2016

The CIHR Chair in ASD Treatment and Care Research 4th Annual Chair Stakeholder Report





## **Making Research Accessible**

- 2 Summary
- 4 Research Collaborations
- 7 Knowledge Mobilization
- 7 Publications
- 10 Academic Presentations
- 11 Non-Academic Presentations and Workshops
- 12 YorkSpace
- 13 The ASD Mental Health Blog
- 14 TEDxYorkUSalon Spectrum
- 16 Teaching & Training

# The Chair in ASD Treatment & Care Research 2016 Annual Report Summary

The fourth year of funding for the Chair in Autism Spectrum Disorders Treatment and Care Research was one of consolidating our investments into an array of research projects, knowledge mobilization and capacity building. We have continued to focus on research areas related to mental health of those with ASD, including studying the effectiveness of existing community interventions, identifying and developing treatments, and working with individuals with ASD, their families, and service providers in the research process.

Over the last year, the Chair collaborated on many projects related to mental health and ASD with multiple community stakeholders. As we move into the final year of the current Chair funding, we aim to complete data collection and move further into knowledge mobilization. We have completed our collaboration with the Toronto Catholic District School Board in the evaluation of their Program to Assist Social Thinking, and Autism Ontario and Integrated Autism Consulting, to evaluate their Transition to Life curriculum. We also developed, and now are analyzing data from, a follow-up survey to the Canadian Autism Spectrum Disorder Alliance National Needs Assessment Survey to see how the service needs of Canadians with autism and their families are changing over time.

We have launched a new funded project: Because of the backbone support from the Chair and further support from Kids Brain Health Network, we successfully received an operating grant from the Canadian Institutes of Health Research to expand the current cognitive behaviour therapy trial, Secret Agent Society – Operation Regulation, to include even more children, with a wider array of cognitive profiles, over the next 5 years. We look forward to updating you as we make further progress on this new project and the ongoing ones.

In 2016, we published many articles based on work funded by the Chair, continued to communicate and disseminate ASD and mental health research to academic and non-academic audiences, and have been helping to treat mental health problems in children and adolescents with ASD. Our ASD Mental Health Blog posted 25 lay summaries of research studies, 3 editorials, 3 news articles, and 3 videos - all focused on ASD and mental health. We also expanded our reach through social media. We have involved 11 undergraduate and 3 graduate students from multiple universities across Ontario as authors on the blog, increasing their learning and experiences with knowledge transfer. Further, as part of our knowledge translation strategy, we held our first TEDxYorkUSalon event, focusing on concerns relevant to adults on the spectrum. Dr. Weiss was an author on 10 new peer reviewed publications in the year, 30 poster/paper presentations at 9 scientific conferences, and provided 8 lectures/workshops on ASD and mental health to community organizations. Three postdoctoral fellows and 10 graduate students (8 with research stipends) and 2 of those with travel funding to conferences), and 3 undergraduate students were supported with funding from the Chair.

As always, I would like to thank the many partners who show such strong support for the program and the stakeholder groups who are involved in our ongoing efforts to conduct meaningful and impactful health-related research. We look forward to updating you at an upcoming stakeholder meeting about the progress. As always, at the heart of this program of research are Canadians with ASD and their families.

Sincerely,

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Dr. Jonathan Weiss, Ph.D., C. Psych Associate Professor, Dept. of Psychology York University Chair in Autism Spectrum Disorders Treatment and Care Research <u>http://www.asdmentalhealth.ca/</u> <u>http://ddmh.lab.yorku.ca/</u>

# The Chair in ASD Treatment and Care Research 2016 Annual Report

The Chair in Autism Spectrum Disorders Treatment and Care Research is dedicated to studying ways to improve the mental health and well-being of people with ASD and their families in Canada. It is a unique research position that aims to work with various stakeholder groups including people with ASD, their families, service providers, and governmental bodies to:

- · Translate research to inform stakeholders about mental health and ASD
- · Study ways of addressing mental health problems in people with ASD
- Provide support to the next generation of Canadian ASD researchers and clinicians

The Chair is funded by the <u>Canadian Institutes of Health Research</u> in partnership with <u>Autism Speaks Canada</u>, the <u>Canadian Autism Spectrum Disorders Alliance</u>, <u>Health Canada</u>, <u>Kids Brain Health Network (formerly NeuroDevNet)</u> and the <u>Sinneave Family Foundation</u>. Additional funds from <u>York University</u>.

Dr. Jonathan Weiss, Associate Professor in the Department of Psychology at York University, was awarded the Chair position in November 2012. He has since held two Stakeholder Advisory Meetings, the most recent one being in November 2014. The primary objective of this meeting was to update the community of stakeholders about past, ongoing and new research projects, and to develop an understanding of how to further work with the community to foster impactful research. You can read more about the meeting on the <u>ASD Mental Health</u> <u>Blog</u>. Through group discussions, stakeholders provided the following recommendations:

- Explore needs and service use in adults, research intervention programs, and examine the impact of sport and active lifestyles for people with ASD
- Encourage partnerships among agencies to improve integration of services, connect with rural and smaller communities, and promote and develop Canada-wide collaborations
- Continue to increase accessibility of information, and expand beyond Toronto and Ontario audiences

In place of a Stakeholder Advisory Day, in May of 2016, we will be holding "Spectrum", our first TEDxYorkUSalon, as part of an integrated knowledge mobilization plan for individuals with ASD, their families, clinicians, and students. We will also be providing updates from the Chair at the CASDA Leadership Summit in Ottawa, in April 2016. Until then, we wanted to provide an update on what the Chair has been doing over the past year.

Here is a summary of the research, stakeholder engagement, knowledge mobilization, and teaching and training the Chair has been involved with from January through December 2016.

#### Toronto Catholic District School Board - The Program to Assist Social Thinking

The Program to Assist Social Thinking (PAST) is a strengths-based socio-emotional intervention currently offered to students with ASD in the Toronto Catholic District School Board (TCDSB). Developed and implemented more than seven years ago by a team of educators with expertise in ASD, PAST is currently provided in five TCDSB schools. PAST has received positive support from educators, families, and students. Through our community-engaged research partnership with TCDSB educators, started in 2014, Dr. Priscilla Burnham Riosa (postdoctoral fellow) led a mixed methods project exploring the effectiveness of PAST. She collected data through qualitative interviews with students, educators and parents, and conducted behavioural observations across several school locations to assess how PAST may be translating into improved student behaviours and well-being. Data collection is complete and data analysis is currently underway.

# Special Olympics Ontario - Sport Participation in Youth with Intellectual Disabilities

Youth with intellectual disabilities struggle to access typical recreational activities, and are less likely than typically developing peers to get involved in community sports or to be physically active. In 2013, the Chair began a partnership with Special Olympics Ontario to identify factors that lead to involvement and retention in sport for youth with intellectual disabilities, by having Special Olympics athletes and their caregivers complete an online survey. Approximately one third of these young athletes had a diagnosis of ASD. In 2014, we travelled to different parts of Ontario, and interviewed 58 of these athletes to understand how they feel about themselves, about others, and about doing different types of activities. This past year, we followed up with all the families to see who continued to participate and examined the factors that relate to athlete retention. These findings were submitted to three high-profile research conferences (two national and one international research conferences). This research has involved multiple graduate students and has led to 5 peer reviewed publications, with others in development. In 2016, we completed all data collection, and have provided constructive feedback to Special Olympics to discuss ways of improving programming for participants. Dr. Weiss also participated in a sport participation panel, alongside fellow researchers, policy makers and service providers, to discuss the importance of sport for youth with ASD and other developmental disabilities. In addition to Chair support, this work is funded in part by Sport Canada and the Social Sciences and Humanities **Research Council.** 

#### Centre for Addiction and Mental Health - Transitions in ASD Services

Even as clear service needs exist in community and health domains for adults with ASD, we do not know how needs change over time and the factors that might drive such change. In collaboration with CAMH, this research project is examining the changing support needs and service delivery in adults with ASD in Ontario and across the country. Two follow-up surveys, one based in Ontario and the other, a follow-up survey to the 2014 CASDA National Needs Assessment Survey, are being used to examine the changing community support needs and service use. For participants based in Ontario, we are seeking to understand the role of Developmental Services Ontario in obtaining services. In 2016, we completed data collection on one of the surveys, and began recruitment for the other. We will produce a final report to the Ministry of Community and Social Services in 2017. This study will inform policy and service planning to address the community supports and health needs of individuals with ASD. This research was funded by a Developmental Services Research Grant Fund from Ontario's Ministry of Community and Social Services Community Supports Policy Branch.

#### Secret Agent Society: Operation Regulation – An Emotion Regulation Intervention for Youth with ASD

Youth with ASD often experience emotional difficulties like anxiety, depression, or anger, which can be related to difficulties with regulating their emotions when faced with stressful situations. The Secret Agent Society - Operation Regulation (SAS-OR) program, developed by Dr. Renae Beaumont, is a cognitive behavioural program to help youth with ASD cope with their emotions and handle day-to-day stressors by teaching tools and strategies. Children learn these strategies through numerous spy-themed activities like an emotion-focused computer game, cue cards, session games, and parent and teacher handouts. As of December 2016, 56 children have successfully completed the trial. SAS-OR also operated as a training opportunity for 22 graduate students who learned to provide therapy to children with ASD. These students worked as program therapists under the supervision of Dr. Weiss and his postdoctoral fellows (Drs. Thomson, Burnham Riosa, & Salem-Guirgis), as well as a PhD candidate (Ms. Wincentak). In 2016, we published a feasibility trial showing that SAS-OR is a clinically useful program to deliver, and completed all service provision related to the randomized trial, leaving 2017 for data analysis, dissemination and training.

#### Autism Ontario and Integrated Autism Consulting - Transition to Life Program

The Transition to Life Program was developed by Integrated Autism Consulting to help address the needs of young adults with Asperger Syndrome, and provide support as they transition from secondary school into adult life. In 2013, the two organizations approached the Chair for assistance in designing an evaluation framework for the 12-week pilot/demonstration course that began in the summer of that year. With funding from the Ontario Ministry of Economic Development, Employment and Infrastructure, the program is now being provided in Barrie, Kingston and Ottawa for adults between the ages of 18 and 28 with Asperger Syndrome. The Chair advised the Transition to Life program about how to conduct program evaluation and assisted in the data analysis of their past implementation. For more information about Transition to Life, visit the Integrated Autism Consulting website at www.integratedautismconsulting.com or the Autism Ontario website at www.autismontario.com/adults.

#### Kids Brain Health Network (formerly NeuroDevNet) - **MYmind: Mindfulness** Training for Adolescents with ASD

Previous research has shown that mindfulness not only helps to improve attention and focus, but can also be effective in reducing stress, increasing control over negative feelings, and improving quality of life. This research project is examining whether participation in MYmind, a mindfulness training program designed for adolescents with ASD and their parents, is related to improved outcomes. Originally developed and tested by researchers in the Netherlands, this program aims to have families experience the benefits of mindfulness meditation and cognitive therapy techniques while learning to relate to one another in a new way.

This initiative has provided training to four graduate students and two post-doctoral fellows from our lab, who are learning how to provide mindfulness therapy to adolescents with ASD, building the capacity of trained professionals for the future. Two cohorts have completed the program since 2016 – altogether, 17 parent-teen dyads have completed the intervention, and another 7 are currently participating. According to participants' feedback, the overall impact of the MYmind program appears to be positive. Following the program, many parents report closer relationships and improved communication with their children. Most youth report improvement in their ability to manage stress and negative emotions, and they noted an increase in self-esteem and awareness of their own and others' feelings. One youth stated, "it's inspiring to think how there are programs like [MYmind] that can help us get through life's difficulties." Kids Brain Health Network has put together a video showcasing the program.

Several organizations (e.g. Geneva Centre for Autism, Lake Ridge Community Support Services, and ISAND) have begun to run these groups in the community, which means that our efforts are directly leading to improved capacity in mental health services.

### **New Collaborations & Funding**

## Université du Québec à Montréal - Understanding and Assessing the Risk of Suicide in People with ID or ASD

**Funding Agency:** Canadian Institutes of Health Research **Principal Investigator:** Dr. Brian Mishara **Co-Leads:** Dr. Julie Mérineau-Côté, Dr. Daphné Morin, Dr. René Proulx, Dr. Cécile Bardon, Dr. Diane Morin, Dr. Jonathan Weiss

Led by Principal Investigator, Dr. Brian Mishara, Dr. Weiss is part of a team aiming to understanding the characteristics of suicide in people with ID or ASD. This first phase of this research, a clinical file review, has been completed, and consultations with stakeholders are underway to develop a tool to measure suicidal risk to assist with prevention efforts.

#### Cognitive Behavior Therapy for Mental Health Problems in Children with Neurodevelopmental Disorders: A Transdiagnostic Approach

### Funding Agency: Canadian Institutes of Health Research Principal Investigator: Dr. Jonathan Weiss

Neurodevelopmental disorders (which include ASD) are estimated to affect 16% of children and up to 70% of these children have mental health problems, like anxiety or depression. Many of these children are often excluded from receiving treatment because of their complex socio-communicative and cognitive profiles. Building off the current success of our randomized trial, this new project will examine whether Secret Agent Society – Operation Regulation improves emotion regulation abilities and decreases emotional and behavioural problems in children with various neurodevelopmental disorders, 8 to 13 years of age. This study will continue to involve many children with ASD, who often have other co-occurring difficulties, such as learning or attentional problems. Funded by CIHR, this new project will expand the scope of who can be involved in our trial, helping even more children and families. The impact of this project could further enable changes in how evidence-based treatment for mental health is delivered.

#### Child Health Initiatives Limiting Disability - Brain Research Improving Growth and Health Trajectories Strategic Patient-Oriented Research (CHILD-BRIGHT SPOR)

Funding Agency: Canadian Institutes of Health Research Co-Lead: Dr. Jonathan Weiss

The <u>CHILD-BRIGHT network</u> aims to achieve brighter futures for children with brain-based developmental disabilities and their families by creating novel interventions to optimize development, promote healthy outcomes, and deliver responsive and supportive services across the life-course. Twenty-six investigators will work on 12 projects. Together with youth and families, CHILD-BRIGHT's pan-Canadian network includes an impactful patient-oriented research program, authentic citizen engagement, multi-pronged knowledge translation and patient-oriented training. Dr. Weiss is a co-lead on the knowledge translation team that will study and mobilize best practices to involve stakeholders in the research process for maximal impact of research-informed practice.

## **Knowledge Mobilization**

The Chair's mandate includes making research on mental health accessible. This can happen in many ways: through publications in peer reviewed journals that are openly accessible, through presentations at scientific and lay conferences, and through online posts about research topics.

#### **Publications**

In 2016, Dr. Weiss co-authored 10 peer-reviewed publications. There are also several manuscripts currently in press and under review that will come out in 2017, based on the research that has occurred in 2016. The following are brief summaries of the articles published in the past year – Dr. Weiss' students and trainees are underlined:

Altomare, A., McCrimmon, A., <u>Cappadocia, C.</u>, Weiss, J.A., Beran, T., & Smith, A. (2016). When push comes to shove. Canadian Journal of School Psychology. doi: <u>10.1177/0829573516683068</u>

How are students with autism spectrum disorder coping with bullying? This study examined the coping strategies suggested by 39 students with ASD between the ages of 8 and 13 years old. Thematic analysis identified 3 themes: approach, avoidance, and the complexities of bullying. These insights may lead to possible avenues for school-based interventions.

Vogan, V., Lake, J. K., <u>Tint, A.</u>, Weiss, J. A., & Lunsky, Y. (2016). Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction. Disability and Health Journal. doi: <u>10.1016/j.dhjo.2016.11.002</u>

To better understand the needs of adults with ASD in healthcare, this study looked at the services adults (ages 18–61 years) with ASD without ID used over a 12- to 18-month period, and their experience accessing services. Beyond a family doctor, the most commonly used services were dentistry, individual counseling, and psychiatry. Those who had medical problems experienced more barriers than those who did not, and those who had medical and mental health problems were less satisfied with services.

#### Weiss, J. A., <u>Burnham Riosa, P.</u>, <u>Robinson, S.</u>, <u>Ryan, S.</u>, <u>Tint, A.</u>, <u>Viecili, M.</u>, <u>MacMullin, J.</u>, & Shine, R. (2016). Understanding Special Olympics experiences from the athlete perspectives using photo-elicitation: A qualitative study. Journal of Applied Research in Intellectual Disabilities. doi: <u>10.1111/jar.12287</u>

Many individuals with intellectual disabilities face challenges participating in organized sport. In this study, the research team looked at the experiences of five athletes with intellectual disability (13 to 33 years of age) involved in Special Olympics. Using photography to document and describe their sport experiences, athletes talked about their connections to teammates and coaches as well as the importance of training and hard work.

### <u>Tint, A.</u>, <u>Maughan, A. L.</u>, & Weiss, J. A. (2016). Community participation of youth with intellectual disability and autism spectrum disorder. Journal of Intellectual Disability Research. doi: <u>10.1111/jir.12311</u>

This study examined community participation in youth with intellectual disability and ASD, and youth with only intellectual disability. The research team found there were no differences in the number and frequency of community activities that the two groups participate in. However, caregivers reported that youth with ASD were less involved in the activities in which they participated, and that social requirements of the activities, such as communication and relationships with peers, made participation more difficult.

# <u>Tint, A.</u>, <u>Thomson, K.</u>, & Weiss, J.A. (2016). A systematic literature review of psychosocial and physical correlates of Special Olympics participation among individuals with intellectual disability. Journal of Intellectual Disability Research. doi: <u>10.1111/jir.12295</u>

The research team reviewed 46 studies to better understand how Special Olympics impacts individuals' physical, psychological/emotional, social and/or intellectual/cognitive wellbeing. Overall, there is more support for physical, psychological/emotional and social outcomes among participants as compared to cognitive/intellectual; however, many studies had methodological issues which limited the ability to generalize the results. Future research with more rigorous study designs are needed to better understand the impact of Special Olympics on individuals with intellectual disabilities.

# Weiss, J., <u>Ting, V.</u>, & Perry, A. (2016). Psychosocial correlates of maladaptive behaviour and psychiatric diagnoses in youth with severe developmental disability. Journal of Intellectual Disability Research, 60(6), 583-593) doi: <u>10.1111/jir.12278</u>

Mental health problems are common in youth with severe or profound intellectual disabilities. The researchers looked at child and family characteristics (e.g., child daily living skills, parent mental health problems, family quality of life), and psychosocial factors (e.g., number of stressful life events, financial hardship) to see if they were related to mental health problems in these youths. Youth with a diagnosed mental health problem were more likely to have better daily living skills but to have experienced more stressful life events than those without a diagnosed mental health problem.

# <u>Robinson, S.</u>, Weiss, J. A., Lunsky, Y., & Ouellette-Kuntz, H. (2016). Informal support and burden among parents of adults with intellectual and/or developmental disabilities. Journal of Applied Research in Intellectual Disabilities, 29(4), 356-365. doi: <u>10.1111/jar.12184</u>

Social support can be a critical resource for families of individuals with intellectual disability. This study examined the relationship between behaviour support needs of 212 adults with intellectual disability and parental burden, and whether perceived helpfulness of informal supports influenced this relationship. The analysis showed that informal support was negatively related to burden, but it did not change how behavioural support needs influence parental burden.

### Weiss, J. A., <u>Tint, A.</u>, Paquette-Smith, M., & Lunsky, Y. (2016). Perceived self-efficacy in parents of adolescents and adults with autism spectrum disorder. Autism, 20(4) 425-434. doi: <u>10.1177/1362361315586292</u>

Many parents of adolescents and adults with ASD report feeling unsure about how to access services and find the right kind of care. The research team looked at how well 324 parents thought they could access and provide care to their child with ASD between the ages of 12–25. They found that lower self-efficacy was related to having an older child, being an immigrant, experiencing more barriers to service access, and caregiver burden. Since parents often play a crucial role in the lives of individuals with ASD across the lifespan, it is important that service providers support the efforts of parents to provide and access care.

### <u>Tint A.</u>, & Weiss, J. A. (2016). Family wellbeing of individuals with autism spectrum disorder: A scoping review. Autism, 20(3), 262-275. doi: <u>10.1177/1362361315580442</u>

Families play an important role in supporting individuals with ASD across the lifespan but little attention is paid to the wellbeing of those families. This review of 86 studies on the topic showed that the definitions and methods to measure family wellbeing are broad and diverse. Future research would benefit from understanding how individuals in the family rely on each other.

#### MacMullin, J., Lunsky, Y., & Weiss, J. A. (2016). Plugged in: Electronic use in children with autism spectrum disorder. Autism, 20(1), 45-54. doi: 10.1177/1362361314566047

Although electronic technology currently plays an integral role for most youth, there are growing concerns of its excessive and compulsive use, particularly for individuals with ASD. In this study, patterns of electronics use in individuals with ASD were compared to typically developing individuals. Compared to parents of individuals without ASD, parents of individuals with ASD were more likely to report that electronics use was currently having a negative impact. This is freely available for download through <u>YorkSpace</u>.





## **Conference Presentations & Posters**

The Chair's research collaborations resulted in 18 poster presentations and 12 paper presentations at peer-reviewed, scientific conferences in 2016. Presentations were on a variety of topics such as emotion regulation in individuals with ASD, electronics use in youth and young adults with ASD, sexual knowledge and victimization in adults with ASD, and the evaluation of interventions for individuals with ASD. These presentations were presented at the following 9 conferences:

- 49th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disability, San Diego, CA in March.
- Ontario Association on Developmental Disabilities (OADD) Research Special Interest Group (RSIG) Conference, London, ON in April.
- CASDA Leadership Summit, Ottawa, ON in April.
- International Meeting for Autism Research (IMFAR), Baltimore, MD in May.
- 42nd Annual Conference for the Association for Behavior Analysis International, Chicago, IL in May.
- Canadian Psychological Association 77th Annual Convention, Victoria, BC in June.
- American Psychological Association Annual Convention, Denver, CO in August.
- International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) World Congress, Melbourne, Australia in August.
- 33rd Annual Conference of the National Association for the Dually Diagnosed (NADD), Niagara Falls, ON in November.

## Presentations & Workshops for Non-Academic Audiences

Over the past year, Dr. Weiss gave 12 talks about mental health and ASD to individuals with ASD, clinicians, educators, family caregivers of individuals with ASD, and policy makers in different branches of government. Here is a selection of some of those talks:

#### Health of Young Adults with Developmental Disabilities Across Ontario

Presented at the Candian Association of Paediatric Health Centres (CAPHC) Presents! Webinar Series in March. The presentation is available by clicking <u>here</u>.

#### Cognitive Behaviour Therapy for Emotion Regulation in Youth with ASD

Presented at the University of Warwick Autism CBT Workshop, Coventry, United Kingdom in April.

#### TEDxYorkUSalon "Spectrum".

Hosted event for people with ASD, parents, researchers, policy makers, clinicians and community organizations with TEDxYorkUSalon, Toronto, ON in May. Talks are available on Youtube, <u>here</u>.

#### Mental Health Problems in Youth with Developmental Disabilities

Presented at the Canadian Association of Paediatric Health Centres (CAPHC) Presents! Webinar Series in July. The presentation is available by clicking <u>here</u>.

#### Bullying in Individuals with Autism Spectrum Disorder

Presented at the Autism Research Training Program, Montreal, QC in August.

## Mindfulness and Cognitive Behavioral Approaches for Youth and Adults with Autism Spectrum Disorder

Invited Presentation at the JFK Partners 4th Annual Autism Spectrum Disorder Conference, Aurora, Colorado in October.

#### Mental Health & Thriving in People with ASD

Presented at the Geneva Centre for Autism International Symposium, Toronto, ON in November.

#### Emotion Regulation Interventions for Youth/Teens with ASD

Presented at the Geneva Centre for Autism International Symposium, Toronto, ON in November.

In addition, Dr. Weiss' research was featured in various news and media outlets, including the following:

"Helping patients with autism navigate the stressful ER" Featured in the CNN Health News, February 29, 2016: http://www.cnn.com/2016/02/29/health/autism-patient-care-er/

**"Cognitive behaviour therapy and mindfulness can help kids with autism"** Featured in Huffington Post - The Blog, November 01, 2016: http://www.huffingtonpost.ca/julie-m-green/cbt-mindfulness-autism b 12674008.html

#### "To support children with developmental disabilities, we must support parents"

Written for Healthy Debate on June 22, 2016: <u>http://healthydebate.ca/opinions/developmental-disabilities-parental-support</u>

## YorkSpace

In 2016, the Chair upheld the commitment to improving the accessibility of information using open access repositories. In accordance with the CIHR Open Access Policy, 25 research studies produced by the Chair are currently available to view and download through the York University open access repository, <u>YorkSpace</u>. These research studies have been viewed 9,746 times, and downloaded 15,147 times.



# The ASD Mental Health Blog



The ASD Mental Health Blog was launched in January 2013 to inform families, service providers, and individuals with ASD about research surrounding ASD and mental health. The blog also offers editorials and news segments on relevant topics and issues, interviews with leading ASD researchers from across Canada, and upcoming research projects from Dr. Weiss' team and collaborators.

At the end of 2016, we had 147 subscribers and 11,302 unique page views. As well, our Twitter account grew to 1,687 tweets and 1,362 followers as of December 31st.

To subscribe to the ASD Mental Health Blog, visit <u>www.asdmentalhealth.blog.yorku.ca</u>. You can also receive updates on blog activity by following us on Twitter (<u>@ASDMentalHealth</u>) and liking us on Facebook (<u>ASD Mental Health Blog</u>). You can also follow Dr. Weiss on his personal Twitter account (<u>@DrJonathanWeiss</u>).

#### Here's an update on each of the different sections:

#### **Research Summaries:**

Each month, the ASD Mental Health Blog shares several ResearchSnapshots (clear language summaries). The template and format were developed by ResearchImpact and have been adopted by Dr. Weiss for summarizing research on ASD and mental health that would be of interest and/ or most helpful to stakeholders. These articles are based on peer-reviewed published research studies and provide a two-page summary, covering 5 key areas: what the research is about, what the researchers did, the main findings, how the reader can use this information, and the takehome message. Each summary also provides a brief biography about the researchers and citation for the original article.

In 2016, we posted 25 new research summaries, which can be downloaded and shared freely by visiting the <u>Research Summaries</u> page on the blog. In total, the Blog features 81 research summaries with a new summary being added every two weeks.

Here are titles of our top 3 summaries from this past year:

- A useful strategy to regulate emotions for children and teens with autism
- The role of positive family processes in change in autism symptoms and maladaptive behaviours in adulthood

 Physician perspectives on providing primary medical care to adults with autism spectrum disorder

#### **Editorials and Videos:**

We've also produced several editorials and videos that evaluate and discuss research findings, pertinent issues, and resources related to ASD and mental health. In 2016, we posted 3 editorials and 3 videos.

#### In the News:

These posts outline and link to news items that feature the work of the Chair, as well as topics and upcoming events that may interest the many different members of the ASD community. This year, we posted 3 new articles.

#### **Upcoming Conferences:**

To encourage knowledge mobilization and the sharing of research findings, the ASD Mental Health Blog provides updates about upcoming research conferences taking place in Canada and the United States. Each conference listed has a link to the conference website, where stakeholders can receive more information, register or submit abstracts.

# TEDXYorkUSalon

x = independently organized TED event

# Spectrum

Independently run, self-organized TEDx events help share ideas in local communities around the world in a TED-like experience. This platform, with a license given to TEDxYorkU, allowed us to run a Salon, an intimate TEDx event.

The aim of our Salon was to provide a forum for ideas within the Canadian ASD community of stakeholders. Recognizing that knowledge mobilization is a learning process among stakeholders with different perspectives and expertise, we involved people with ASD, parents, researchers, educators, policy makers, and service providers as presenters on topics relevant to transition-age youth and adults.

The TEDxYorkUSalon "Spectrum" was held on May 28th, 2016, selling out quickly. We filled the Glendon Theatre in Toronto to capacity with 146 attendees. On that day, 130 were in the audience (at least 18 who identified themselves as family members, 17 as professionals who work with people living with ASD, 6 students and 6 who wanted to identify as self-advocates). Topics ranged from how parents were empowered by participating in autism research to the changes that clinicians see the healthcare system needs to make for adults with autism. Community leaders rallied everyone to come together and work with one voice to support individuals and their caregivers.

#### One parent shared after the event:

"It was a really neat event for many reasons. One, it was so beautifully and thoughtfully organized. The attention to detail was phenomenal. As a teacher and a mom of a son with autism, I notice and appreciate such things... I don't think he has ever been treated so thoughtfully and respectfully..."

#### **One participant:**

"[The event gave them] access to a wide variety of perspectives. Although different, there was an underlying sense of the possible - that challenges can be overcome. Not everything is an obstacle."



We asked participants "to what extent did you find the TEDx forum useful in achieving the following objectives", on a sliding scale from 0 – not at all – to 100 – perfectly. The average scores and standard deviations are listed following the objectives below:

- Provide inspiration, optimism and hope regarding the future of the ASD research = 74.7 (20.3)
- Make topics of ASD research accessible to the public = 73.0 (20.5)
- Reach out to the community as researchers = 75.3 (18.5)

The talks have been viewed online over 32,000 times and can be found at <u>www.tedxyorkusalon.org</u> or on ASD Mental Health's <u>YouTube channel</u> – where the impact of the event will go far beyond those in attendance that day. One of our partners of the event, the Kids Brain Health Network, created a 3-minute video summary of the event which can be viewed <u>here</u>.

Based on the success of this first event, in 2017, we will be hosting a second TEDxYorkUSalon "AutismInnovations". This Salon focuses on innovations for people with ASD within their community by 4 Canadian TEDx speakers and showcases research from local universities in a series of 3-minute lightening talks by 13 academics from the Greater Toronto and Hamilton Area. Please visit: www.tedxyorkusalon.org for more details.



## **Teaching and Training**

Part of the Chair's mandate is to support the next generation of ASD researchers. In 2016, the Chair continued to fund three postdoctoral fellows and a number of graduate students:

- Dr. Priscilla Burnham Riosa's (PhD, BCBA-D, University of Guelph) research interests are in understanding the impact of ASD on the individual, the family, and other social contexts. She and Dr. Weiss are collaborating with educators from the Toronto Catholic District School Board to examine the Program to Assist Social Thinking (PAST), a school-based intervention designed to support students with ASD. Dr. Burnham Riosa also recently began exploring therapeutic alliance in the Secret Agent Society: Operation Regulation intervention, and the impact this may have on program outcomes.
- **Dr. Sandra Salem-Guirgis's (PhD, BCBA-D, University of Manitoba)** research at York University focuses on the effects of different types of interventions including mindfulness based therapies and cognitive behaviour therapies on children and teenagers with autism and their parents. She is interested in the evaluation of behavioural and clinically based interventions that target not only behaviour and performance but also socio-emotional functioning and family functioning within the ASD and DD populations.
- Dr. Jonathan Lai's (PhD, McMaster University) research focuses on knowledge mobilization to inform policy through: 1) understanding the health and service needs of individuals with ASD and the factors that influence service utilization and community inclusion, and 2) knowledge translation through the ASDMentalHealth Blog, social media, and stakeholder engagement events (i.e. TEDx Salon events). Previously, he was co-funded by Kids Brain Health Network to work with Autism Speaks Canada on the implementation of Worktopia, a pre-vocational training program for youth with ASD and related initiatives. He is interested in bridging the gaps between brain science, mental health and society-at-large through moving research into evidence-based policies and programs.

Several graduate students received research or travel funding to present research at scientific conferences, including: Michelle Viecili, Jennifer MacMullin, Andrea Maughan, Karen Black, and Carly Albaum. You can learn about their research interests on the Developmental Disabilities and Mental Health <u>website</u>.

In addition to the post-doctoral fellow and graduate students, two lab coordinators, three additional research assistants, and three volunteers worked for the Chair in the last year:

- **Carly Albaum** was a Lab Coordinator for Dr. Weiss from May 2014 to July 2016. She received her BA in the Specialized Honours Psychology Program, completing her undergraduate thesis under the supervision of Dr. Weiss. Carly is currently pursuing her graduate training in Clinical-Developmental Psychology under the supervision of Dr. Weiss.
- Paula Tablon has been a Lab Coordinator for Dr. Weiss since June 2016. She completed her Honours BA in Psychology. Working for the Chair has provided her with many opportunities to help develop, coordinate and conduct clinical research in ASD. Paula intends to pursue graduate training in Clinical Psychology.
- Maria Khan was a Research Assistant for Dr. Weiss from June 2015 to June 2016, working on the SAS-OR program. She received her BA in the Specialized Honours Psychology program, completing an independent study under the supervision of Dr. Weiss. Maria is currently pursuing graduate training in School & Clinical Child Psychology at the University of Alberta.
- Flora Roudbarani has been working as a Research Assistant for Dr. Weiss since June 2016, working on the SAS-OR program. She obtained a BSc in Psychology from McMaster University and a MEd in Developmental Psychology at OISE/University of Toronto. Flora is interested in pursuing graduate training in Clinical-Developmental Psychology while being involved in ASD research.
- Mira Goldstein is a Research Assistant on the MYmind project and a Psychology Honours thesis student. Her thesis examines the relationship between participation in MYmind and mindfulness and mental health in parents of adolescents with ASD.
- **Gemma Cruz** began her involvement in the lab in July 2016 as a volunteer and Psychology Honours thesis student with Dr. Weiss, using data from the SAS-OR program. Gemma hopes to conduct research and work alongside children and young adults on the ASD spectrum to find ways to improve their overall quality of life.
- **Kayla Halberstadt** is a volunteer in the lab currently working on her Honours BSc in Psychology. Kayla hopes to continue her education, striving towards a career helping those with disabilities.
- Julia Martini is a volunteer in the lab who is currently completing a double degree in Psychology and Teacher Education. After completing her honours thesis with Dr. Weiss next year, Julia aspires to enter a graduate program in Clinical-Developmental Psychology with the hopes of one day providing therapy to children and adults and being involved in ASD research.





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