The CIHR Chair in ASD Treatment and Care Research

2013 - 2014

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# 1st Annual Chair Stakeholder Report

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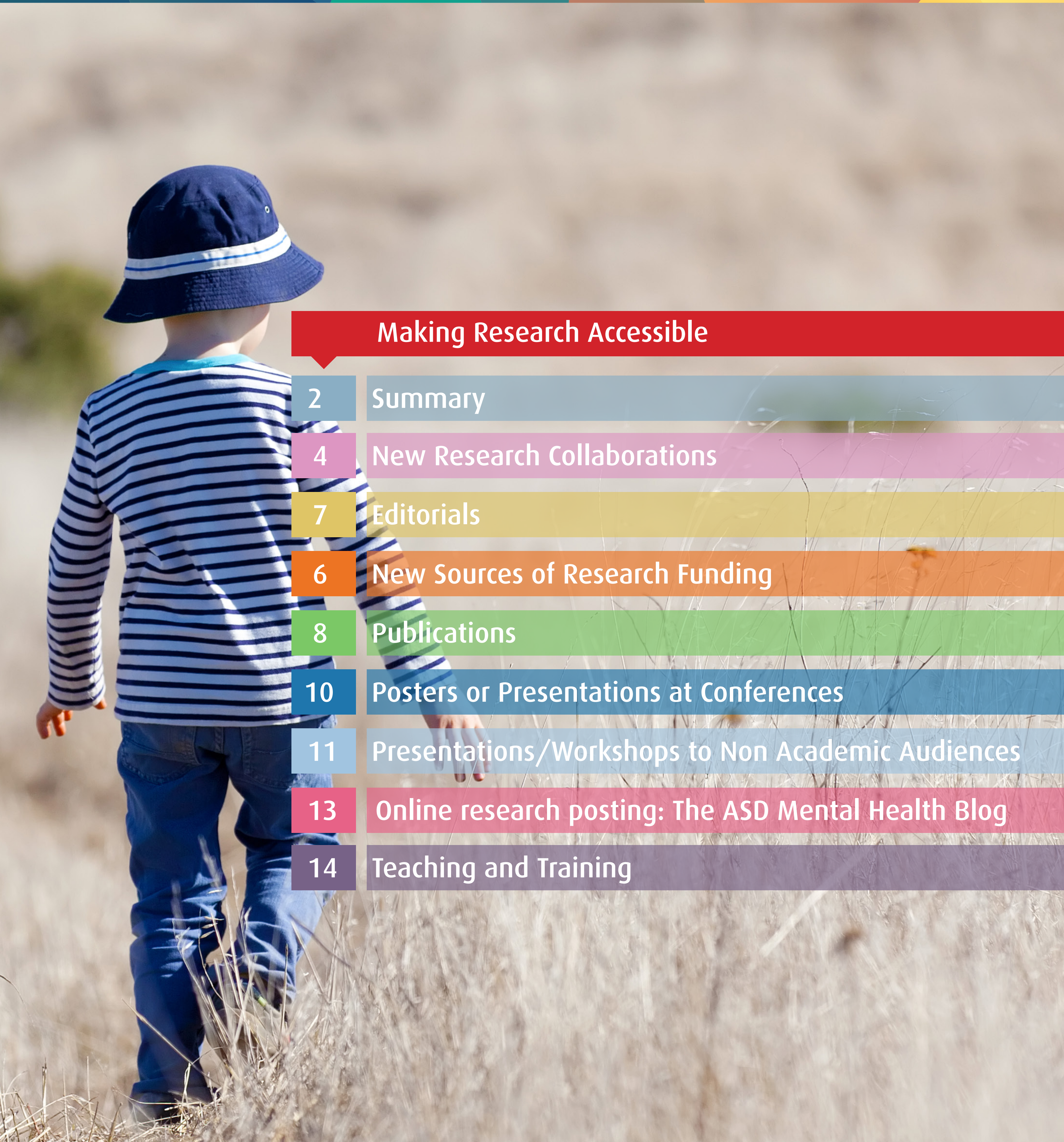


# Making Research Accessible

2 Summary

4 New Research Collaborations

7 Editorials

6 New Sources of Research Funding

8 Publications

10 Posters or Presentations at Conferences

11 Presentations/Workshops to Non Academic Audiences

13 Online research posting: The ASD Mental Health Blog

14 Teaching and Training

# The Chair in Autism Treatment & Care Research 2013 Newsletter Summary

It has been a tremendously successful first year for the Chair in Autism Spectrum Disorders Treatment and Care Research. In January 2013, a Stakeholder Advisory Meeting was held with a broad community of stakeholders to inform the research directions for the Chair. A number of recommendations emerged: 1) Focus on research areas related to mental health treatment of those with ASD, including studying the effectiveness of existing community interventions, and identifying and developing treatment; 2) Engage individuals with ASD, their families, and service providers in the research process through the media, social media, electronic communication, working with service providers, and by putting families first; 3) Present research outcomes in ways that are accessible to non-academics - using multimedia, plain language summaries, social media, and in-person presentations. In addition to these directions, the Chair has a mandate to foster the next generation of researchers in the area of Treatment and Care of ASD.

Over the last year, the Chair collaborated on 11 new projects related to mental health and ASD, with multiple community stakeholders. Collaborations include: 1) the Toronto Catholic District School Board (to evaluate their unique and comprehensive ASD school support program); 2) Special Olympics Ontario (to examine how youth with ASD are involved in sports and how this relates to their well-being); 3) the Canadian Autism Spectrum Disorders Alliance (to develop a national survey of service needs); 4) the Spectrum of Hope Autism Foundation (to provide a unique cognitive behavioural emotion regulation therapy to children with ASD); 5) the Geneva Centre for Autism (to help them evaluate their newly implemented social skills program); 6) Autism Ontario and Integrated Autism Consulting (to evaluate their Transition to Life curriculum to help young adults with ASD transition into successful employment); and 7) Conestoga College (to evaluate a mindfulness training for students at the College with ASD). We look forward to updating you as we make continued progress on these ongoing projects.

In 2013, we made several gains in communicating and disseminating ASD and mental health research to academic and non-academic audiences. There was a heavy emphasis on making research accessible, with the launch of the ASD Mental Health Blog. In 2013, we posted 15 lay summaries of research studies on the topic, 6 videos, 7 editorials, and 6 news articles, all focused on ASD and mental health. We have employed undergraduate and graduate students as authors for the blog, increasing their learning and experiences with knowledge transfer. Dr. Weiss was an author on 6 new peer reviewed publications, 24 posters or presentations at conferences, and provided 12 workshops on ASD and mental health to community organizations. Two postdoctoral fellows were hired, and 5 graduate students were supported with funding from the Chair. Dr. Weiss was also appointed as a member of the Ontario Ministry of Children and Youth Services Clinical Expert Committee on Autism Spectrum Disorders to help inform policies on the treatment and care of youth with ASD.

The foundation of a program of community-engaged research is now firmly rooted and 2014 should begin to show the results of these collaborations. As always, the Chair in ASD Treatment and Care Research is indebted to the numerous partners who continue to show such strong support for the program and the multiple local and national 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 Advisory Day about the progress. As always, at the heart of this program of research are individuals and families, who are partners in every project we take on to improve the treatment and care of Canadians with ASD.

Sincerely,

Jonathan Weiss

Dr. Jonathan Weiss, Ph.D., C. Psych

Assistant Professor, Dept. of Psychology
York University
Chair in Autism Spectrum Disorders
Treatment and Care Research

www.asdmentalhealth.ca
www.ddmh.lab.yorku.ca

# The Chair in Autism Treatment and Care Research 2013 Newsletter

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 Autism Spectrum Disorders (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, services providers, and governmental bodies; to translate research to inform stakeholders about mental health and ASD; to study ways of addressing mental health problems in people with ASD; and to provide support to the next generation of Canadian ASD researchers and clinicians. The Chair is funded by the Canadian Institutes of Health Research in partnership with Autism Speaks Canada, the Canadian Autism Spectrum Disorders Alliance, Health Canada, NeuroDevNet and the Sinneave Family Foundation. Additional funds come from the Spectrum of Hope Autism Foundation and support from York University and ORION's O3 Collaboration.

Dr. Jonathan Weiss, Assistant Professor in the Department of Psychology at York University, was awarded the Chair position in November 2012, and the first Chair Stakeholder Advisory Meeting was held in January 2013. The primary objective of this meeting was to facilitate dialogue within the community of stakeholders and inform the research directions for the Chair. You can read more about the day, including a summary of it and access videos of the speakers, on the ASD Mental Health Blog. Through group discussions, stakeholders provided the following suggestions:

- Focus on priority research areas related to mental health treatment of those with ASD, including a focus on working with organizations around existing interventions, and develop novel treatments.

- Engage individuals with ASD, their families, and service providers in the process of conducting research. It is important to listen to what individuals, families, and service providers are saying to shape research questions.

- Present research outcomes in ways that increase accessibility to non-academic audiences, such as innovative multimedia, plain language summaries, media, social media, and in-person presentations.

We intend on holding another Stakeholder Advisory Day in the spring of 2014. In the meantime, we wanted to provide an update on what the Chair has been doing in the last year. Here is a summary of the research, stakeholder engagement, and teaching from January 2013 to January 2014.

# New Research in 2013

## New research collaborations

### 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 high functioning 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 the area of 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, we will be evaluating PAST to study its potential to improve the socio-emotional well-being of students with ASD in elementary and high school. Over the last year we have worked collaboratively to develop a research design and are aiming to pilot this design in Spring 2014.

### Special Olympics Ontario - Participation and Impact of Sport

Special Olympics is an organization that provides year-round sports training and competition for people with intellectual disabilities (ID), including many people with ASD. We have partnered with Special Olympics Ontario to conduct the first study to identify factors that lead to involvement and retention in sport for youth with ID and ASD, by collecting information from Special Olympics athletes and their caregivers. We will also be able to examine the factors that relate to mental health problems and to well-being in athletes. In the summer of 2013, we invited caregivers of all registered Special Olympics Ontario athletes, who were 11-21 years of age, to participate in an online survey, and we've had tremendous success. To date, 522 caregivers of youth with developmental disabilities from across Ontario have participated, with 40% reporting that the athlete has a diagnosis of ASD. This is providing us with a unique opportunity to study the effects of sport programming on the health and well-being of youth with ASD compared to youth with ID who do not have ASD. Currently, the second phase of the study is underway; we are interviewing up to 150 athletes about why they participate in sport, how they feel about their social experiences, their self-esteem, and about being in Special Olympics. We are also working with Special Olympics Ontario to put out a newsletter specifically about this research and are starting to speak with them about ways to enrich the experience of sport for athletes with ASD. We also recently posted information about Special Olympics and ASD on our blog, if you'd like to know more.

### Canadian Autism Spectrum Disorders Alliance - National Service Needs Assessment of Individuals with ASD

The National Canadian ASD Alliance (CASDA) approached the Chair for assistance in developing a survey that they could use to better understand the service needs of individuals with ASD across the country. At the end of the project, CASDA aims to provide the Public Health Agency of Canada with a report identifying the range of services needed to adequately support individuals with ASD, as well as documents on what currently exists across the country and the current gaps impacting Canadians. We have worked collaboratively to develop the survey questions, and aim to begin data collection in 2014.

## Spectrum of Hope Autism Foundation - Therapy for Children with ASD

It's common for youth with ASD to struggle with emotional difficulties, like anxiety, depression, or anger, and this is often because of difficulties in regulating their emotions when faced with stressful situations. The Secret Agent Society program (developed by Dr. Renae Beaumont) is a cognitive behavioural social skills group that has been shown to be effective in improving the emotional understanding and social skills of children with Asperger syndrome/ASD. To further build on the Secret Agent Society program, an adaptation coined Operation Regulation aims to use a variety of activities and tools, like an emotion focused computer game, cue cards, session games, and parent and teacher handouts, to help youth with ASD cope with their emotions and handle the day-to-day stressors in their lives. We are collaborating with the creator of the Secret Agent Society, Dr. Renae Beaumont, and the Spectrum of Hope Autism Foundation to provide this therapy and evaluate its effects. We intend to use Operation Regulation to help youth who have emotional difficulties and in a preventative way, helping children become more resilient before they develop challenges. Launched in the Fall of 2013, we have had four successful graduates and aim to provide this service freely to 15 children by the end of 2014. The initiative also provides training to four Clinical Psychology graduate students, who are learning how to provide therapy to children with ASD; building capacity for trained professionals of the future.

## Geneva Centre for Autism's pilot of their Secret Agent Society

The Chair partnered with the Geneva Centre for Autism to evaluate the use of a social skills training group, Secret Agent Society, for youth with ASD. The Secret Agent Society aims to build social skills in youth with ASD in a group environment. The Geneva Centre for Autism set about running the group for the first time, and asked for help in evaluating their delivery of it and to put a process in place for ongoing program evaluation. Six youth and parents participated in the group, and youth, parent and teacher measures were completed at different time points to assess change. Parents reported significant improvements in social skills for the majority of children. We provided feedback to the Geneva Centre on how they could continue to collect data to ensure ongoing program evaluation and effective program delivery, and they are now running other groups. The project was featured in NeuroDevNet's 2012/2013 Annual Report. This collaboration was supported by a Mitacs-Accelerate Graduate Research Internship Program to Suzanne Robinson at York University, with partnership from the Sinneave Family Foundation and NeuroDevNet.

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

Transition from secondary school is one of the most stressful times in the lives of young adults, but for those with Asperger Syndrome the event is overwhelming and anxiety provoking. The intent of this project was to respond to the increasing needs of young adults in Ontario with Asperger Syndrome transitioning from the secondary school setting into independent living. There is currently a significant gap in services and supports for this population, their parents, and for the professionals that attempt to support their complex needs. Autism Ontario and Integrated Autism Services developed the Transition to Life curriculum to address this need, and approached the Chair for assistance in designing an evaluation framework. Transition to Life is a 12-week pilot/demonstration course for young adults ages 18-28 with Asperger Syndrome, providing individual support and coaching on specific needs related to the transition process, and sessions for parents to assist in the development of a plan for the future. The intent is that this course would become available for professionals and individuals with Asperger Syndrome, graduating from secondary school, throughout the country. We are currently helping to analyze the data collected to assess for participant changes in the course.

# New Sources of External Research Funding

The Chair has also been involved in obtaining new sources of research funding focussed on projects that aim to improve the mental health and well-being of individuals with ASD and their families. Most of these projects are collaborations with researchers from other institutions, and speaks to how research in this area needs to involve a team approach, if we are to conduct research that leads to informed policies and practice.

## Health Care Access Research in developmental disabilities program (H-CARDD)

**Funding Agency:** Ontario Ministry of Health and Long-Term Care Health System Research (2013 – 2016)
**Principal Investigator:** Dr. Yona Lunsky
**Co-Leads:** Dr. Robert Balogh, Dr. Barry Isaacs, B., Dr. Ian Casson, Dr. Virginie Cobigo, Dr. J. Lee, Dr. E. Lin, Dr. Lynn Martin, Dr. Hélène Ouellette-Kuntz, Dr. Simone Vigod, Dr. Jonathan Weiss

The purpose of this program is to minimize the differences in health outcomes of individuals with developmental disabilities in Ontario, including people with ASD. The newly funded phase of H-CARDD is a three-year program that will provide information about subgroups of individuals with developmental disabilities and these research findings will be used in practices in primary and emergency care. Dr. Weiss is co-lead on the project and is examining health service use of transition age youth (18-24 years of age), across the province. He and his co-lead, Dr. Barry Isaacs (Surrey Place Centre) are studying disparities between the physical and mental health of transition age youth with developmental disabilities compared to typically developing peers in Ontario, and how this relates to differences in their emergency services and psychiatric service use. We also aim to assess how ASD is related to such health and service outcomes. Our knowledge user group comprises staff from the Ontario Ministries of Community and Social Services, of Children and Youth Services, and of Education.

## Working Together to Support Transitions

**Funding Agency:** Ontario Ministry of Community and Social Services (2013 – 2015)
**Principal Investigator:** Dr. Helene Ouellette-Kuntz
**Co-Investigators:** Dr. Shira Avni, Dr. Yona Lunsky, Dr. Patricia Minnes, Dr. Jonathan Weiss

Ongoing research suggests that few families experience significant changes in services and supports within the first year of their application for Adult Developmental Services for their son or daughter with a developmental disability. This includes many adults with ASD. Family caregivers of adults with developmental disabilities in Ontario have been participating in an ongoing survey where they report on the services they need and their experiences with the service system. To read more about this ongoing research, see the Multidimensional Assessment of Providers and Systems (MAPS) website (mapsresearch.ca). The current research funding allows us to continue to follow-up with parents for an additional 12 months, to understand what happens in Year 3 of entering into the adult service system. We will explore the experiences of families both waiting and transitioning, and how best to provide better outcomes.

## Forecasting Service Needs for Youth With Autism Transitioning to the Adult Developmental Services Sector

**Funding Agency:** Ontario Ministry of Community and Social Services (2013 – 2014)
**Principal Investigator:** Dr. Helene Ouellette-Kuntz
**Co-Investigators:** Dr. Yona Lunsky, Dr. Jonathan Weiss

Effective service planning for individuals with ASD transitioning into the adult sector requires a better understanding of the proportion of youth and young adults with autism who meet service eligibility criteria, and their level of support needs. The main objectives of this study, headed out of MAPS, include the following: a) To estimate the number of youth 16–24 years of age with ASD whose families seek developmental services from the Ontario Ministry of Community and Social Services, and the proportion of those who meet eligibility criteria for those services; b) To describe the support needs of those youth; c) To develop a model to forecast their adult developmental service needs; and d) To meet with Ministry officials to discuss the feasibility of undertaking a study to validate the forecasting model.

## The SPY-ID Project: Sport Participation in Youth with Intellectual Disabilities

**Funding Agency:** Social Sciences and Humanities Research Council of Canada & Department of Canadian Heritage (Sport Canada) (2013 – 2016)
**Principal Investigator:** Dr. Jonathan Weiss
**Co-applicants:** Dr. Jessica Fraser-Thomas, Dr. Robert Balogh, Dr. Yona Lunsky, Dr. Jean Cote, Mr. Tom Davies.

This project aims to identify factors that lead to involvement and retention in sport for youth with developmental disabilities, including many youth with ASD. It is the largest federally funded project to look at sport experiences and impacts for youth with developmental disabilities in Canada. This project can lead to improvements in sport initiatives that can impact these individuals as youth and also guide their interests and activities into adulthood.

## Adding Injury to Insult: An Exploration of Risk Factors for Peer Victimization in Children with Autism Spectrum Disorder

**Funding Agency:** Social Sciences and Humanities Research Council of Canada (SSHRC) (2013 – 2015)
**Principal Investigator:** Dr. Adam McCrimmon
**Co-applicants:** Dr. Tanya Beran, M. Catherine Cappadocia, Dr. Jonathan Weiss (Co-PI)

The primary objective of this study is to develop an understanding of specific risk factors related to peer victimization (i.e., bullying) in students with ASD. Enhanced understanding of specific risk factors for peer victimization, especially in students from a population that experiences elevated incidence, can improve our understanding of bullying in the general population and result in enhanced developmental outcomes for all students. Headed out of the University of Calgary, children and adolescents aged 8-17 with ASD will attend one or two in-depth assessments to learn about their experiences from their unique perspective, and to understand what may place them at risk. The research team is also learning about this from parent and teacher perspectives.

## Mental Health Screening Tool and Mindfulness Based Supports for Students with Autism Spectrum Disorder

**Funding Agency:** Ontario Ministry of Training, Colleges and Universities (2013 - 2016)
**Principle Investigators:** Dr. Janos Botschner and Dr. Jonathan Weiss
**Co-investigator:** J. Hamilton Wilson

Ontario's post-secondary education system faces considerable challenges as it seeks to address the risks of poor academic achievement for students with ASD who experience concurrent mental health issues. The goals of this project are to develop, pilot, and evaluate a risk-based approach for engaging, screening, and supporting post-secondary students with ASD who are experiencing mental health issues. Specifically, we will develop and evaluate a campus-based early mental health intervention for individuals with ASD involving: a student engagement process; a rapid screening tool; and the delivery of a program of mindfulness based training and support. We anticipate that this intervention will lead to: enhanced coping skills; an amelioration of psychiatric symptoms; and an expansion of opportunities for the experiences of natural support; which will contribute to improved academic performance and retention.

# Knowledge mobilization

The Chair's mandate includes making research on mental health accessible, and 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

Research findings have the greatest impact when they are accessible, and in line with CIHR's Open Access policy, and we have been posting many of our research publications online, in open access repositories. For instance, on the York University open access repository, YorkSpace, the Chair's research studies have been viewed 567 times and downloaded 1332 times in 2013. In 2013, Dr. Weiss was involved in 6 peer reviewed publications, described below. There are also a number of manuscripts under review and that will come out in 2014 based on the research that occurred in 2013.

A number of the publications came from a completed research project understanding the experience of families who provide care to individuals with ASD or intellectual disabilities, funded in part through a New Investigator Fellowship from the Ontario Mental Health Foundation.

Weiss, J. A., Wingsiong, A., & Lunsky, Y. (in press). Defining crisis in families of individuals with Autism Spectrum Disorders. Autism: International Journal of Research and Practice.

> Parents of children diagnosed with ASD often report higher levels of depression, anxiety, and mental health–related issues compared to parents of children with other disabilities. Sometimes, these experiences can lead to crisis in the family, and understanding this event is important to mental health practice, since it can serve as a guide in delivering service to at-risk families. This study investigated the subjective experience of crisis in 155 mothers of people with ASD, and found that crisis is characterized by factors influencing four major areas: demands, internal capabilities, external resources, and subjective appraisal. Understanding what crisis means to families of individuals with ASD can help inform effective preventative and crisis services.

McMorris, C., Weiss, J. A., Cappelletti, G., & Lunsky, Y. (2013). Family and staff perspectives on service use for individuals with intellectual disabilities in crisis. Journal of Mental Health Research in Intellectual Disabilities, 6(1), 14-28.

> Caregivers of individuals with intellectual disabilities are often responsible for managing psychiatric crises if it occurs. The purpose of this study was to examine the experiences of families who use crisis and short-term transitional supports from the perspectives of families and of support staff. Families and staff spoke about their positive and negative experiences in seeking support, the staff characteristics that enabled these positive experiences, the challenges they encountered with crisis and transitional support services as well as the general service system, and the impact of service limitations.

Weiss, J. A., Robinson, S., Fung, S., Tint, A., Chalmers, P., & Lunsky, Y (2013). Family hardiness, social support, and self-efficacy in mothers of individuals with Autism Spectrum Disorders. Research in Autism Spectrum Disorders, 7, 1310 – 1317.

> Family hardiness is an important construct in order to understand coping in parents of individuals with ASD, who are often at risk for considerable distress in the face of multiple stressors. This study examined family hardiness, perceived social support and parent self-efficacy as predictors of family distress in 138 mothers of individuals with ASD, 4–41 years of age. We demonstrated that perceived self-efficacy and social support mediated the link between the accumulation of stressors and family hardiness, and that hardiness was a partial mediator in explaining how stressors were associated with family distress. This study demonstrated just how important social support and empowerment are for families to remain resilient in the face of stressors.

## Other publications involved evaluating community-based services for individuals with ASD or discussing service policies and practice.

Weiss, J. A., Viecili, M., Sloman, L., & Lunsky, Y. (2013). Direct and indirect psychosocial outcomes for children with Autism Spectrum Disorder and their parents following a parent-involved social skills group intervention. Journal of the Canadian Academy of Child and Adolescent Psychiatry, 22(4), 303-309.

> This study examined the direct and indirect outcomes of a social skills group intervention for children with high functioning ASD and their parents. Thirty-five children and their parents participated in the program evaluation. Children and parents completed measures of child social skills and problem behaviours. Children reported on their self-concept, and parents reported on their psychological acceptance and empowerment. Results indicated significant increases in overall child social skills according to parent and child report, in child general self-worth, and in parent service empowerment and psychological acceptance. This study was funded by a grant from the Provincial Centre of Excellence at the Children's Hospital of Eastern Ontario, and was meant to help bring in a process of program evaluation, so that the social skills program could continually monitor their service delivery.

Villeneuve, M., Chatenoud, C., Hutchinson, N. L., Minnes, P., Perry, A., Dionne, C., Frankel, E. B., Isaacs, B., Loh, A., Versnel, J., & Weiss, J. (2013). The experience of parents as their children with developmental disabilities transition from early intervention to kindergarten. Canadian Journal of Education, 36(1), 4-43.

> Recent research suggests that the transition process is critical to the early school experiences of children with developmental disabilities, yet challenging for their parents. This research was conducted by a CIHR Emerging Team Grant project called HELPS Inc. (Health, Education, and Learning Partnerships for Social Inclusion), a research group that studies the transition experiences of young children with developmental disabilities (including ASD) as they transition from early childhood service contexts into school. The data demonstrate the unique experiences and meanings of collaboration held by families, and highlight the challenges these differences pose for healthcare providers and educators who are committed to involving parents in the transition process.

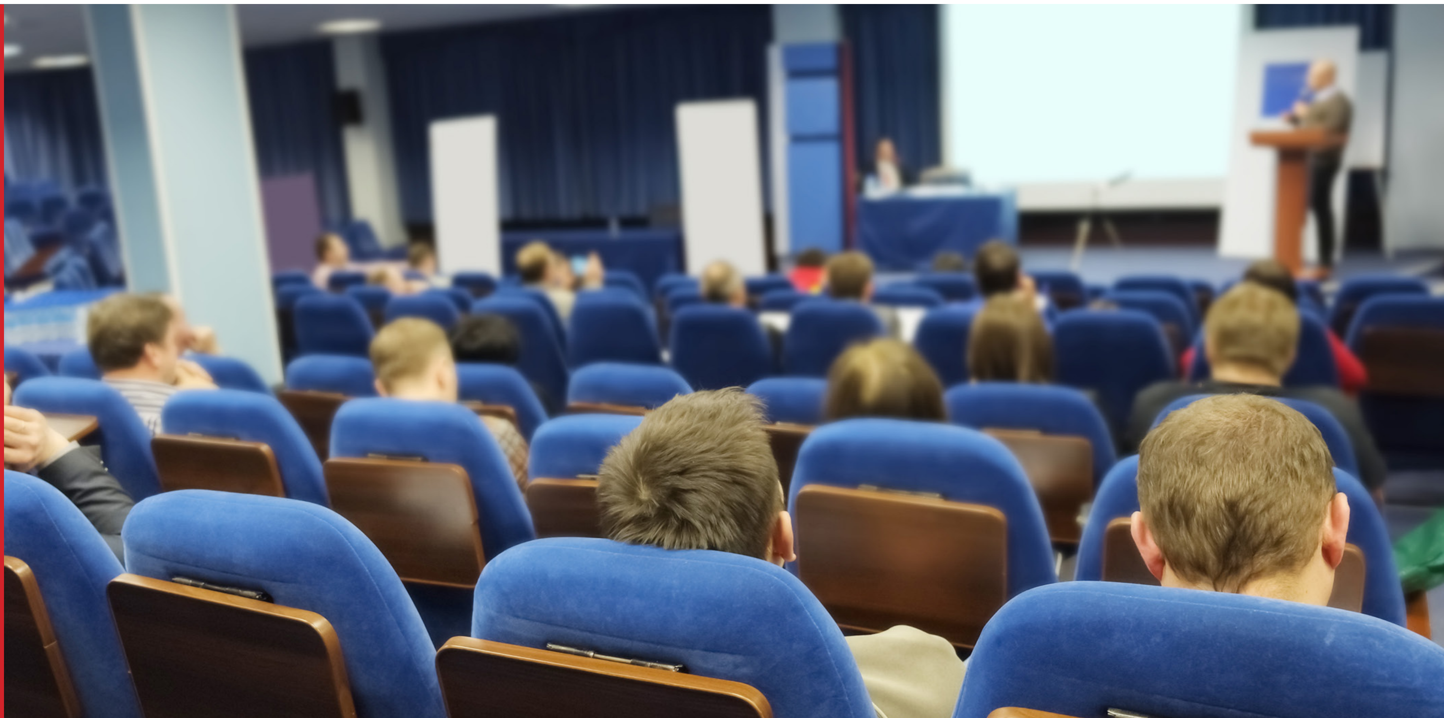
Lunsky, Y., Lake, J. K., Balogh, R., Weiss, J., & Morris, S. (2013). A review of Canadian mental health research on intellectual and developmental disabilities. Journal of Mental Health Research in Intellectual Disabilities, 6(2), 106-126.

> This article reviewed Canadian research that involves individuals with "dual diagnosis"; defined as having a developmental disability and mental health problem. The review spanned the past 20 years of research, and placed it within a historical and policy context. Canadian researchers have made important contributions with regard to understanding inpatient and outpatient mental health services, families, ASD, specific disorders and behaviours, aboriginal mental health, forensics, and emergency services. Following a summary of the studies, the authors offer some suggestions and directions for future research in Canada.

# Conference Presentations and Posters

The Chair's research collaboration resulted in 19 presentations at peer reviewed, scientific conferences in the last year. More specifically, this included 17 poster presentations and 2 paper presentations at American Association on Intellectual and Developmental Disabilities Conference, Ontario Association on Developmental Disabilities (Research Special Interest Group Conference), International Meeting for Autism Research, Society for Research in Child Development, Research in Child Development Conference, Health and Well-being in Developmental Disabilities Conference, and the Autism Community Training Annual Conference. Involved in these presentations were 4 graduate students and 2 postdoctoral fellows who received travel funding from the Chair to present this research. Here is just a sample of the topics that were covered in these presentations:

- Child, parent, and systemic correlates of comorbid anxiety and depression in adolescents and adults with ASD
- Barriers to care for families of youth with ASD and depression
- Antipsychotic medication use in adolescents and adults with ASD
- Mental health services for youth with severe developmental disabilities
- Investigating predictors of depression in individuals with ASD: Caregiver distress, negative life events, and ASD diagnosis
- Suicide attempts in adults with Asperger Syndrome
- Bullying experiences in children and adolescents with ASD
- Sexuality in ASD: Knowledge, perceptions, and experience
- Photo-elicitation study of Special Olympics participation
- Understanding crisis in mothers of children with ASD
- Parent perceived support, coping, mastery, and well-being
- Prevalence and types of significant life events experienced by adults with ASD
- Emotion regulation in individuals with ASD



# Presentations/Workshops to Non Academic Audiences

Dr. Weiss has given 12 talks about mental health and ASD over 2013, 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, many of which you can view online:

## A review of the research on mental health problems in youth with ASD, and the need for a mental health promotion framework

Presented at the Western University Autism Centre of Excellence Distinguished Lecturer Series (London, ON). Dr. Weiss provided a review of the research that looks at estimates and correlates of mental health problem in individuals with ASD to 80 clinicians, to help them further understand why so many youth with ASD struggle with emotional difficulties, and what we can do to promote wellness and resilience.

## Emergency services, hospitalizations, and mental health care for adolescents and adults with ASD

Presented at the Autism Community Training Annual Conference (Vancouver, BC). Dr. Weiss presented preliminary findings from a CIHR-funded study on the health and service use in adolescents and adults with ASD in Ontario to over 200 researchers, family members and clinicians. Dr. Weiss emphasized the importance of understanding the individual, family, and larger social and ecological factors when studying mental health, care, and emergency service use.

## Mental health & ASD: The importance of healthy relationships

Presented at the Kids Ability Annual Conference (Waterloo, ON). Dr. Weiss spoke to over 400 parents, caregivers, and clinicians about the importance of health relationships in helping youth with ASD develop resilience and reduce the risk of mental health problems.

## Bullying strategies for youth with ASD

Presented at an Autism Ontario webinar (Toronto, ON). Children with ASD often experience bullying at school, and it is important that parents and professionals work together to address this problem. This webinar reviewed ways of supporting youth who are experiencing bullying to increase their coping skills and to help stop the problem from happening in the future. Effective interventions require knowledge and a team approach, and this workshop discussed what children can do, and what adults can do, to make everyone feel safer.

## Understanding and addressing mental health problems in children and youth with Autism Spectrum Disorders

Keynote address at the Geneva Centre Summer Training Institute (Toronto, ON). Dr. Weiss summarized up-to-date research findings on the rates, presentations, and impacts of mental health problems in children with ASD; risk factors related to mental health problems (especially bullying); and assessment and treatment of these individuals. The conference was focused on educators, and Dr. Weiss reached over 2000 educators from across the province.

## ASD and Mental Health: Journalist workshop

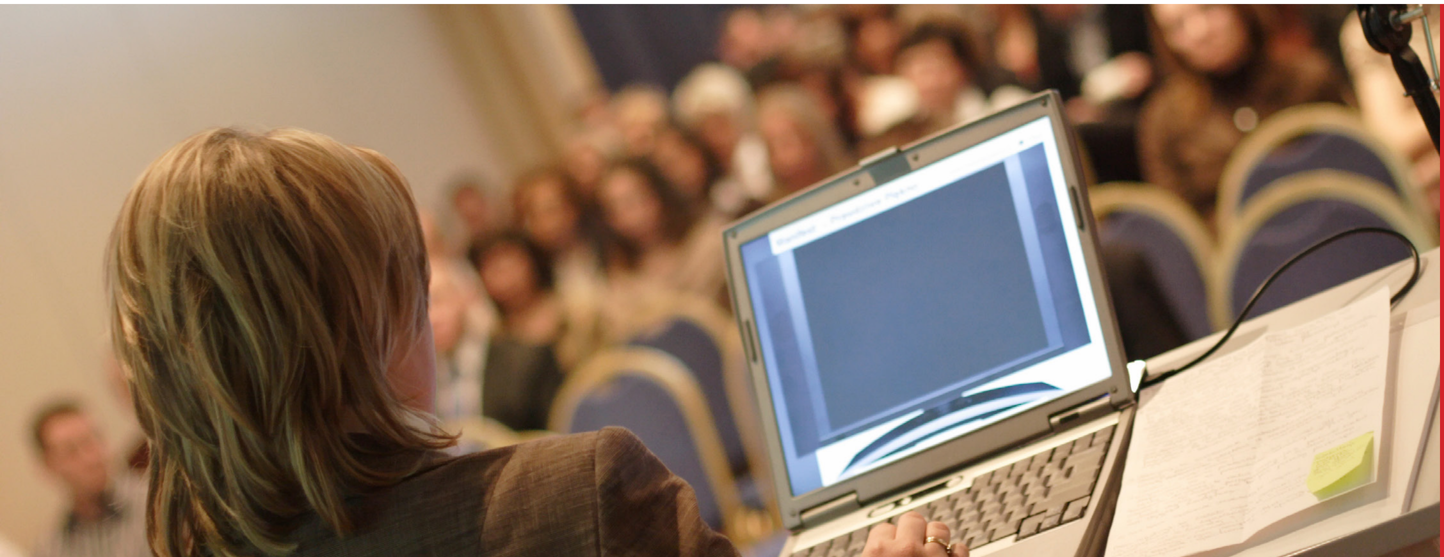
Invited Speaker at the CIHR Journalist Workshop, CIHR Communications and Public Outreach branch and the Institute of Human Development, Child and Youth Health (Toronto, ON). Dr. Weiss spoke about the importance of promoting mental health in individuals with ASD.

## Don’t push me around! Limiting the causes and consequences of bullying

Panel Speaker at CIHR Cafe Scientifique (Toronto, ON). Dr. Weiss spoke about the impact of bullying on youth with ASD.

## Health and well-being of youth with intellectual disability who participate in Special Olympics in Ontario

Presented at a CARE-ID webinar (Toronto, ON). Dr. Weiss provided a webinar to clinicians and researchers who work with individuals with ASD and intellectual disabilities across the country. Participation in sport is an important activity for youth with and without disabilities and is linked to numerous benefits. Youth with intellectual disabilities, who represent approximately 2% of the Canadian population, continue to struggle to access typical recreational, leisure, and social activities. Studying programs that involve youth with ASD and intellectual disabilities in sport can be a useful way to identify factors that contribute to their health and well-being. This presentation examined the psychosocial correlates of youth physical and mental health problems.



# Online research posting: The ASD Mental Health Blog

Stemming from recommendations from the initial Stakeholder Advisory Day in January 2013, we launched the ASD Mental Health Blog as a way to keep families, service providers, and individuals with ASD informed about research into ASD and mental health. The purpose of the Blog is to make knowledge accessible - not simply about showcasing the research from the Chair. The tags that often come up in the posts speak to the topics that we cover, such as therapy for anxiety and depression, risk factors for mental health problems, parent/caregiver support, mindfulness, sexuality, bullying, lifespan issues, and service use. The Blog can also be followed on Twitter and Facebook. We create a new post every 2 weeks and will continue to do this throughout 2014. Our Blog was also featured in the ResearchImpact blog for its innovated use of social media to make research accessible.

## We've divided the Blog into different sections:

### In the News and Conferences:

These posts link to news pieces (videos, online articles, radio) about events related to ASD. This includes events such as 'World Autism Awareness Day' and news articles related to prevalence rates and ASD, and so far we've uploaded 6 news posts. We also try to post about upcoming ASD conferences.

### Research Summaries:

Based on the well respected Research Impact summary format, we select peer reviewed published research studies and summarize them in two pages, noting the take-home message, the methods used, the main results and how the knowledge can be used. In 2013, we posted 15 research summaries, which can be downloaded and shared freely.

### Videos:

We've also posted 7 research-related videos on the Blog, which range from 2 minutes to over 2 hours, depending on the content. An example of a short clip is an animated StoryCorps video in which a youth with ASD interviews his mom about parenting. Longer videos include recordings of Dr. Weiss discussing bullying and mental health problems in youth with ASD, as well as a video from a half-day workshop on ASD and Sexual Safety, which was supported by the Chair, and run by Michelle Viecili and Stephanie Brown, two graduate students in our Department of Psychology at York University.

### Editorials:

We've also produced a number of editorials that focus on research findings and resources related to ASD and mental health. The editorials cover topics such as family caregivers, sexuality, mindfulness and emergency services. In 2013, we posted 7 editorials.

# Teaching and training

Part of the Chair's mandate is to support the next generation of ASD researchers in this area. In 2013 the Chair began funding two postdoctoral fellows and a number of graduate students:

- Dr. Priscilla Burnham Riosa (PhD, BCBA-D, University of Guelph). Dr. Burnham Riosa's research interests are in understanding the impact of ASD on the individual, the family, and other social contexts. During her postdoctoral fellowship, 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 navigate the unwritten rues of social interaction.

- Dr. Kendra Thomson (PhD, BCBA-D, C. Psych Candidate, University of Manitoba). Dr. Thomson has previously conducted research evaluating a self-instructional manual for teaching direct-care staff how to conduct discrete-trials teaching in an early intervention program for children with ASD. Under the supervision of Dr. Weiss, she is examining the effectiveness of a manualized emotion regulation intervention, the Secret Agent Society: Operation Regulation intervention, which is designed to improve the emotional understanding and social skills of children with ASD.

- Victoria Ting entered the Clinical-Developmental Psychology graduate program at York University in September 2013 under the supervision of Dr. Weiss, and her research is funded by the Chair and an Ontario Graduate Scholarship. She is interested in the effect of parental co-regulation on children's emotion regulation skills and physiological arousal. She will also be looking at the relationship between child emotion regulation and internalizing/ externalizing problems (e.g. anxiety, hyperactivity).

Two of Dr. Weiss' students defended their Master's theses in the summer of 2013, and are continuing on to complete their PhD in Clinical Developmental Psychology:

- Stephanie Fung's thesis used the diathesis-stress model to investigate stressors (such as parent distress and negative life events) and vulnerabilities (child age, ASD diagnosis, and intellectual functioning) as predictors of depression in youth with ASD. Suzanne Robinson's thesis explored experiences of burden in parents applying for developmental services for their adult son or daughter with developmental disabilities. Specifically, the research focused on the various sources of social support that parents find helpful and may reduce the experience of parental burden while waiting for adult services.

Two additional research assistants also began working with the Chair program in the last year:

- Lisa Chan (MA, OISE, University of Toronto) has been a Research Assistant for Dr. Weiss since January 2013. Working for the Chair has provided Lisa with the opportunity to help develop and coordinate clinical research on cognitive behavioural therapy treatments for children/youth with ASD that target anxiety disorders and emotion regulation skills. She is helping with the administration and scoring of standardized tests, conducting interviews with parents and children, and developing and maintaining datasets. She has also conducted a literature review with Dr. Weiss that was presented at the Health and Well-Being in Developmental Disabilities Conference, and the results of the review are currently being written up as a manuscript for publication.

- Casey Fulford started working as a Lab Coordinator and Research Assistant for Dr. Weiss in May 2013. She recently completed her undergraduate degree in Psychology and intends to continue on with graduate school in clinical psychology. Working for the Chair has provided Casey with many opportunities to be involved in studies and hone her research skills, including administration and scoring of standardized tests, conducting intake interviews with parents, and developing a research poster for a conference. She is also gaining experience working with individuals with ASD.

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