## ABSTRACTS FROM THE 2015 RSIG RESEARCH DAY THOROLD ON, APRIL 17 – PRESENTATIONS

## Dimensions of Treatment Quality and Their Relation to Child Characteristics and Outcomes

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### Objectives

Intensive Behavioural Intervention (IBI) is the treatment of choice for young children with autism spectrum disorders, however outcomes are variable. This variability may be due to child, family, and treatment factors. Research has focused on treatment quantity with little attention given to quality, in part because it is difficult to measure. The York Measure of Quality of IBI (YMQI; Perry, Flanagan, & Prichard, 2008) is the only systematic measure used to define and evaluate the quality of IBI, based on video segments of children engaged in IBI. A recent study showed good psychometrics of the measure overall, however indicated that the YMQI may be measuring different dimensions of quality (Blacklock, Shine, & Perry, 2013). Our most recent poster (Blacklock, Taheri, & Perry, 2014) presented an exploratory factor analysis of the YMQI which revealed four factors: Pace and Organization; Engagement and Motivation; Technical Correctness; and Generalization. Next, we will explore how these different aspects of IBI quality change over approximately one year in treatment, as well as how they relate to child characteristics at the start of IBI and after one year of intervention.

### Methods

As part of a larger IBI study (Perry, Dunn Geier, & Freeman, in preparation), 402 monthly videos of 38 children were coded using the YMQI. Subscale scores based on the above-mentioned factors will be calculated. We will graphically examine how these subscale scores change over one year. We will also examine the relationship between initial child characteristics (age, autism severity, cognitive and adaptive level) and treatment quality subscale scores. Next, we will explore the relations of the subscale scores to children's outcomes (cognitive and adaptive skills, and autism severity at outcome, as well as cognitive and adaptive rates of development during IBI). Finally, regression models with interaction terms will be estimated in order to examine how the interactions of the YMQI subscale scores with child characteristics at the start of IBI are related to children's outcomes.

### Results

By examining the subscale scores of the YMQI across time, we will explore which aspects of IBI quality show drift, improvement, or stability over one year. By examining the relationship of the subscale scores to child characteristics at the start of intervention, we will explore whether children with different characteristics receive treatment that is focused more on specific aspects of quality. Finally, we will explore whether these relationships, and whether intervention focused on specific aspects of quality, leads to different outcomes.

### **Discussion/Conclusions**

The quality of IBI is very rarely examined, and has not been looked at across time in a treatment program. This research will be the first to do so and to examine the relationship between aspects of IBI quality to child characteristics at the beginning of IBI as well as their outcomes after approximately one year of intervention. This research will have implications for IBI training and supervision and will inform future research on the quality of IBI.

# Getting Enough Supplements? A Preliminary Study on Treatment Response in 22Q11.2ds-Related Hypocalcemia

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### Objectives

Hypocalcemia is highly prevalent in 22q11.2 deletion syndrome (22q11.2DS), the second most common genetic cause of developmental delay after Down syndrome. Hypocalcemia in 22q11.2DS is generally the result of inadequate parathyroid hormone secretion, but low levels of magnesium and/or hypothyroidism may also be relevant. The presentation of hypocalcemia varies from symptomless to life-threatening situations such as serious cardiac arrhythmias and tonic clonic seizures. Common symptoms include fatigue, emotional irritability, tingling, carpopedal spasm and abnormal involuntary movements. Hypocalcemia is treatable with vitamin D, calcium, with/without magnesium supplementation. However, to the best of our knowledge, treatment response in 22q11.2DS has not been studied.

### Methods

We reviewed medical records of 72 adults with a confirmed 22q11.2 deletion and a history of hypocalcemia. We selected 22 patients (15 female, 7 male; mean  $\pm$  SD 31.0  $\pm$  8.8 year); full scale IQ (FSIQ) mean  $\pm$  SD 69.4  $\pm$  10.5) with documentation in our records of at least 1 calcium assessment < 1.12 mmol/L ever. Subsequently, we checked "last visit" laboratory pH-corrected ionized calcium (calcium) levels as an indicator of treatment response. We correlated calcium levels with FSIQ, and with "last visit" intact parathyroid hormone (PTH), thyroid stimulating hormone (TSH) and magnesium levels. Patients were excluded from the study when laboratory results were > 5 years ago. We used parametric tests. All analyses were two-tailed and performed using SPSS; p values < 0.05 were considered significant.

### Results

All 22 patients were recommended to take supplements; vitamin D (n = 22), calcium (n = 21) and magnesium (n = 6). 14 out of 22 adults with previous calcium levels < 1.12 mmol/L also demonstrated "last visit" calcium levels < 1.12 mmol/L (mean  $\pm$  SD 1.10  $\pm$  0.07). No significant correlations were found between calcium levels and FSIQ, levels of PTH, TSH, or magnesium.

### Discussion/Conclusions

These preliminary data suggest that many adults with 22q11.2DS and hypocalcemia are not achieving normalization of calcium levels. Future research, including assessments of compliance with treatment and dosages of supplements, is necessary in formulating recommendations and long-term care plans for patients with 22q11.2DS.

# A Family-Researcher Partnership: Behind the Scenes of the "F-words" in Childhood Disability Integrated Knowledge Translation Journey

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### Objectives

In 2012, Drs. Rosenbaum & Gorter published: "The F-words" in childhood disability: I swear this is how we should think!" Transforming the World Health Organization's (WHO) ICF Framework into a fun and memorable framework, the article highlighted six factors important to ALL children's development - Function, Family, Fitness, Fun, Friends, and Future. Unbeknownst to the authors at the time of publication, the "F-words" would soon begin to capture the attention of families, practitioners, and researchers around the world. The objective of this poster is to take you behind the scenes of the "F-words in Childhood Disability" Knowledge Translation (KT) journey thus far and to explore how an integrated team of families and researchers are working together to move the "F-words" concepts into practice.

### Methods

Since the "F-words" paper first appeared, it has been downloaded > 790 times and presented at > 30 local, national, and international meetings. Although these diffusion strategies are useful for targeting the scientific community, additional KT strategies are needed to capture the attention of a broader audience. In early 2014, we formed an integrated "F-words in Childhood Disability" research team with the goal to spread awareness of the "F-words" ideas to potential knowledge users - especially families and practitioners. Our first project included the development, implementation, dissemination, and evaluation of a family-centred "F-words" awareness video. The project followed a formalized multi-staged KT process and was carried out over a five-month time period. The video, posted on the CanChild website, used written descriptions, parents' reflections, pictures, music, and graphics to captivate the audience. Various dissemination/publicity strategies (i.e., emails, social networks, etc.) were utilized to distribute the video. The video was evaluated over a twomonth period by tracking the number of views and through an online survey. Subsequently, the team has presented at five conferences and the video has been entered into the CIHR IHDCYH Talks Video Competition.

### Results

After the initial two-month evaluation, there were 715 views and 137 survey responses. Of the survey responses, 89% lived in Canada, 55% had not previously heard of the "F-words," 98% "extremely liked"/"liked the ideas," and 88% indicated they would share the video. The video is still posted on the CanChild website (www.canchild.ca) and currently has > 990 views on YouTube. In the CIHR IHDCYH Talks Video Competition the video received a total of 1,697 views and 290 likes in one month.

### **Discussion/Conclusions**

Creating an online video was only the first step in moving the "F-words" into practice. As a feasible and low cost project, the video allowed us to spread awareness to a wide audience, inspire new ideas, and gather insight into the reception of the "F-words" concepts, before undergoing a larger KT initiative. Engaging families throughout the project was critical to the success of our work. Families are the experts in their children's lives and we encourage practitioners and researchers to work with families as equal partners.

### Health Profile of Transition Age Youth With Developmental Disabilities

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#### Objectives

Individuals with developmental disabilities (DD) often have complex health needs, and experience difficulty in accessing appropriate services. While there is a growing literature on these issues with respect to adults with DD, few studies have focused on transition age youth (TAY), who are moving from the child to the adult system. The current study examines the demographics and incidence of health conditions of TAY with DD compared to a random sample of TAY without DD.

### Methods

Health Care Access Research in Developmental Disabilities (HCARDD) is an ongoing collaborative program developed to address disparities in health status and health care access faced by individuals with DD in Ontario, Canada. The current study analyzed data from a sample of 15,980 Ontarians with DD ages 18-24 years. The sample was derived from a larger cohort of 66,484 individuals with DD ages 18-64 as of April 1, 2009, constructed by linking Ontario administrative health data held at the Institute for Clinical Evaluative Sciences and social services data held by the Ontario Ministry of Community and Social Services. The comparison sample is a 20% random sample of Ontarians without DD ages 18-24 years (N = 393,263). Descriptive statistics was used to compare the demographics between the two groups. Logistic regression was used to compare the groups on incidence of mental health or addictions diagnoses. Groups were also compared on a measure of overall morbidity (Resource Utilization Band) that sorts people into five categories ranging from "healthy" to having "high morbidity."

### Results

As a group TAY with DD were more likely to be younger, male, and live in poorer neighbourhoods and less likely to live in urban areas compared to TAY without DD. Over forty-four percent (44.5%) of TAY with DD compared to 21.1% without DD had a psychiatric or substance abuse diagnosis (OR = 2.97, p < 0.001). On the measure of overall morbidity TAY will DD were more like to fall into the moderate, high and very high morbidity categories and less likely to fall into the healthy and low morbidity categories compared to those without DD, d = 0.43.

### **Discussion/Conclusions**

Transition age youth with DD have greater health and mental health needs compared to their same age peers. These differences are important to understanding their health care access needs.

# Interprofessional Education and Practice in Developmental Disabilities and ASD: From Classroom to Community at Queen's University

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#### Background

With the deinstitutionalization movement in Canada, health care professionals are caring for a greater number of individuals with intellectual disabilities (ID) in their practices, and inevitably require additional training to provide this care. At Queen's University, the Division of Developmental Disabilities, has responded to this need, developing innovative educational curriculum promoting interprofessional education (IPE) and collaborative practice (IPC) as it relates to ID curriculum and health care provision. A developmental curriculum was provided across three teaching initiatives to graduate health care students by facilitating an introduction, exposure, experience and advanced practice in ID and ASD. Evaluation was collected across all three courses and research conducted on the introduction to ID course.

#### Objectives

The overarching curriculum purpose was threefold (1) to foster IPE learning across and within disciplines; (2) develop awareness and benefits of IP collaborative client-centred practice; and (3) to provide consumer exposure and engagement with individuals with ID and ASD. The purpose of this study was to measure health care students' change in knowledge, skills and attitudes towards individuals with ID and how it affects their readiness for interprofessional care. The research was targeted at graduate students from the fields of medicine, nursing, clinical psychology and rehabilitation (i.e., occupational therapy and physiotherapy).

#### Methods

Course curriculum was developed using a blended teaching approach with a combination of online learning, lectures, team-based problem solving and client interviews. Research was completed on 247 learners utilizing a prepost course questionnaire addressing content areas of knowledge, skills and attitude and by analyzing individual professional differences.

#### Results

Significant differences were found indicating improvements in student knowledge and skills for the majority of disciplines after course participation. A positive trend was found in outcome responses for student attitudinal change ranging from neutral to positive attributions about individuals with ID.

#### **Discussion/Conclusions**

This paper outlines improvements in student learning and positive attitudinal change following an educational course concerning optimal health care and collaborative practice in intellectual disabilities. It is proposed that an interprofessional blended training curriculum for future health care professionals can foster best practice and quality service for this currently underserved population.

# ABSTRACTS FROM THE 2015 RSIG RESEARCH DAY THOROLD ON, APRIL 17 – POSTERS

# Family Support in the Democratic Republic of the Congo: Existing Strengths and Hopes for the Future

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### Background

Family support is professional help or more informal assistance that responds to families' emotional, financial, informational, and logistical needs, and is intended to enhance the quality of life of the family member with a disability and the family unit.

### Objectives

This study sought to answer the questions: (a) What is a local example of an entity that provides effective and meaningful support to families who have a member with IDD in Kinshasa? and (b) what makes this support effective and meaningful?

### Methods

For seven months, the senior author engaged in participant observation in the homes of families that have members with IDD, during family self-help association meetings and activities, and in the wider communities in which these families function (e.g., markets, workplaces, special schools, and physical therapy clinics often frequented by the families). We also conducted semi-structured interviews with 14 family members affiliated with family support associations.

### Results

Using data from participant observation field notes and semi-structured interview transcripts, we (a) describe ANAPEHMCO, a family self-help association in Kinshasa, Democratic Republic of the Congo (DRC), (b) classify the nature of the support provided by this organization, (c) show how this support is effective and meaningful for families, and (d) discuss how associations such as the example provided can be particularly valuable for supporting individuals and families in conflict, post-conflict, or developing contexts.

### **Discussion/Conclusions**

Families themselves are often the first creators and providers of family support in conflict and post-conflict contexts, where state priorities for family support are often low or non-existent. As nations develop and begin to structure formal state programs for family support, they would be wise to partner with families to draw upon their experiential knowledge in delivering family support.

# Personal Response to Qualitative Data on Canadian and South Asian Mothers Raising a Child With a Developmental Disability

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### Objectives

In the past, I (Nilani) have had many opportunities to volunteer with children with autism and I have developed an interest in learning more about autism and other developmental disabilities. For the purposes of a third-year year project course at McMaster University entitled "HTH SCI 3H03 - Inquiry," I decided to pursue a project that is related to this domain. This past year, I have assisted Nidhi Luthra with data collection and data entry for her dissertation entitled: "Experience of South Asian Immigrant and Canadian Mothers of Children with a Disability." The goal of my project is to compile and analyze my reflections and responses to the different themes I have encountered while transcribing the in-depth interview component of the study. This poster will present some themes from what the mothers said but will focus mainly on my personal responses to these mothers' stories.

### Methods

"Experience of South Asian Immigrant and Canadian Mothers of Children with a Disability" is an ongoing mixed-methods study that consists of two components: a quantitative questionnaire and qualitative in-depth interviews. The data collection for this study is ongoing. Thus far, I have been able to complete reflections on 15 interviews with mothers. It is expected that there may be more interviews by April.

### Results

As of now, I have been able to identify themes such as concern for the future, financial issues, struggles navigating the system, the symbiotic relationship between mothers and their children, positive and negative cultural impacts, etc. These themes have served as inspiration for my reflections and I hope to identify more themes as data collection continues. I have been both surprised and saddened by some things the mothers have expressed, but also inspired by their resilience.

### **Discussion/Conclusions**

The poster will elaborate on the themes I have been able to identify through the data collected from the interviews and my own personal reflections and responses to these themes.

## Living With A Sibling Diagnosed With Fetal Alcohol Spectrum Disorder

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### Objectives

The purpose of this study is to explore the world of individuals living with a sibling who has been diagnosed with Fetal Alcohol Spectrum Disorder (FASD). More specifically, this research will be examining the relationship quality in terms of attitudes or behaviours exhibited towards the sibling with FASD and the coping mechanisms used by these siblings. Although some research has looked at siblings of children with ASD or other disabilities, to date there has been a gap in the literature regarding siblings of a brother or sister diagnosed with FASD. Studies that have examined the sibling's experience in other long term diagnoses have been inconsistent in terms of findings, with few sibling interviews conducted. Additionally, it has been reported that in adulthood, many sibling anticipate greater caregiving responsibilities of their sibling with a developmental disability as their parents age (Greenberg et al., 1999; Krauss et al., 1996) and take on the role of primary caregivers once parents are no longer able to do so (Bigby, 1997). That said, this study will allow siblings to express their concerns in order to establish where siblings are struggling and where they are flourishing in order to better tailor supports for families.

### Methods

Twenty siblings without FASD will be asked to participate in a semi-structured qualitative interview through the use of art-based methods (Gauntlett 2007; Gross & Hayne, 1998), more specifically a family totem pole. This activity will shed light on family relationships while allowing art to mediate their experience as siblings of individuals with FASD. Interviews will be analyzed using the interpretive phenomenological analysis (IPA; Shaw, 2010). Additionally siblings who do not have FASD will be asked to fill out 2 scales, the Sibling Inventory of Behaviour Scale (Hetherington, Henderson & Reiss, 1999) and the Siblings Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006). These scales will be used in conjunction with the interview in a mixed methods approach to gain a better knowledge of siblings' relationship quality, coping and adaptation, as well as their daily stressors.

### Results

Data collection is ongoing, so results can only be hypothesized at the time of abstract submission. Some previous siblings researchers have found that non-affected siblings report negative experiences (Neely-Barnes & Graff, 2011; Wilson et al., 1992), while other studies have found that non-diagnosed siblings look at their relationship positively (Hodapp & Urbano, 2007; Kaminsky & Dewey, 2001, 2002). Research with parents of children with FASD have identified numerous stressors (Watson et al., 2013), but parents also speak positively about their experiences parenting a child with FASD. As our study is exploratory in nature, we expect to see a mix of both positive and negative statements related to their experience and the richness of the interview data will help to clarify this experience.

### **Discussion/Conclusions**

This study will allow clinicians to tailor supports and provide siblings with the tools to create mutual growth and development, as they will be most likely be a long-term caregiver for their sibling with a disability.

## **Curriculum of Caring: A Pilot Study**

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### Objectives

Recent research has shown that medical students' empathy and compassion decline throughout their training, resulting in detachment, worsened medical outcomes, and increased likelihood of burnout. The following study examined whether certain educational methods stimulated students to approach and communicate more attentively and engagingly with patient educators (PEs) in a mock clinical setting, specifically PEs affected by developmental disabilities (DD). The focus on DD stemmed from the comorbidities, stigmas, and communication barriers experienced by this population, and the overall suboptimal care it receives. More broadly, the study sought to create a more positive culture around DD, and provide PEs with relevant lived experience an opportunity to participate in innovative research.

### Methods

First-year students were recruited via email from the DeGroote School of Medicine (n = 27; mean age =  $23.1 \pm 3$ , [20-37]) and randomly assigned to either control or intervention groups. The control group (designed to mimic traditional, didactic methods) received an introductory lecture about caring for individuals with DD, followed by a retention-based quiz. The intervention group received the same introductory lecture, followed by two videos of individuals affected by DD talking about their lives and healthcare needs, and concluded with a reflective writing and discussion activity. It was hypothesized that exposure to and reflection upon these stories would serve as an emotional primer to foster empathic and imaginative thought, and in turn more person-centred behaviours in clinical encounters. All students then circulated through four stations, each designed around a particular PE: two with mild intellectual disabilities; a mother of a child with DD; and one affected by autism spectrum disorder and bipolar disorder. In each station, students conducted a brief (~10 minute) interview, after which they completed self-evaluations, were evaluated by the PE (and their caregiver, where applicable), and also by a third-year medical student acting as an objective rater (all using six-point Likert scales). The evaluations measured attributes such as professionalism, attentiveness, engagement, and responsiveness.

### Results

Initial descriptive analyses revealed slightly higher scores in the intervention group across all measurements: self-evaluations (4.49 versus 4.37), objective rater (5.01 versus 4.75), PE ratings (5.44 versus 5.33), and caregiver ratings (5.35 versus 5.28). In addition, students in the intervention group showed greater increases in self-reported measurements of comfort (27%), competence (80%), and confidence (56%) in working with individuals affected by DD, as indicated by pre- and post-session questionnaires. The control group, in comparison, showed more modest increases (15%, 42%, and 19%, respectively). It is unclear whether observed differences are significant, as inferential analysis is currently underway.

### **Discussion/Conclusions**

The current study found (1) more reflective, discussion-focused exposure to DD (i.e., intervention group) appeared to lead to higher performance on interviews in a simulated clinical setting; (2) marked increases in self-reported measurements of comfort, competence, and confidence following encounters with PEs; and that (3) participants consistently described their experience as meaningful and valuable. It is hoped that subsequent research could further develop these teaching models within a larger sample, as well as establish a more inclusive culture around developmental disabilities.

# Fiction as a Research Method: A Short Story of Life in Residential Group Homes Used to Generate Interdisciplinary Discussion

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Objectives

Using a work of creative fiction this piece intends to challenge the dominant academic journal with its use of accessible plain language. A piece of writing born in the narrative of one person of support revolving around the impressions made in the first days of work and life in residential group homes. An honest account of experiences living and working in a supportive setting is told, and encourages its reader to engage a social model lens in review.

### Methods

A short story is presented to a group of interdisciplinary students at Ryerson University of varying race, ethnicity, ability, age, and gender. The writing is used as a tool for learning, generating conversation, and carrying a disability studies framework across disciplines and experiences. This ongoing project intends to collect the discussion and feedback generated when the short story is used catalytically, to analyze and uncover the benefits of an interdisciplinary perspective, as well as the effectiveness of fiction as a method.

### Results

Throughout ongoing discussions students responded positively to the approachable fictional style of writing. When engaged in discussion students from disciplines such as Child and Youth Work, English, and Early Childhood Education began to pull details from the interpretive writing. This began opening gateways to relative discussions around concepts such as social role valourization, the social model, and a hierarchy of disability. The work continues to establish pathways from the fictional short story to reference different complex disability studies perspectives to more samples of students.

### **Discussion/Conclusions**

Using fiction as a method this work intends to bring social model understanding and disability studies subject matter across disciplines. It will examine the gains of cross disciplinary education and the benefits a social model lens presents for varying professions. The poster will present a case for fiction as a research method, the accessibility of plain language in academics, and an account of the ongoing discussions as a result.

## Living With a Sibling With Autism Spectrum Disorder

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### Objectives

Raising a child with Autism Spectrum Disorder (ASD) has a potential impact on the mental health and overall well-being of family members due to parenting stress (Chan & Goh, 2014; Hayes & Watson, 2013). However, children with siblings who have ASD are not frequently investigated. When siblings are researched in family studies, accounts about sibling interaction are often provided by mothers, which have shown discordance with sibling reports (Moyson & Roeyers, 2012). A recent study by Petalas and colleagues (2009) demonstrated that children with a brother or sister with ASD may have a higher risk of developing emotional and prosocial behaviour problems when compared with siblings of children with intellectual disabilities and children with typical development. Conversely, other studies have found positive effects in children with siblings with ASD (Rivers & Stoneman, 2003; Verte, Roeyers, & Buysse, 2003), such as greater affection and admiration of their brother or sister with ASD and lower levels of competitiveness and quarrelling compared to siblings who have typical development (Kaminsky & Dewey, 2001). Thus, it is important to develop a balanced investigation of sibling interactions that can explain the nature of the sibling relationship when one sibling has ASD. The purpose of this study is to obtain a greater understanding of the experiences of siblings who have a brother or sister with ASD, using a mixed methods approach.

### Methods

Participants in the proposed mixed methods study will be 20 families with children who have ASD. A mixed-method approach will be utilized and consist of two questionnaires as well as an in-depth interview and arts-based methods. The Sibling Relationship Questionnaire (SRQ; Furman & Buhrmester, 1985) and The Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2005), both reliable and valid measures, will assist in quantifying problematic behaviours and challenges or uplifts that are experienced by siblings. In the second component of the study, the researchers will gain first hand accounts from siblings about what it is like to have a brother or sister with ASD using semi-structured interviews and artsbased methods (i.e., drawing a totem pole of the family). Interviews will be analyzed using Interpretative Phenomenology Analysis (IPA).

#### **Discussion/Conclusions**

Data collection is ongoing, but this poster will provide introductory insight into the lived experience of siblings with brothers or sisters with ASD. It will convey both of the positive and negative side of these experiences, plus provide an understanding of what this experience is really like. With deinstitutionalization, many individuals with ASD are living with their families and many siblings are helping to provide supports for their siblings once their parents can no longer provide care. Therefore, this study will greatly contribute to family research and address gaps in sibling research by exploring the opportunities and challenges of children with siblings with ASD. In addition, a strength of the study is the mixed-method approach, which is often not employed in sibling research. Quantitative questionnaires can objectively measure the outcomes of sibling relationships, while qualitative methods can capture unique perspectives and personal accounts that can sometimes be lost in objective measures.

# Child, Family, and Community Predictors of Child Psychosocial Functioning in a Canadian Sample of Special Olympics Athletes

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### Objectives

Individuals with intellectual and developmental disabilities (IDD) often struggle with adaptive/social functioning, which relates to an individual's ability to cope with environmental demands on a day-to-day basis (The British Psychological Society, 2000). Researchers have found that individual factors, such as age (Tsatsanis, Fuerst, & Rourke, 1997), gender (Grella, 2003), ASD (Fitzgerald, 2011), and child health (Lucyx et al., 2012); family factors such as negative life events (Consoli et al., 2014); and community factors, such as school supports (Coster et al., 2013), are linked to changes in psychosocial functioning, within differing populations. However, thus far there is a paucity of research that assesses how child, family, and community factors together are related to psychosocial functioning in individuals with IDD. The purpose of the current study was to develop a greater understanding of the correlates of psychosocial functioning by examining them together in a large sample of youth with IDD.

### Methods

We recruited 517 caregivers of youth and young adults with IDD registered with Special Olympics Ontario (11 to 22 years of age; M = 17.11, SD = 3.00) to complete an online or paper-pencil survey of sport participation in youth (representing 19% of registered Special Olympics participants). Child factors included ASD diagnosis, age, number of chronic health conditions, and adaptive behaviour based on the Waisman Activities of Daily Living Scale (Maenner et al., 2013). Family factors included respondent self-reported health (Roman et al., 2009), general family functioning (McMaster Family Assessment Device (Byles et al., 1998). The next factor was number of negative life events (Willemen, Schuengel, & Koot, 2010). Community factors included the community and school resources (Participation and Environment Measure for Children and Youth, community and school resource scales; Coster et al., 2012). Psychosocial functioning was measured through parents report on the Psychosocial subscale of the Pediatric Quality of Life Inventory (Varni et al., 2003).

### Results

The overall model accounted for a significant amount of variance in child psychosocial functioning, based on multiple regression analysis (F(9, 350) = 21.19, p < .001; R<sup>2</sup> = .34). Significant predictors included (a) child factors (R<sup>2</sup> change = .12; age (t(350) = 2.73, p = .007), ASD diagnosis (t(350) = -3.11, p = .002), and the number of health conditions (t(350) = -2.34, p = .020); (b) family factors (R<sup>2</sup> change = .07; parent-reported physical health (t(350) = 2.60, p = .010), general family functioning (t(350) = 2.06, p = .040), negative life events (t(350) = -2.39, p = .017); and (c) community factors (R<sup>2</sup> change = .16; school resources (t(350) = 7.89, p < .001)).

### **Discussion/Conclusions**

Although correlational, results of this study provide valuable information about the important role child, family, and community factors can play in the psychosocial functioning of individuals with IDD involved in community sports. Further research to elucidate the transactional relationships amongst these factors will help us better understand how to enhance psychosocial functioning in individuals with IDD.

# The "Even More Basic" Level of Fundamental Movement Skills

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### Objectives

Our project was based in observing and describing the fundamental movement skills of a group of teens and young adults with moderate to low functioning Autism Spectrum Disorder for the purpose of expanding and refining their movement capacities and designing progressive activities that were "even more basic" than the typical fundamental baselines associated with novice movers.

### Methods

We systematically observed a group of 12 teens and young adults over a period of 18 months in both aquatic and gymnasium environments participating in gross motor, fine motor, games skills and fitness and conditioning activities. We used Laban movement theory (Maletic, 1987) to guide our observations and analysis of movement and consulted Gallahue's (1998, 2001) guidelines for fundamental motor skill development and Liu's (2012) application of motor milestones as comparative frameworks. We based our activity design in the findings of a longitudinal phenomenological analysis of movement patterns of children, youth and adults with ASD (Connolly, 2008).

### Results

Our consolidated cross case comparative analyses yielded findings regarding sequencing of progressive and simplifying tasks and the necessity of both individualizing to specific movement tendencies and creating relevant movement experiences to enhance interest and adherence. In this session we hope to describe the strategies of Break it down/Build it up, station based pedagogy, and embedding under-developed (or absent) and transferable movement patterns to the design of progressions for basic skills.

### **Discussion/Conclusions**

Many children, youth and teens with disabilities experience challenges with what might be considered "basic" skills (e.g., running, take offs, landings) not only because of neurological or developmental issues, but also because of lack of opportunity for play, participation and practice and a lack of preparation among practitioners about how to make "basic" even simpler, or progressively broken down into more fundamental elements. This paper explores the "even more basic" dimension of fundamental movement skills and uses examples and applications across a spectrum of disability, from moderate functioning to low functioning participants. The strategies will be helpful for practitioners who are working in inclusive and/ or supported approaches as well as specialized and individualized programs. Additionally, practitioners may discover applicable strategies for typically developing learners who are experiencing movement challenges.

## Exploring the Viability of Liaison and Follow-Up Support Models for Post-Secondary Student Development Centres

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### Objectives

The purpose of this study was to examine whether liaison and follow-up support models for post-secondary student development centres could influence successful results for students with disabilities. It was believed that implementation of liaison and follow-up models that drew on students and faculty members within the institution's disciplines could complement disability staff engagement practices for students that accessed student disability centres.

### Methods

This study relied on qualitative research techniques. 18 questions, 3 questions from 6 qualitative design domains including "experience and value questions, opinion and value questions, feeling questions, knowledge questions, sensory questions, background and demographic questions," were presented to 8 managers (n = 8) of post-secondary disability services offices. These managers are part of a network that is responsible to deliver support services to the 43,000 students (12.8% of the post-secondary student population) across Ontario's College and University system. 4 respondents were male and 4 were female. 5 managers represented college disability services offices and 3 represented university disability services offices.

### Results

The study resulted in over 100 pages of data which was then analysed to identify common themes from the responses. The findings demonstrated that managers in both the college and university settings did not support the concept of utilizing other faculty members and students from other disciplines within their institutions to complement their respective service delivery capacity. However, the study did identify that issues related to enhanced transition planning from secondary to post-secondary education, improved faculty and student education about disability and accommodations, improved universal instructional design programs, better integrated student supports for students with Asperger syndrome and mental health needs and more inclusion efforts on and off campus were all required to help students with disability maximize their opportunities for success in post-secondary education programs.

### Discussion/Conclusions

The managers had over 150 years of experience working with students with disabilities. The poster related to the study will illustrate the results of the study.

# Rural and Urban Health Care Professionals' Attitudes and Awareness of Fetal Alcohol Spectrum Disorder in Ontario, Canada: A Secondary Data Analysis of the FAS Survey for Health Professionals

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### Objectives

Fetal alcohol spectrum disorder (FASD) is an umbrella term that refers to a continuum of effects that are associated with prenatal exposure to alcohol. Health care professionals play a critical role in the prevention of FASD, particularly through suggestions regarding alcohol use and alcohol consumption during pregnancy, yet researchers have demonstrated that many practicing health care professionals remain under-educated about FASD. National survey results suggest that Canadian health care providers, while aware of some aspects of FASD, require further training and education to support their work of caring for both individuals at risk for having a child with FASD and for individuals with FASD and their families (Clarke, Tough, Hicks, & Clarren, 2005; Tough et al., 2005). However, the level of knowledge of FASD held by Ontario health care professionals remains unexplored.

### Methods

A secondary data analysis was conducted using data obtained from the 2001-2002 Fetal Alcohol Syndrome (FAS) Survey for Health Professionals. Ontario-specific data (n = 884) was used to understand the knowledge, attitudes, and awareness of FASD held by paediatricians (n = 287), psychiatrists (n = 181), midwives (n = 68), family physicians (n = 288), and obstetricians (n = 60). Health professionals that did not indicate their medical specialty or whether they considered their practice to be urban or rural were removed from analyses (N = 834).

### Results

Nearly all (99.5%) of the surveyed health care professionals had previously heard of FAS, and the majority of these practitioners either agreed or strongly agreed (92.1%) that prenatal alcohol exposure poses a significant risk factor for permanent brain damage. In addition, of the surveyed health care professionals who treat women of childbearing age, only 73.2% reported discussing the risks of alcohol during pregnancy and only 62.4% of surveyed professionals agreed with the practice of telling patients to drink in moderation. Furthermore, respondents' definition of "moderation" differed significantly based on their medical specialty. On average, family physicians considered a greater number of drinking occasions per week to be moderate (M = 3.44, SD = 2.32) compared to pediatricians (M = 2.31, SD = 1.90) and midwives (M = 2.51, SD = 2.36) (F(4,788) = 4.41, p = 0.002). Although the percentage of health care professionals who discuss alcohol use with female patients greatly increased when those women were in a position likely to conceive (94.7%), there was also some discrepancy when it came to alcohol use during pregnancy. Only 87.9% of respondents recommended that pregnant women completely abstain from alcohol for the duration of their pregnancy. Rural health care professionals reported that they were more likely to ask pregnant women if they were currently drinking alcohol compared to urban professionals (p = .007). Rural health care professionals also reported feeling more prepared to care for biological mothers in the area of alcohol abuse or dependency compared to urban professionals (p = .011).

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#### **Discussion/Conclusions**

Although the data is thirteen years old, the results of this secondary data analysis are still relevant as they support the current findings that consistent recommendations are not provided by health care professionals when advising women of child bearing age about alcohol use. This finding may be due to a lack of education regarding FASD received by health care professionals or the absence of medical guidelines surrounding this topic. Furthermore, the results of this secondary data analysis provide a starting point for understanding the knowledge and awareness of FASD in Ontario.

#### Acknowledgements

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### Family Strengths Improve Well-Being of Family Members With Developmental Disabilities

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#### Objectives

Persons with developmental disabilities and their families often cope with increased health, economic, and social risks. Effective family coping depends upon the overall health of the family coupled with each family member's ability to promote positive well-being for self and others. This presentation will share findings from three family-centred studies that looked at coping strategies in unique ways. The first study examined how online self-help groups improved families' abilities to care for children with autism. The second study identified characteristics of resilience in young adult siblings of children with autism. The third study outlined positive coping abilities in parents who were caring for adult children with developmental disability and mental illness who lived at home. Overall, these studies examined which family strengths may promote the well-being of both caregivers and members with developmental disabilities.

### Methods

The studies used semi-structured interviews to explore a) self-help group experiences of 22 parents of children with autism, b) resilience characteristics of 14 young-adult siblings of children with autism, and c) coping abilities of 15 parents caring for adult children with dual diagnosis. Research participants were recruited through notices distributed at local agencies and by word of mouth. Interviews were analyzed using qualitative techniques in which the researchers assigned codes and categories to significant statements in a line-by-line examination of the transcripts and then identified common themes across participants.

### Results

Overall, the three studies suggested five areas of family strengths which positively impacted families and family members with developmental disabilities. First, the ability to see positive aspects of disability improved family coping and supportive family relationships for family members with developmental disability. Second, close family relationships provided support for parents, siblings, and family members with developmental disability. Third, ability to access resources, such as financial, educational, and residential care options, decreased the stressful impact on all family members. Fourth, supportive relationships with friends, extended family, and from self-help groups improved family members' coping ability, which in turn improved supportive relationships between caregivers and family members with developmental disability. Fifth, the ability to effectively advocate for needed services and to educate public and professionals about developmental disabilities improved caregivers' efforts.

### **Discussion/Conclusions**

These findings support interventions that enhance family strengths in order to improve the well-being of persons with developmental disability across the life span. Specifically, positive outlooks about disability and emotionally supportive relationships serve to improve family coping skills and by extension families' ability to provide instrumental and emotional support for members with developmental disability. Siblings need emotional support from parents and supportive relationships with friends are particular-

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ly important for adolescent siblings. Nurturing family relationships improve coping for all family members, as do supportive relationships outside of the family, including self-help groups. Enhancing parents' ability to access, advocate, and educate the general public and service professionals about needed resources can increase supportive relationships and services which improve the quality of life for persons with developmental disabilities and their families. Although small sample size limits generalizability, finding common elements in three different studies strengthens the findings.

## Using Visual Search Strategies to Understanding Intermodal Perception in Children With an Autism Spectrum Disorder

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### Objectives

Children with Autism Spectrum Disorder (ASD) experience difficulty when processing information from more than one sensory modality (Iarocci & McDonald 2006), compared to typically developing children, and this difficulty is particularly evident in the processing of linguistic information (Bebko, Demark, Weis, & Gomez, 2006). However, linguistic information is inherently social and it is a challenge to separate the social aspects of an event from the linguistic aspects of an event; therefore, while children with ASD do demonstrate a deficit in processing intersensory linguistic information, it is unclear whether the cause of the deficit is a result of the linguistic nature of the information or the social nature of the information. To address this question, the current study assessed visual processing strategies in groups of children presented with audiovisual stimuli and manipulated the language and social content.

### Methods

Participants included 20 children with ASD and a control group of 20 children with typical development ranging in age from six to 16 years. The participants viewed a presentation screen displaying four identical videos in each of the four quadrants. The videos in each trial had differing levels of linguistic and social content. While the participants completed the task, an eye-tracking device recorded eye movements. For the present study, a coding scheme

was constructed to categorize eye movements as either "efficient" or "inefficient." Eye movements were categorized as "efficient" if participants fixated at areas of the task that provided meaningful information. For example, in a video with linguistic content, a fixation on the mouth would be categorized as "efficient." Furthermore, eye movements were categorized as "inefficient" if participants fixated at areas of the task that did not provide meaningful information. For example, a fixation on the black background of a task would be categorized as "inefficient." Once the eye movements were categorized, the amount of "efficient" and "inefficient" gaze shifts between groups were compared across stimuli.

### Results

Preliminary analysis (N = 33) revealed a significant main effect of group, such that the TD group used more efficient visual search strategies to process the stimuli compared to the ASD group, F(1, 31) = 6.94, r = .18, p = .013. There was no significant main effect of trial type, and no interaction between group and trial type (all ps > 0.05).

### **Discussion/Conclusions**

The findings of differences in efficiency of intersensory processing for social and linguistic information in children with ASD is an important finding as it helps clarify where some of the intersensory difficulties may be in ASD.

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# Adults With Cerebral Palsy: Characteristics and Health Issues

### Objectives

Cerebral Palsy (CP) is the most common cause of complex and physical disability in childhood. Previous literature has shown that individuals with CP experience comorbid physical and mental health issues, as well as low life expectancy. It is not well understood what demographic and clinical variables are associated with the presence of specific physical and mental health issues among persons with CP, with and without a developmental disability (DD). Using large administrative health databases, the current research aimed to identify adults in Ontario with CP with or without DD, and to describe their characteristics and comorbid physical and mental health issues.

### Methods

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program that aims to enhance the overall health and wellbeing of individuals with DD through improved healthcare policy and improved services. H-CARDD created a cohort of adults (ages 18 to 64) with CP from administrative health databases consisting of regularly collected records from physician visits, hospitalizations, and emergency department visits. For comparison we also created 2 groups: (1) Ontarians with DD (excluding CP); and (2) a random sample of the general Ontario population (excluding DD and excluding CP). The three groups were described and contrasted on demographics, and mental and physical health comorbidities.

### Results

14,155 adults with CP were identified from the Ontario health databases; of these 33% also had a DD. Persons with CP had demographic patterns similar to comparison group of Ontarians with DD. When compared to the general population, individuals with CP were younger and more likely to be male. Consistent with findings among Ontarians with DD, adults with CP were more likely to have a psychiatric comorbidity than the general population. Asthma was the most common physical health condition in persons with CP, with a higher prevalence than what was found in those with DD, and the general population.

### Discussion/Conclusions

This research successfully used administrative health data to identify and describe the demographics and health status of adults in Ontario with CP. These results can be used to inform health and social service providers and help to guide policy development for adults with CP.

# Performance Validity Tests and Autism Spectrum Disorders: An Early Investigation

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### Objectives

There is a growing evidence for the use of performance validity tests (PVT) with children during neuropsychological testing. The literature supports the use of adult PVTs in children with a variety of medical and neuropsychiatric diagnoses. However, there is a paucity of literature examining whether it is appropriate to use PVTs with children on the autism spectrum disorder (ASD). The current study examines PVT profiles in a sample of children with ASD to identify factors that may explain PVT failures.

### Methods

Data were collected from 43 children (91% male) with ASD referred for neuropsychological assessment. Mean age was 12.1 years (SD = 3.7, range: 5-19). Mean FSIQ was 84.3 (SD = 84.3, range: 46-124), while mean PPVT-III score was 100.7 (SD = 21.1, range: 51-134). Performance validity was assessed using the Green family of PVTs: Word Memory Test, Medical Symptom Validity Test and Non-Verbal Medical Symptom Validity Test. Adaptive functioning was measured using the Behavior Rating Inventory of Executive Function (BRIEF).

### Results

While the majority (81%) of the sample had no PVT failure, 8 out of 43 children failed at least one. PVT failure was associated with being younger, lower cognitive functioning and paradoxically, fewer executive deficits on the BRIEF.

### **Discussion/Conclusions**

The poster will discuss the implications of these results to interpreting cognitive data in diagnostic considerations and the limitations of the use of PVTs in children with ASD. Also, the puzzling relationship between PVT failures and BRIEF scores will be discussed.

# Encouraging Adults With Intellectual and Developmental Disabilities to Have an Annual Health Check-Up – Not as Simple as it Seems

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### Objectives

Annual health check-ups lead to early identification and treatment of undiagnosed conditions, and aid in the prevention of more complex health problems among adults with intellectual and developmental disabilities (IDD). Despite the evidence of these benefits, adults with IDD attend an annual health check-up less frequently than the general population. Selfreferral is the primary way patients attend the annual health check-up, therefore, to improve attendance it is crucial to engage patients/caregivers. The purpose of the ongoing multi-phase study is to explore the effectiveness of an intervention to increase uptake of annual health check-up by adults with IDD. The poster will focus on the first phase and will examine how accessible the intervention is to this population.

### Methods

A population-based intervention was implemented, which aimed to increase uptake of the annual health check-up by adults with IDD. An accessible language information package was sent in the last week of October 2014 to individuals with IDD who are Ontario Disability Support Program recipients (N = 39, 868). The package included details about the annual health check-up, its importance, instructions on how to book an appointment, and a link to a video of the written information in the mail out. It also included researcher contact information and instructions to take part in a voluntary phone interview regarding the intervention package and the annual health check-up. Data collection is ongoing. To date, 153 participants have taken part in the telephone interview, including 72 (47%) proxies who responded on behalf of the

adult with IDD and 81 (53%) adults with IDD. Adults with IDD (who participated themselves or for whom a proxy participated) range from 22 to 68 years of age (M = 39.76, SD = 12.22). There are 81 (53%) male adults with IDD, 71 (46%) female persons with IDD, and 1 (1%) person who did not identify as male or female.

### Results

Of the 39,868 information packages that were mailed out, 1,233 (approximately 3%) were returned as undelivered. To date, there have been 133 visits to our website (for which the link was provided in the information package) and our information video was viewed 123 times. Four hundred and seven people contacted the research team about the study. From the individuals that contacted us 153 (37.6%) have taken part in the interviews. In the poster we will be exploring demographic differences (e.g., age, gender, and living situation) between individuals with IDD who read the information package themselves (55%) and those who had it read to them (45%). We will also examine the differences between the persons with IDD who found the information easy to understand (60%) and those who did not (40%).

### **Discussion/Conclusions**

Findings from this study will provide essential information regarding the accessibility of a health education intervention via mailing of information. This information will allow for the development of accessible and effective interventions to increase uptake of the annual health check-up and possibly specific disease screening among adults with IDD, ultimately leading to enhanced overall health for persons with IDD.

## **Respite Care for Children With Intellectual Disabilities: Perceptions of Need for Pain Training and Preferences**

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### Objectives

Inadequately managed pain among children with intellectual disabilities is a common problem, which is likely due to challenges in effectively communicating their pain to others, including providing pain self-reports of their pain (Chen-Lim et al., 2012; Dubois et al., 2010; Twycross & Williams, 2013). Thus, caregivers often play an important role in assessing these children's pain (Breau et al., 2003). Respite caregivers are common non-custodial caregivers of children with intellectual disabilities, and the importance of respite care as support for these children's families continues to grow (Chan & Sigafoos, 2000). Research conducted by Genik, McMurtry and Breau (in preparation) found pain training to be quite uncommon among respite caregivers in their sample (5/54 respite caregivers). Further, some pain-related beliefs held by these caregivers (e.g., the ability of children with intellectual disabilities to sense pain) were inconsistent with current research. The objective of this study is to gather information about perceived pain assessment and management training needs from both front line and management staff in organizations which provide respite care services to children with intellectual disabilities.

### Methods

Participants consist of (1) active respite caregivers and (2) respite care management staff employed in organizations providing children's respite services. As part of a larger study, respite caregivers and management completed a brief 15 item researcher-generated questionnaire. This measure gathers information on a number of topics such as: (1) interest in, applicability of, and importance of pain training programs (statements with scaled rating responses; 0 = "Strongly Disagree"; 10 = "Strongly Agree"), (2) training program format preferences (rank order selection, e.g., in person versus online training, length of training), and (3) preferred topics to include (open-ended responses).

### Results

Data collection is 90% complete; data analysis will be completed by the end of March. Responses from respite caregivers will be analyzed separately from responses from management staff. All scaled rating and rank-ordered questions will be analyzed using frequency analyses. For example, means and ranges will be used to describe ratings of perceived importance of pain training programs. The five open-ended questions will be analyzed through content analysis. The researcher will begin by reviewing each open ended question. In collaboration with a primary investigator, coding categories will be developed using open coding and inductive methods. This coding scheme will then be refined, and two additional coders will be trained to use the scheme. Cohen's Kappa will be used to calculate reliability between coders, and discrepancies will be resolved amongst the coders and primary investigators. Following completion of coding and adequate reliability, frequency analyses will be used to further explore the data.

### **Discussion/Conclusions**

This poster will provide novel data on respite caregiver and management staff's perceived pain training needs in working with children

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with intellectual disabilities. Limitations and implications of the results will be discussed in the context of this program of research; the next phase is to incorporate these results in combination with extant research literature to develop and pilot a pain training program designed for respite caregivers.

# Knowledge About the Diagnosis and Treatment of Children With ASD: Perspectives From Medical Professionals and Teachers

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### Objectives

Individuals with Autism Spectrum Disorder (ASD) demonstrate a wide range of impairments in communication and social function, as well as repetitive behaviours and restricted interests (Devlin & Scherer, 2012). According to the Centers for Disease Control and Prevention (2014), approximately, 1 in 68 children is diagnosed with ASD. Parents of children with ASD have raised concerns regarding the delay in diagnosis of ASD (Keenan et al., 2010), medical practitioners' knowledge about diagnosis and treatment of ASD (Carbone et al., 2010), and lack of social support due to the paucity of financial and medical resources (Glazzard & Overall, 2012). Educational and health care professionals play an important role in identification and treatment of children with ASD. Nonetheless, research shows that although children with ASD often show signs of autism as early as six month of age, they do not receive a diagnosis until the age of 3-4 years (Rhoades, Scarpa, & Salley, 2007). As Rhoades, Scarpa, and Salley (2007) suggested, many health care providers feel incompetent in both the assessment and diagnosis of ASD. The purpose of this research is to investigate the knowledge of educational and health care professionals regarding the diagnosis and treatment of ASD in Ontario.

### Methods

Participants will be medical practitioners, nurses, and teachers in Ontario. My research will employ a two-phase, mixed methods approach. During the first phase, participants will fill out a questionnaire regarding their knowledge and attitudes about ASD. The second phase will incorporate semi-structured interviews, in which participants will be asked to answer questions with regard to their knowledge about the identification, diagnosis, and treatment of ASD, as well as their attitudes and approach about ASD. The participants will also be asked about their experiences of working with this population.

### Results

The results of this study are pending as the data collection will be undertaken during the months of June and October, 2015.

### **Discussion/Conclusions**

The results of this study will provide a better understanding of educational and health care professionals' knowledge with regards to the diagnosis and treatment of ASD. Findings will also have implications for raising awareness in health care and educational systems regarding the steps that need to be taken in order to enhance diagnosis and treatment of ASD.

# Self-Reported Instructional Competence and Confidence in Parents of Teens Diagnosed With Autism Spectrum Disorder: An Analysis of the **Relationship Between Competence, Confidence and Related Factors**

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### Objectives

The aim of this research study is to explore the theoretical and applied implications for the delivery of provincial ABA programs, increase knowledge within Kerry's Place about parent perspectives on competence (i.e., instructional control) and confidence and gather information on areas most in need of training. Researchers hypothesize that parent levels of competence are directly correlated with parent levels of confidence.

### Methods

This study included 52 parents of youths diagnosed with ASD, ages 11-18 who were currently receiving services at Kerry's Place Toronto ABA sites. Each parent completed the Self Reported Levels of Competence and Confidence Parenting Questionnaire. Questionnaires contained 11 questions in multiple choice format, 8 on parent competence and 3 on parent confidence levels,. Data resulting from individual questions were put into Statistical Package for the Social Sciences (SPSS). An Analysis of variance (ANOVA) was used to examine the effects of Number of sessions (i.e., groups), youth's level of functioning, type of curriculum, and location of program delivery. Finally, the overall results were analyzed.

### Results

A series of ANOVAS revealed that the level of functioning, family size, age and location of the program had no significant effect on parent levels of competence or confidence. Parents of children exposed to a greater number of groups showed greater competence in their parenting skills. Parents of boys were found to be more competent than parents of girls. Parents of youth exposed to the Social curriculum had greater competence than those exposed to other domains. Parents exposed to a greater number of sessions and parents of boys showed a greater level of confidence for one of the questions. Consistent with the researchers' prediction, an inter correlation matrix determined that, for many of the questions, competence and confidence were highly correlated. Greater levels of instructional control in the form of parent follow through correlated with increased overall parent confidence, and specifically with confidence in managing their youth in the community. Higher levels of parent instructional control in the form of presenting quality instructions inversely correlated with lower levels of worry about giving instructions. Higher levels of gaining appropriate attention inversely correlated with lower levels of worry. Finally, higher parental confidence levels in managing their youth in the community correlated with greater overall parent confidence.

### **Discussion/Conclusions**

This study confirms that self-reported parent competence and confidence levels directly correlate. That parents of youth who attended higher number of previous sessions reported higher levels of competence and confidence naturally follows since the youth had more educational opportunities. Similarly, parents of youth attending more sessions may have had more training. Parents of youth who attended the Social group were more competent and confident. This may be a result of youth having more adaptive and communication skills (i.e., prerequisites for the group). Results also demonstrated that increased confidence directly correlated with increased competence, specifically to gain youths' attention, deliver higher quality directions and to better follow through with original instructions. Further research is recommended focusing on building parents' level of instructional control within the community.

# Using a Behavioural Skills Training Approach to Teach Parents Instructional Control Will Increase Parent Confidence in Delivering Instructions and Overall Confidence Levels

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### Objectives

The aim of this research study is to fill a research gap which appears to exist regarding levels of instructional control and confidence for parents of adolescents. This study examined self reported levels of competence (i.e., instructional control) and confidence of parents with adolescents diagnosed with ASD, 11–18 years old, before and following a Four-Phase Behavioural Skills Parent Training model in gaining instructional control. Researchers hypothesized that there will be an overall increase in self-reported levels of competence and confidence following the Four-Phase Behavioural Skills Training package.

### Methods

This Pre-Test/Post-Test design consisted of 5 parents of youth aged 11-18, currently enrolled in Kerry's Place Autism ABA Services. These parents reported low levels of instructional control and confidence in the previous Parenting Perspective Questionnaires created by the same authors. Researchers administered a Parenting Perspective Questionnaire pre-test. Parents then participated in a Four-Phase Behavioural Skills Training: (1) Parent Didactic Workshop, (2) Video Modeling and Role Play, (3 & 4) Individual Parent/Child Coaching Sessions. BTs took data while one of them also coached the parents and provided feedback on their performance, when necessary. The Parenting Perspective Questionnaire was re-administered as a posttest to determine possible changes in their view of their abilities to manage their child's behaviour. Results were then scored and analyzed.

### Results

Results from the Pre-Test/Post Test Questionnaires showed an overall increase in selfreported levels of competence and confidence at

the completion of the study. Specifically, 80% of parents reported an increase in gaining attention prior to delivering an instruction. In Question 2, 60% of parents reported an increase in delivering concise instructions one time only. In Question 3, 60% parents relayed an increase in getting follow through with instructions. Question 4, 80% of parents reported an unchanged level of worry about giving instructions. In Question 5, 40% of parents reported increased confidence in managing their youth's behaviour in the community. Finally, in Question 6, 80% of parents reported an increase in their overall confidence levels. After parents completed Phase 2 of training, data were taken using the Instructional Control Component Checklist. IOA data were collected for 90% of the sessions. Mean IOA was 98.9% (range was 96%-100%) across the 5 participants.

### **Discussion/Conclusions**

This research study demonstrated that providing didactic instruction combined with a BST model for training instructional control to parents of youth aged 11-18 diagnosed with ASD, correlated with increased levels of parent competence. The parents' self-reported levels of both competence and confidence were corroborated by data from the Pre-Test/Post-Test Questionnaire. Additionally, through evaluation forms given out at the start of Phase 3, as well as parent oral reports, parents reported that the information taught was very useful and helpful in their current managing of their children. This study focussed on increasing instructional control with simple onestep instructions. Future studies may wish to include teaching simple one-step instructions directly in the community, as well as teaching multiple-step instructions.

# Canadian Parents' Journey to Obtaining a Diagnosis: Current Challenges and Areas of Support

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### Objectives

Obtaining a clear and timely diagnosis can be very confusing, difficult, and stressful for parents of children with developmental disabilities (DD). This experience may be even more challenging when the child has Autism Spectrum Disorder (ASD). Although the current literature suggests that the overall diagnostic process is a negative experience for parents (Mansell & Morris, 2004; Osborne & Reed, 2008; Siklos & Kerns, 2005), few cross-Canada studies have been conducted. The aim of this study is to investigate the parents' perspective of the diagnostic process as a function of child characteristics (severity of DD, diagnosis of ASD) and demographics (SES, location, immigrant status).

### Methods

Data comes from the Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) Extended Survey which was completed online or paper by 208 parents (91.5% biological mothers) of children with severe DD (71.6% boys) aged 4-19 (M = 11). 122 children (58.7%) had ASD in addition to severe DD. This nationwide survey included questions focusing on the diagnostic process parents had gone through, latency from when they were first concerned to the initial diagnosis, how many and what sorts of professionals were involved, and how satisfied parents were with the process. Qualitative analyses were used to study parents' responses to an open-ended question regarding their experiences in obtaining a clear diagnosis.

### Results

In our sample, parents of children with ASD reported a later age of first concern  $(X^{2}(2,203) = 38.34, p < 0.001, V = 0.44)$  and a later age of diagnosis  $(X^{2}(4,204) = 53.85, p < 0.001,$ V = 0.51) than parents of children with other DDs. However, children with other DDs were less likely to obtain a definitive diagnosis. SES, community size and immigrant status were not found to be related to parent ratings of difficulty in obtaining a diagnosis. Preliminary qualitative analyses revealed that the lengthy waiting time to obtain a diagnosis, compounded with seeing multiple doctors and undergoing various assessments, lead many parents to feel frustrated. Early communication about expectations and parent-professional collaboration contributed to a more positive parent experience.

### Discussion/Conclusion

Although it is expected that certain disorders would be diagnosed at birth and others later on in childhood, the waiting time for diagnoses and number of professionals seen before obtaining a clear diagnosis is cause for concern. Findings indicate that despite these challenges, some parents report positive experiences. In order to increase positive parent experiences with the diagnostic system, building a strong parent-professional relationship should be emphasized.

## Participation, Self-Advocacy and the Convention on the Rights of Persons With Disabilities for Transitional Age Youth

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### Objectives

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that individuals with disabilities, specifically intellectual disabilities in this case, have a right to meaningful employment, community involvement and a right to education including higher education. In order to be able to ensure that these rights are enacted persons with disabilities need effective self-advocacy skills. The purpose of my research will be to see how self-advocacy skills and rights knowledge can better prepare youth with intellectual disabilities for the transition from high school to post-secondary education and training and to work. The literature states that youth who have good self-advocacy skills are better equipped to engage in effective self-determination giving them the ability to select personal goals, plan steps to achieve these goals, and to assess their progress toward goal attainment (Kleinert, Harrison, Fisher, & Kleinert, 2010). When children and youth are taught self-advocacy skills they are more likely to have a better quality of life and are more likely to challenge others who see them as incapable (Kleinert et al., 2010; Test, Fowler, Wood, Brewer, & Eddy, 2005). When making choices regarding their future it is important for youth with intellectual disabilities to see choices as meaningful, they must understand the options from which they are choosing and also understand the personal consequences that will come from each option (Fyson & Cromby, 2013). However these steps are not always ensured when they are making choice for themselves. The focal research question of this project is: How can the teaching of self-advocacy skills give youth with intellectual disabilities the tools to actively participate in decisions affecting their future, and what type of self-advocacy skills are needed to do so as seen by professionals working with Transitional age youth with ID and parents of transitional aged youth with ID?

#### Methods

I plan to interview 5-10 professional informants and 5-10 parents of individuals that have intellectual disabilities within the transitional aged youth stage. These will be semi-structured interviews that will be of one hour in length. Within and across group thematic analyses will be conducted on the interviews from these interviews.

#### Results

The results of this study are pending as the interviews will be undertaken in January-February 2015.

### Discussion/Conclusions

The findings of this study will have real world application in that it will help to better understand the self-advocacy skills individuals with intellectual disabilities need to be better equipped to transition out of high school and better self-advocate for their choice. Whether this choice will be further education, community involvement or the work place, self-advocacy skills can be taught to them to better help them in this environment as they have right to each option. The self-advocacy skills that are identified by the study participants as being most helpful for individuals with intellectual disabilities to be better equipped to participate in this transition will be used in a follow-up study to examine effective self-advocacy education strategies for youth.

# A Comparison of Sibling Relationships in Families of Children With Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder

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### Objectives

Disabilities are becoming increasingly prevalent, and like the general population, individuals with disabilities are also experiencing increased life expectancy due to medical advances and improved living conditions (Heller et al., 2010). Since the deinstitutionalization movement, 60 percent of individuals diagnosed with a developmental disability (DD) are currently living at home with their parents and caregivers (Abrams, 2009; Hodapp et al., 2010), and due to this increased prevalence, future planning becomes imperative. Studies have shown that it is often a sibling who takes on the support and caregiving role in the life of a person with DD when the parent is no longer able to (Griffiths & Unger, 1994). However, very little research has examined how siblings adapt to their brother or sister with DD. To date there is also limited examination in regards to siblings of children with Autism Spectrum Disorder (ASD) and to the researcher's knowledge, no studies investigating siblings of children with Fetal Alcohol Spectrum Disorder (FASD). Differences in the behavioural challenges posed by children with ASD and FASD are critical, and to the extent that those difficulties vary across diagnoses, differences in sibling reactions are possible. It is important to make clear why siblings' experiences would be expected to differ as a function of their sibling's diagnosis, and if researchers can determine where siblings of children with specific disabilities struggle, supports can be tailored to help lighten their experience.

### Methods

As part of a larger mixed methods research project examining the experiences of families raising children with ASD and FASD in Ontario, Canada, this study will involve collecting, analyzing, and integrating both qualitative and quantitative data (Teddlie & Tashakkori, 2009). A total of forty families from the province of Ontario that have both a child diagnosed with either ASD or FASD and at least one sibling without a disability will be recruited. In-depth, semi-structured interviews will be conducted, which will be informed by a basic interpretive approach (BIA) (Merriam, 2002). Participants will also complete a number of quantitative questionnaires, including the Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2002, 2006) and the Sibling Inventory of Behaviour Scale (Schaefer & Edgerton, 1981; Hetherington, Henderson & Reiss, 1999)

### Results

Data collection and analysis is currently ongoing. Results will be available for this presentation.

### **Discussion/Conclusions**

The results of this study will provide an understanding of the lived experiences of siblings living with brothers and sisters who have been diagnosed with ASD and FASD. Results of this study may also be helpful in developing and implementing appropriate supports for siblings of children with DD. Limitations and directions for research will be discussed.

# The Effects of Family Relationships While Raising a Child With Autism Spectrum Disorder

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### Objectives

Families can experience numerous challenges while raising a child diagnosed with an Autism Spectrum Disorder (ASD), and family dynamics and coping techniques can either promote or impede relationships among family members. While research has been conducted on caregivers, few studies have considered the effects of caring for a child diagnosed with a disability on the child's siblings. This study attempts to increase the literature on the effects of family dynamics and coping mechanisms on family relationships while raising a family member diagnosed with ASD. A focus is placed on the family challenges and experiences that occur as their family member is transitioning to Adulthood. Such research is essential as an increasing number of children are being diagnosed with ASD.

### Methods

Material for this study was obtained through detailed, qualitative interviews of young adults diagnosed with ASD. Their caregivers and siblings were also interviewed. Participants consisted of five families (caregivers N = 7; individuals diagnosed with ASD = 5; siblings = 4). All of the interviews were directed by experts in the field of Autism, and the interviewers allowed the participants to select their preferred interview location. The interviews were audio-taped and were later transcribed and analyzed for relevant quotations and common themes.

### Results

Findings from the interviews demonstrate that supportive family dynamics are an essential factor in family resilience. Caregivers who engaged in mutual positive support and communication with their partners expressed greater coping abilities than caregivers who revealed a lack of support from their partners. Additionally, gender appeared to influence the methods of support that caregivers provided for their child diagnosed with ASD. Female caregivers were more likely to focus on researching and obtaining resources and supports for their children, while male caregivers focused on providing emotional and financial support. Siblings of children diagnosed with ASD frequently expressed resentment and jealousy of the amount of attention and resources their sibling received, particularly if their sibling was diagnosed on the lower end of the autism spectrum. However, all siblings also identified positive facets of growing up with a sibling with ASD. Participants also revealed a lack of resources which focus on assisting siblings and male caregivers of individuals with disabilities.

### **Discussion/Conclusions**

The interviews reveal that caregiver resilience was impacted by the levels of support and communication that partners engaged in. Additionally, findings also indicate a need for greater supports for siblings and male caregivers of individuals with ASD, particularly with an increasing number of individuals diagnosed with ASD. Individuals in the field of Social Work and Mental Health can meet these arising needs by facilitating male-oriented and sibling-oriented support groups and by providing additional resources focused on those particular demographics.

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# DD Cares: What is the Experience of Staff Involved in an Initiative to Improve Emergency Care for Patients With Developmental Disabilities?

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#### Objectives

The Sunnybrook Health Sciences Centre Emergency Department (ED) implemented an initiative to improve care for patients with developmental disabilities (DD) called DD CARES. The process seeks to improve staff awareness of patients with DD and provide staff with support and strategies during the patient's ED visit. This study collected data during the first year of implementation and aimed to assess the following dimensions: (1) staff awareness of the initiative; (2) how the initiative fit within current practices; (3) burden of the initiative on staff time; 4) access to ongoing support and training opportunities; and (4) impact on care provided to patients with DD. The goal was to use staff feedback to modify the DD CARES process throughout implementation, optimize the efficacy of the initiative, and to enhance patient care.

### Methods

Following involvement in the care of a patient with developmental disabilities, ED staff were asked to complete a brief follow-up survey. The survey assessed fit and burden of the initiative, ongoing training and support opportunities, and how they felt the process impacted patient care (modified from the expanded evidence-based practice scale by Aarons et al., 2012). Later, questions specific to the staff member's role in the DD CARES process were added. The survey was completed by 35 respondents, and the additional questions were completed by 14 respondents.

#### Results

Preliminary results suggest that all staff were aware of the DD CARES initiative and its purpose. In terms of fit and burden, respondents largely felt the process fit with their clinical approach (94%), and most (83%) indicated they were receptive and had time to implement the initiative. In terms of organizational support, most respondents (79%) felt that sufficient training and opportunities to learn about DD CARES had been provided. The majority (80%) of clinical care leaders (CCL) reported that they had printed and attached tip sheets to patient charts, however less than one third (29%) of physicians or nurses indicated they had viewed these tip sheets. Almost all (91%) respondents felt that DD CARES had a very positive impact on patient care for this population.

#### **Discussion/Conclusions**

Preliminary findings suggest that ED staff were aware of the DD CARES initiative, and felt they had the time and opportunity to learn about and implement it. Critically, staff also felt the process improved patient care for individuals with DD. Gaps reported in some of the processes suggest further improvement to the process may be needed to facilitate communication among ED staff members so that care is optimized. Improved care for individuals with DD may prevent repeat ED visits for same/similar problems.

# From Research Into Practice: Identifying Non-Pharmaceutical Treatment for Students Living With Concussion and Mild Injuries to the Brain

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### Objectives

Cognitive, affective and physical symptoms affect a significant minority of persons whom have sustained a mild head injury (MHI; i.e., concussion). Since MHI in children 17 years old and younger accounts for 10% of all hospital admissions (e.g., Schneier et al., 2006), addressing sequelae of MHI is of significant priority within the educational system, as this environment is optimal for implementation of rehabilitation strategies. Therefore, translation of evidence-based rehabilitation and psychoeducational strategies designed to identify effective treatments for reducing the constellation of symptoms experienced by this population into clinical practice is important. There is a paucity of evidence regarding novel nonpharmacological treatments for MHI symptom reduction. Recently, there has been increased interest in the investigation of the psychological construct of mindfulness and its role in clinical intervention. While there are various conceptualizations of mindfulness, most working definitions describe mindfulness as non-elaborative, non-judgmental, present-centered awareness on each thought, feeling, or sensation (Bishop, 2004; Kabat-Zinn, 1900). Overall, mindfulness has to do with universal human qualities of attention and awareness and systematically developing these attributes is can lead to improved psychological health. Empirical literature has identified mindfulness as a potential avenue for the treatment of individuals suffering from chronic and acute MHI symptoms and a review of this literature on MHI and mindfulness could further support and promote efforts to investigate the benefits of mindfulness for persons suffering from heterogeneous MHI symptoms.

### Methods

A systematic review of the literature was performed examining evidence that observed benefits of mindfulness in clinical and non-clinical populations with specific focus directed toward the brain injury population. This review begins with a description of the construct of mindfulness. Next, observations from cross-sectional and longitudinal studies supporting mindfulness in clinical and educational settings were reviewed. This evidence was supported through neural imaging studies examining potential mindfulness-related neurological changes mediating observed benefits. Finally, studies observing the benefits of mindfulness in brain injury and pediatric populations were discussed along with potential future research.

#### Results

There exists voluminous evidence supporting benefits of mindfulness in clinical and non-clinical populations. Randomized controlled trials have found clinically significant benefits of mindfulness interventions in improving a constellation of symptoms including depression, reducing the propensity for stimulus over-selectivity, reducing mental fatigue and improved overall psychological well-being. Mindfulness interventions have also observed improvements in self-report quality of life, self-efficacy and increased social problem solving skills. Qualitative data has indicated that participants, even those very skeptical of the treatment, found it to be life changing and very beneficial.

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Overall, evidence suggests that when one learns to allocate attention and cognition mindfully, it is a clinical efficacious rehabilitation strategy for head injury populations. Mindfulness skills can be easily adapted to various immediate contexts (e.g., the classroom, the playing field), and have a positive impact on overall psychological and physical health.

# Predictors of Emergency Department Staff's Perceived Readiness Working With Individuals With Developmental Disabilities

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### Objectives

DD CARES is a program designed to improve the care of individuals with developmental disabilities (DD) in primary and emergency care settings. Two emergency departments in different regions of Ontario took part in the DD CARES intervention beginning in fall 2014, which included educating emergency department (ED) staff on strategies for treating adults with DD. As part of implementing this practice change initiative, we plan to evaluate the effectiveness of this component of the DD CARES intervention using pre- and post-surveys of ED staff. There were three objectives to this evaluation: 1) to measure attitudes, emotions, comfort level, and perceived skill of health care providers in providing care to individuals with DD before and after the intervention, 2) to measure readiness for change before the intervention, and 3) to determine if there was any change in attitudes, comfort level, and perceived skill of health care providers.

### Methods

A one-page quantitative survey to measure the comfort, skill, attitudes and emotions of ED staff in providing care to individuals with DD, was developed for delivery at emergency departments at implementation sites. At both sites, surveys were delivered individually to ED staff by an internal facilitator to ensure a representative sample. Quantitative survey items were measured on 3-point (skills) and 5-point (comfort level) Likert scales. Due to small sample sizes at each location, 5-point scales were collapsed. Response frequencies for each question were generated and compared between intervention sites. Differences in scores between sites will be tested for statistical significance using the Mann-Whitney U test. Follow-up surveys will be collected in March 2015 at the end of the intervention time period. Pre and Post data will be compared within and across sites once data has been collected.

### Results

Seventy-nine surveys were collected at site one, and 22 at site two. The majority of respondents at both sites were registered nurses (64.56%) and 86.36%). Preliminary results demonstrate that the majority of staff at both sites feel comfortable discussing disability with a patient or caregiver (77.63% and 57.14%). However, the majority of staff at both sites (49.35% and 36.37%) indicated that they were not equipped with the proper resources to make desired accommodations, and most staff (53.33% and 59.09%) were unfamiliar with local community resources for individuals with developmental disabilities. Moreover, when asked to choose the statement that best described their interest in implementing DD CARES at their site, less than half of the ED staff said that they plan to be involved in implementing DD CARES tools in the department (47.14% and 31.82%).

### **Discussion/Conclusions**

Preliminary findings suggest that most staff feel fairly positive about their ability to care for individuals with DD, but that there is room for improvement in staff awareness of community resources and a need for more resources to make accommodations. The post-survey will allow the measurement of change in staff comfort, knowledge, attitudes and perceived skills, after receiving the intervention and after having the opportunity to adapt their care.

# What Factors Influence the Health of Older Adults With Developmental Disability in Northern Ontario?

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### Objectives

A number of studies from a Southern Ontario perspective have demonstrated that individuals with developmental disabilities (DD) have lower participation rates in cancer screening as well as higher rates of obesity (Cobigo et al., 2013) which increase onset of diabetes and cardiovascular illness. In addition, researchers state that mortality and morbidity rates in the DD population exceed mortality and morbidity rates for the general population (Ouelette-Kuntz et al., 2005), plus poverty and rurality decrease screening rates. However, empirical research on the health of individuals with disabilities from a Northern Ontario perspective does not exist. The current study will provide evidence based information to outline the factors that influence health outcomes for adults with DD in the 45 to 65 age bracket.

### Methods

The proposed research project will employ a mixed methods approach, informed by the Social Determinants of Health Theory. The quantitative component will duplicate the methods employed from Southern Ontario studies (Balogh et al., 2014; Cobigo et al., 2013) that compared DD participation rates in health screening assessments and engagement to those adults in the general population. The qualitative component will employ purposeful sampling with older adults with DD who live independently or with family/associate families and will include dyadic/multiple interview techniques. The interview questions will elicit data regarding the presence of a family physician and dentist; nature of engagement; referral protocols and information that is gathered during those engagements (e.g., BP, weight, diet). The study will also examine how factors related to the Social Determinants

of Health (e.g., poverty, education rurality) may impact engagement and screening rates of older adults with DD.

### Results

The results of this study are not yet available as data collection has not yet begun. Informed by results from similar studies, (Conlon et al., 2010; Lightfoot et al., 2010) addressing health disparities in the general Northern Ontario population, expected results from this research are that the health status for individuals with DD from Northern Ontario will exceed Southern Ontario mortality and morbidity rates. It is anticipated that the qualitative component of the research will identify and demonstrate what factors (e.g., the presence of a family physician, quality of engagement with the physician, extent of referrals for health assessments, cancer screening examinations) influence lower health status for the DD population. This information is necessary to help identify gaps in health service delivery to adults with DD so that best practices can be developed. Once the information is identified, it will be shared with individuals, families, medical and dental practitioners and agencies that support people with DD to improve health outcomes for individuals with DD across Northern Ontario.

# Cognitive-Behavioural Therapy (CBT) for Treating Anxiety Among Children With Intellectual Disabilities: A Literature Review and a Proposal

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#### Objectives

Anxiety is one of the most commonly reported problems among children with intellectual disabilities (ID). Yet, to date, few evidence-based anxiety treatment protocols have been developed that take into consideration the developmental needs of these children. The present project was undertaken to survey the current CBT literature in order provide some recommendations for treating anxiety in children with ID using the CBT approach.

#### Methods

We searched PsycINFO for relevant studies from 1980 to 2014. Additional references were obtained through reviewing reference lists of relevant articles. Due to the few number of published articles found on the use of CBT in treating anxiety among children with ID (i.e., n = 2), the search was broadened to include publications that explored and/or discussed adaptations of CBT in treating anxiety among adults with ID. Studies focusing on individuals with Autism Spectrum Disorder were excluded due to qualitatively different nature of these populations in processing emotions. The search resulted in 10 articles in total. The articles were then reviewed to identify modifications to the CBT procedures that have been proposed and subsequently proved effective in treating individuals with ID for anxiety.

## Results

Based on the current literature and years of clinical experiences of the current authors, several guidelines in adapting CBT in working with children with ID are proposed. These include significant involvement from parents, the addition of emotion identification as a component of treatment, an increased use of visual aids, the use of concrete activities in discussing abstract concepts, frequent review of concepts taught, and a heavier emphasis on the behavioural component of CBT. Examples of applying these general strategies in treatment sessions will be provided in the presentation.

#### **Discussion/Conclusions**

Whereas CBT is a well-established treatment for children and adolescents without ID, the clinical work and research on adapting CBT treatments for children with ID lags far behind. The current project represents a first-step towards establishing a manualized CBT treatment protocol for anxiety among children with ID. Empirical research based on the current recommendations is much needed to substantiate CBT as an effective alternative for treating anxiety in this population.

# Barriers and Facilitators to Successful Transitioning of Adults With Developmental Disabilities From Inpatient Psychiatric Services to Community Settings

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# Objectives

Transitioning from a hospital into a group home can sometimes be a difficult and lengthy process for adults with developmental disabilities (DD). To ensure that community placement is successful, several factors must be taken into consideration, such as environmental accommodations, availability of health and psychiatric services, or interdisciplinary communication. A handful of studies have considered the experience of hospital discharge from the patient and family perspective, but few studies have explored the ingredients that promote successful discharge from the viewpoint of hospital and community staff. The purpose of this study is to identify barriers and facilitators in these transitions, as seen through the view of hospital and community staff, through an in-depth review of 5 recent hospital discharges.

# Methods

We employed a case series approach to gain an in-depth understanding of patient needs and discharge issues for 5 men discharged from a specialized psychiatric inpatient unit over the course of 1 year. Data sources included hospital charts, and interviews with hospital staff (n = 6) and community agency staff (n = 7), as well as surveys completed by staff from receiving agencies. Interview and survey questions focused on elements of the discharge process, follow-up care, and crisis experienced after discharge.

# Results

Major themes from the interviews included the importance of communication between hospital and community, role clarity, presence of point persons at the hospital and community agencies, staff readiness and comfort with the client, and family involvement. Staff also stressed the significance of consistency in discharge planning, scheduled follow-ups, and availability of hospital support to the community.

# **Discussion/Conclusions**

This poster will present key data obtained in the study that emphasizes strengths and weaknesses of the current transition model for individuals with DD. Moving forward, the findings of this project will highlight important issues and provide groundwork to improving the discharge and transition, building up staff capacity, and creating a cost-effective process for resource-intensive, complex clients.

# The Societal Impact of an Exercise Program for Adults With Autism and Intellectual Disability: Interviews With Gym Bystanders

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## Objectives

Peer-mediated interventions, including peer support in the classroom, peer buddy systems, as well as peer incidental teaching, are known to have a positive impact on several social and communication behaviours in individuals with autism spectrum disorder (ASD).<sup>1</sup> However, very little research to date has reviewed the impact of such inclusion among these peers or other community individuals (i.e., the "bystanders" of the intervention). Therefore, the purpose of this study was to examine the perspectives of the bystanders of an adapted physical exercise (APEX) program for adults with ASD and intellectual disability (ID), regarding their attitudes towards individuals with ASD-ID exercising within a typical gym environment. This research will provide information on how the inclusion of people with disabilities in a community-based exercise facility is perceived by other gym users.

## Methods

The APEX program provides a 12-week wholebody exercise training program for individuals with ASD-ID. Over the 12 weeks, the investigators identified gym members (n = 6) and staff (n = 1) who had been present during several APEX program training sessions. The investigators approached those who were identified as being "present" to participate in an individual semi-structured interview. Prior to participating in an individualized, audio-recorded, semi-structured interview, all participants (3 males, 4 females, age range 19-49 years, all university students) read and signed an informed consent form. The interviews were transcribed verbatim and reviewed multiple times in order to establish broad, common themes based on similar participant answers to particular interview questions.

# Results

Three broad categories were established: (1) the importance of inclusivity and exposure, (2) personal workout routines were unaffected, and (3) supportive of inclusive fitness facilities. Each theme is supported by multiple quotes ("meaning units") from a minimum of three participants.

## **Discussion/Conclusions**

Analyses revealed that there is promising evidence to suggest that integration of individuals with disabilities into a community fitness setting have several worthwhile and positive benefits for the general gym user. Through this integration, we are fostering and creating a more understanding and accepting community for which all individuals with differences can thrive. We are also teaching our communities to become more comfortable with, open to, and understanding of individuals with disabilities. However, it is important to note some associated limitations. The small sample size comprised solely of students may not represent the views of the general population. Also, recruitment began as the APEX program was still in progress, making it possible that participants who were recruited may have been focusing on the APEX program in preparation for their individual interview. This introduces the possibility of social desirability bias. Despite these limitations, these findings suggest that further research is needed in order to determine more specifically how this integration is perceived by the general population.

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# An Evaluation of Participatory Action Research

## Objectives

Research focused on persons with intellectual and developmental disabilities (IDD) has traditionally placed these individuals in the passive role of "participant." Participatory Action Research (PAR) is a research approach that helps persons with IDD contribute meaningfully to the research. PAR is a process in which the community under study participates actively with the researcher throughout the entire research, from initial design to final presentation of results, and seeks information to guide future actions. Furthermore, it provides a unique opportunity to involve the people most affected by the research in the research and to capitalize on their credibility and authenticity. The study's goals were to 1) evaluate the feasibility and utility of the PAR approach in IDD research, and 2) determine the degree of inclusiveness this approach offers persons with IDD.

## Methods

The PAR approach was used in a project which investigated Person-Directed Planning as a means to build community capacity. It involved three planning teams working with four individuals with IDD. Through focus groups, the planning teams reflected on their success in building community capacity through PDP, and developed products to share their stories with other planning teams, and the public. Four meetings were held with each focus group. We monitored how PAR was implemented and whether it fostered participation among the collaborators with IDD and their planning teams. Through surveys and group discussions, we examined: (1) the time and percentage of contribution to the discussion by each team member, (2) the extent to which team members contributed to decisions made about the research and its outputs, (3) the benefits and challenges of using PAR in IDD research as perceived by team members.

## Results

Analysis of the focus group discussions revealed that there was clear evidence of planning, acting, and thoughtful reflection through the focus group activities. Planning team members, contributed as much as the researchers. Survey data revealed that researchers and participants agreed that the "power" was shared equally between them and that it was easy to communicate with each other. Further analysis showed that the individuals with IDD were heavily involved in the discussion and planning of the project. However, as the task complexity increased and the support needs of the collaborator with IDD increased, the amount of time the individual with IDD contributed decreased.

# **Discussion/Conclusions**

The research and planning teams were able to follow and implement a PAR approach successfully. Furthermore, PAR facilitated completion of the greater research project. The methods were successful at engaging persons with IDD as they actively contributed to the planning and conception of the team projects. Despite some challenges and limitations, the study was a positive experience for the research team and the project teams. This encourages further research to apply PAR principles in research with persons with IDD.

# Participation, Self-Advocacy, and the Convention on the Rights of Persons With Disabilities for Transitional Aged Youth

Authors:	

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# Objectives

The purpose of my study is to better understand if and how the fundamental right to participation (set forth in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) article 3) is being implemented for transitional age youth with intellectual disabilities in regards to employment (UNCRPD 27), education (UNCRPD 24), relationships (UNCRPD 23), and community involvement (UNCRPD 19). In this study, I will examine how the right to participate in life decisions, set forth by the UNCRPD, is being implemented by parents and developmental, mental health and educational services professionals for transitional age youth with intellectual disabilities as they leave high school. The proposed study is important as, to the best of my knowledge, there has yet to be a study that focuses on the participatory rights of transitional age youth with intellectual disabilities. The rights set forth by the UNCRPD attempt to protect the rights of persons with disabilities, however, the rights of persons with intellectual disabilities continue to be ignored and abused (Tarulli et al., 2004). Despite Article 3, the dreams and aspirations of transitional age youth are often silenced because of perceived barriers and limitations.

# Methods

Semi-structured interviews will be conducted with five to ten professional informants recruited through the Niagara regional Committee on Transitional Aged Youth, and five to ten parents of transitional aged youth with intellectual disabilities. As this is a qualitative study, all results will be analyzed for themes based on the UNCRPD articles 3, 27, 24, 23 and 19.

## Results

The results of this study are pending as we are very early in our study, however I hypothesize that the right to participate is not being fully implemented for transitional age youth with intellectual disabilities in the decisions affecting life after high school.

## Discussion/Conclusions

This study will create an awareness of the needs and challenges faced by transitional aged youth with intellectual disabilities in the decision making process that will affect their futures, specifically raising awareness of education, employment, and community participation barriers. This awareness will provide a foundation for the future development of training materials in self-advocacy for transitional aged youth with intellectual disabilities. The data from this research will be used to create a game in my masters that will help transitional aged youth to learn about their choices after high school and to learn how to participate actively in the decisions affecting their future.

# The Development and Use of a Frailty Index for Aging Adults With Intellectual and Developmental Disabilities

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# Objectives

The population of persons with intellectual developmental disorders (IDD) is growing larger and older compared to previous generations. In general, they face higher risks for negative health outcomes and increased health care needs. This study assesses the ability of a frailty measure to predict time to admission to long-term care from home care, and to compare it to an existing measure of health instability currently used in Ontario. This study also compares the rates of long-term care assessments of adults with (IDD) to those without IDD. The identification of frail individuals could provide the opportunity for maintained independence and improved quality of life.

# Methods

Individuals with IDD (aged 18-99 years) living in the community and receiving home care between 2007 and 2014 were included, identified through various Ontario health data sources (n = 4,510). To measure health instability, the Changes in Health, End Stage disease, Signs and Symptoms (CHESS) scale, embedded in the Residence Assessment Instrument-Home Care (RAI-HC) was used. To measure frailty, a frailty index that captures the accumulation of health deficits, adapted for the IDD population, was developed using well-established criteria. A modified Cox proportional hazards model will be used to find the association with time to admission to long-term care. A random sample of 20% of the population accessing home care without IDD will be used for comparing rates of long-term care assessments.

# Results

Results are not yet available but preliminary analyses suggest that health instability is less common in home care recipients with IDD compared to those without but admission to long-term care is more common.

# **Discussion/Conclusions**

It was anticipated that adults with IDD experience aging much earlier than the general population and are at increased risk for long-term care. The creation of a frailty measure specific for an IDD population has never been done in a Canadian health care setting. Early identification of individuals at risk for admission to LTC would benefit health policy planning and health care service allotment.

# More Than Meets the Eye: Autistic Courtship Behaviours Explained by Theory of Mind

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# Objectives

Many youth and young adults with autism are interested in having a romantic relationship (Byers et al., 2013). Success in this area is often challenged, however, by inappropriate courtship behaviours (Stokes et al., 2007). In this study, we investigated the roles of communication and Theory of Mind (ToM) as possible mediators explaining the association between autism and inappropriate courtship. A non-clinical sample varying in number of autistic symptoms was used for this purpose.

## Methods

A total of 124 university students (Mage = 19.7 years, 85% female) completed an online survey consisting of four measures including the Autism Quotient (AQ) of Baron-Cohen et al. (2001a) and the Courtship Behaviour Scale (CBS) of Stokes et al. (2007). Two measures of ToM were also completed. The first was the Eyes Test-Revised (Baron-Cohen et al., 2001b) which assesses the ability to infer complex mental states from the eye expressions of others. The second was a self-report measure of the tendency to over-perceive the behaviour of others as flirtatious. This measure was created for the present study.

## Results

First, the zero-order correlation between the measure of autistic symptoms (AQ) and inappropriate courtship (CBS) was evaluated and found not statistically significant. However, the communication subscale score of the AQ did predict inappropriate courtship (r = .22, p < .05). PROCESS mediation analyses (Hayes, 2013) subsequently suggested that this effect was indirect and complex, involving both aspects of ToM. Difficulties in communication predicted poorer ToM as assessed by the Eyes Test, and poorer ToM was associated with increased inappropriate courtship. Serial mediation analysis also revealed a second pathway, in which poorer ToM was associated with increased perception of others' flirtations, which was then associated with increased inappropriate courtship.

## **Discussion/Conclusions**

The results did not suggest a direct link between total autistic symptoms and inappropriate courtship behaviours but did support a link between autistic communication symptoms and inappropriate courtship behaviours. Two paths were revealed for the latter relationship. One path was mediated by difficulties inferring mental states from eye expressions. The second path involved two mediators. Difficulties inferring mental states were associated with an assumption that others are flirting with them, and the latter factor was associated with a greater variety of self-reported inappropriate courtship behaviours. Our findings highlight the role played by a delayed theory of mind in the courtship challenges of individuals with autism. Identifying factors that make forming relationships difficult in this population is important so that practitioners can address them and help interested individuals with autism fulfil their relational potential. The development of a better model of the factors associated with inappropriate courtship behaviours may also assist forensic psychologists asked to assess and possibly exculpate some individuals with developmental disabilities who are accused of "stalking." Results should be interpreted with caution given the limited psychometric validation of one of the measures (the measure of others' flirtatious behaviours)

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and use of a non-clinical sample. To our knowledge, this is the first study to examine factors that may account for the association between autistic symptoms and inappropriate courtship behaviours.

# Presence With a Purpose: Attitudes of Patients With Developmental Disability Towards Health Care Students

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# Objectives

Medical and nursing students benefit from early clinical encounters to build professional competencies, particularly communication skills. At the same time, there is a necessary emphasis on appropriate consent and autonomy in their own care. While most individuals in the general population do not mind having a student either present or otherwise involved with their clinical encounters, there are occasions when personal preference and health care education conflict. Many studies have evaluated patient attitudes towards students across a variety of specialties. To our knowledge, no study has specifically evaluated the opinions of individuals with developmental disabilities (DD). Our objectives in this study is to identify the attitudes, preferences, and comfort level of individuals with DD towards the presence and involvement of medical and nursing students during clinical encounters.

## Methods

Individuals with a DD in the Hamilton-Niagara region were invited to participate in this study. Developmental Service Providers were involved with invitations to participants. Participants were provided with focus group questions in advance and encouraged to bring communication aids and/or care providers. Data was collected from the focus group discussions and individual written responses. Two independent reviewers analyzed the data and compared results for emerging themes.

#### Results

Twenty-two individuals participated in this study, most of whom had previous experiences with health care students. There was a wide range of attitudes expressed. Some were positively disposed towards medical and nursing students and were happy to have contributed to someone's learning. There was a perception of better care and improved communication with the health care team as additional benefits. Others were indifferent to students and the role they play in a clinical setting. The final group were strongly opposed to the presence of care students during clinical encounters due to significant concerns regarding confidentiality. Improved introductions and confidentiality statements, as well as presence of both the doctor and student in the room, helped relieve such concerns, though not completely. Furthermore, individuals expressed confusion over the role and purpose of students' presence, as well as uneasiness with deviation from the norm of seeing a practicing doctor and nurse.

## **Discussion/Conclusions**

A variety of attitudes, preferences, and comfort level towards the participation of health care students is described. The themes that emerged from focus groups were developed into recommendations for engaging persons with DD in clinician training. The results of this study should serve to influence health care training to improve the professional competencies of medical and nursing students and quality of care people with DD receive.

# How to Make it Work: An In-Depth Case Study of Inclusion in a Community Figure Skating Club

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## Objectives

The purpose of this research is to develop a framework that community sport organizations will be able to use to allow for the full integration of children with disabilities into the sport community.

## Methods

The approach used for this study is an in-depth case study of a community figure skating club, and is one of few clubs housed under Skate Ontario that specifies "special needs accommodation" in their description. The methods used are semi-structured interviews with coaches. parents, and children (both with and without a special need accommodation). In addition to interviews, the researcher will lead a focus group with the Board of Directors of the figure skating club. The final method to be used for this study will be document analysis including records from the local club as well as Skate Ontario.

## Results

Preliminary analysis suggests that simply meeting standards does not necessarily guarantee an environment that is authentically inclusive. Coaching pedagogies that utilize task breakdown seem to be indicators contributing to more individualized programming and has more authentic inclusion. The current literature trends are not going in the direction of task breakdown within the sport organization and therefore the study should yield useful and interesting results.

# **Discussion/Conclusions**

This research aids in the progression of both the Sport Management literature as well as the field of adaptive physical activity. Currently, there is very minimal works that address the issue of inclusion at the community sport level from the organization's view.

# Measuring The Stress of Parents of Children With ASD in Modern Times: Comparing Phone and Email Communication

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## Objectives

Although increased support has been found to reduce the stress experienced by families of children with an autism spectrum disorder (ASD) (e.g., Weiss et al., 2013) parent ratings indicate low perceived support from professional organizations (Hall & Graff, 2011). The ability of an organization to determine the stress of families that contact them is an important first step to responding according to the family's needs. Autism Ontario (AO) is a charitable organization that provides a province-wide and leading source of information and referral on ASD in Ontario. Between 2007 and 2009, 63% of contact to Family Support Coordinators (FSCs) of AO occurred through email. However, it is more difficult to express or interpret emotions over email because of the absence of verbal and body language cues more typically present in phone or in-person communication (Byron, 2008; Ekman et al., 2004) and, as a result, there is a greater risk for FSCs to misinterpret family stress over email. Since 2013, AO has been collecting data on the stress of families who contact the organization either over the phone or via email. This project presents a comparison of the results of parent stress before and after contact with AO FSCs through either phone or email communication.

# Methods

Phone stress was collected on an ongoing basis. FSCs keep a record of all phone calls received and, when communication involves parents requesting information and assistance, FSCs reported parent stress before and after phone communication into an online database. Email stress was collected at four equally-spaced time points throughout the year. Each of the time points served as a trigger for FSCs to forward the email addresses of families who had contacted them in the preceding week to the AO research team. The researchers then sent these families a brief online survey that inquired about their overall experiences with email communication with AO that past week, including reporting on how much stress they had been experiencing prior to contacting FSCs and how much stress they experienced after the email exchange.

# Results

Over a 9-month period, phone stress data was collected from 329 families and email stress data from 49 families. A large number of families communicating with FSCs over email considered themselves "very stressed" (35%) prior to contacting FSCs. This is in contrast with only 5% of families who contacted FSCs over the phone, the majority of whom rated themselves as being either "moderately stressed" (35%) or "a little stressed" (34%) prior to contact with FSCs. 53% of families who initiated contact over email reported a reduction in stress following their correspondence with FSCs while another 41% reported no change. Similarly, 48% of families who initiated contact over the phone reported a reduction in stress, while the remaining 52% of families reported no change.

# **Discussion/Conclusions**

The findings suggest that, despite the increased possibility of emotional detachment in email correspondence, it is still possible for organizations to measure and help alleviate the stress of families of children with ASD through email communication

# Comparing Predictors of Quality of Life in Families With or Without Children With Severe Developmental Disabilities

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## Objectives

Research suggests that both children with developmental disabilities (DD) and their parents face challenges that may result in reduced quality of life. For example, parents of children with DD report that they have difficulty identifying friends for their children (Guralnick et al., 2006) even though they believe that having friendships will positively contribute to their child's quality of life (Overton & Rausch, 2002). Similarly, parents of children with DD also report difficulty maintaining their own social relationships due to the increased demands on time that are associated with caring for their child with DD (Helitzer, Cunningham, Sabo, VanLeit, & Crowe, 2002). The social outcomes for families of children with DD are not homogeneous and it is possible that factors such as the child's specific diagnosis (Sigman & Ruskin, 1999), level of communicative impairment, behaviour problems (Renty & Roeyers, 2006), and school setting (Carter et al., 2014) may be predictive of the number of friendships and quality of life of the child as well as the subjective well-being and quality of life of the parent. The goal of the present study was to determine what factors are predictive of quality of life in children with severe DD and their parents, when compared to families of typically developing (TD) children.

# Methods

This study is part of the larger GO4KIDDS project looking at the experiences of children with severe DD in Canada. Parents of 454 children with severe DD (age M = 11.18, 70% male) and 210 TD children (age M = 10.65, 69% male) completed surveys on the general health, well-being and social inclusion of both the children and the parents.

# Results

Preliminary results suggest that 66% (n = 236) of parents of children with severe DD reported that their own social lives had suffered as a result of caring for their child. Similarly, 28% (n = 119) of children with severe DD were reported as having no friends (non-relatives) and 71% (n = 291) of parents of children with severe DD, reported that their child's friendships were of either "poor" or "very poor" quality. Parent reports indicated that 62% (n = 262) of children with severe DD were judged to be "quite happy" or "very happy" but parent reports indicated that only 29% (n = 121) were believed to be reaching their full potential. Ongoing analysis will focus on identifying predictive relationships between child and parent characteristics (e.g., child's specific diagnosis, parent's physical health) and factors related to quality of life (e.g., number of friends, happiness).

# **Discussion/Conclusions**

Our results indicate that, although children with severe DD and their families face increased challenges to social well-being and quality of life when compared to their TD peers, results are variable within this group. This highlights the need to look at resilience factors and individual differences that are predictive of more positive outcomes for families (Gardiner & Larocci, 2012). Such information can be used to guide family interventions and inform the provision of services that can best address the needs of families of children with severe DD.

# Life Events and Psychopathology in Adolescents and Adults With Autism Spectrum Disorders

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## Objectives

There is growing research to suggest that individuals with Autism Spectrum Disorders (ASD) are more likely to suffer from comorbid psychiatric diagnoses than the general population (Leyfer et al., 2006). However, very little is known about how particular psychiatric disorders are related to the experience of life events within this population. This is important given that both life events and psychiatric disorders contribute to the experience of crisis within this population. Life events experienced by those with ASD can impact interpersonal and routine-based distress but we do not know much about which life events are most likely to occur in this population. The current study examines the prevalence and types of life events that adolescents and adults with ASD experience and will explore the relationship between life events and mental health issues.

## Methods

Three hundred and ninety-six families participated in a longitudinal study on the health service use of their adolescent or adult children with ASD. Of those, 283 families provided information on life events at baseline and 3 follow-up periods. Similar to Milovanov et al. (2013), items from the significant life events scale were collapsed into 18 categories. The descriptions provided by parents under the "other" category were re-coded into the 18 categories where possible.

## Results

At baseline, 58.0% of the sample reported experiencing one or more life events over the past two months, the most frequently reported life events being mistreatment (22.3%), serious illness of a close relative, caregiver or friend (11.7%), and a change in primary staff/worker (11.7%). Individuals with a current psychiatric diagnosis were more likely to have had at least one significant life event in that 2-month period (67.2%),  $\chi^2$  (1, N = 283) = 8.18, p = .004.

## **Discussion/Conclusions**

We are currently examining cumulative life events over a 6-month period, and the association between such life events and psychiatric issues. From baseline data alone, we see that life events are common in this population, and that the occurrence of life events is associated with psychiatric disorder. It is important to support individuals with ASD when life events occur given the impact that life events may have on their emotional well-being.

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# Supported Entrepreneurship: The Social Return on Investment

## Objectives

As part of the Social Business and Marginalized Social Groups Community University Research Alliance based at the university of Toronto, Common Ground Co-operative and Brock University researchers have been examining the impacts of Common Ground Co-operative's approach to supported entrepreneurship for persons with developmental disabilities. The present study focused on calculating the organization's social return on investment (SROI) (Nicholls et al., 2009). Common Ground Co-operative provides administrative, educational and job coach support to 62 persons with developmental disabilities in five social enterprises all located in Toronto. These 62 people are non-share capital partners in these enterprises.

# Methods

This study built on themes from earlier studies (Bishop, 2013; Owen, Readhead, Bishop, Hope, & Campbell, in press). The present study added four individual interviews and a focus group with five social enterprise partners. In addition, phone interviews were conducted with five parents of partners. The focus group and interviews were designed to obtain descriptions of specific outcomes of participation Common Ground Co-operative training and job support for the partners and their families. Accounting calculations of SROI included comparison of the organization's services to proxies from other job training and employment support programs. Additional SROI calculations were based on organizational efficiencies identified in an earlier study (Bishop, 2013) and calculated by analysis of five years of financial statements.

# Results

Interview and focus group results were analyzed in the context of the impact of Common Ground Co-operative on quality of life of persons with developmental disabilities (Schalock & Verdugo, 2012). Partners and family members described changes in social enterprise partners' independence, social participation and well-being. In addition, family participants described reduction in their stress when their family member was accepted into Common Ground Co-operative's programs. Proxy comparisons were used to calculate the value of Common Ground Co-operative's training and employment support. The Common Ground Co-operative Foundations Program training was compared with College Community Integration Through Co-operative Education (CICE) programs and the organization's ongoing employment support was compared with a community organization that provides day program and community participation supports for persons with developmental disabilities. The added value of volunteers, low staff sick day claims and low staff turnover (both related to organizational culture), and minor carbon savings were also factored into the SROI calculations. SROI is not an exact accounting calculation however, using two realistic approaches to Common Ground Co-operative's funding and examining the savings and added value calculated through the SROI process, the range in annual return was 28%-51%.

# **Discussion/Conclusions**

The SROI narrative and accounting descriptions of the program content and outcomes provide a compelling picture of the return that funders can expect from their investment in Common Ground Co-operative. In a climate of constrained government funding and increasing pressure on corporate and private donors, SROI provides a way for social service organizations to clarify the contributions they make to the individuals they serve directly and to the larger society. The proposed presentation will elaborate on the results and implications of SROI for service advocates and administrators.

# Support Groups for Parents of Adults With Developmental Disabilities: Barriers to Attendance

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# Objectives

Parents of adult children with developmental disabilities often experience high levels of stress and poor psychological and physical wellbeing. Despite this, very few interventions exist to support parents. This is particularly concerning given our knowledge that parents who are highly stressed are less able to support their child, and experience poorer mental health. To address this issue, we offered parents a free support group aimed at reducing stress, depression, and anxiety, while increasing empowerment, psychological wellbeing, and acceptance. Although these sessions were free and respite care was provided, parents faced a number of barriers attending the groups. The following study aimed to discover which specific barriers to attending parent groups were encountered by parents with adult children with developmental disabilities.

# Methods

Flyers advertising the Parent Support Project were circulated to parents of adults with a developmental disability through Developmental Services Ontario, Toronto region (DSO). Parents interested in the project, contacted the research team to register. Not all parents who contacted the research team were able to participate. Of those that participated, not all parents remained in the group for the full 7 weeks. Barriers to attendance were explored in 2 ways: (1) via parents who contacted us, but were unable to attend; and (2) via parents who registered and attended at least one session.

# Results

In total, 96 parents expressed an interest in participating in the parent groups. Of these parents, almost half (49.0%) were unable to attend the groups after expressing initial interest. The most commonly reported barrier to attendance was timing. Over half of parents could not attend the group at that time because of work, school or other parenting responsibilities. Nearly 1 in 5 parents could not attend because of transportation issues, with the setting being either too far, or not being able to use public transportation. Other reasons for not participating included child issues (either child care, or child health), or parent issues including parent health or language barriers. Of the 49 parents who were able to attend the groups, the majority (85.7%) attended the groups regularly (attended at least 4 of the 7 sessions), with only 14.3% either withdrawing (4) or attending fewer than 3 sessions (3). The most commonly cited barriers to regular attendance included: (1) child issues (40% - includes childcare, child health problems), (2) parent issues (40% - includes health problems, language), and (3) transportation.

# Discussion/Conclusions

Results suggest there are a number of different barriers parents of adults with developmental disabilities encounter to attending parent support groups. These barriers should be considered when developing and organizing future groups for parents to help make them more accessible.

# Service Delivery to Individuals Affected by Autism Spectrum Disorders and Their Families

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## Objectives

An individual with ASD requires access to services that help with daily life, educational goals, employment and other lifestyle needs. The importance of services during the transition into and throughout adulthood has shown significance and can have an effect on the ability to obtain employment and support. This study analyzes the accessibility of services and support for adolescents transitioning into adulthood with Autism Spectrum Disorder. It also outlines the barriers to overcome in order to utilize services to benefit both the individual as well as their families.

## Methods

Qualitative interviews were conducted by experts in the Autism field and obtained information from young adolescent and adult individuals diagnosed with Autism Spectrum Disorder, their siblings and family members. The interviews were completed in a preferred place by the participant. The topic of service delivery was covered by both the participant and their caregivers. Five families were interviewed (caregiver N = 7; individuals diagnosed with ASD = 5; siblings = 4). Interviews were audio-taped and transcribed and have been coded for themes.

## Results

The response from the interviews showed that there were barriers in order to access services. In a specific situation, there was a hard time obtaining services from the school the child attended, it was not until the mother intervened and outlined what should be done that any progression was made. The difficulty in finding available services is only half the battle, being able to afford these services is a separate issue. The data shows that service delivery for Individuals with Autism Spectrum Disorder is inaccessible at times and has many barriers. However, even though it is hard to access, services can be extremely helpful and beneficial.

## **Discussion/Conclusions**

Resilience in relation to service delivery has a significant connection. The individual who uses the available services will seek help from their family to access them. These services can be provided by local groups, government sectors and separate companies. Funding for use can be distributed by the government to families based on their situation. Families rely on these services for normal day-to-day life experiences or for more stressful situations. All of these can be helpful to both the individual and the family psychologically and socially. The difficulty of achieving success is not reflected in the ability of the individual but in the services that fail to deliver. As indicated by the above research, individuals with ASD and their families can benefit from multiple service agencies in order to receive an adequate amount of needed support and therefore require adequate funding.

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# From Adjustment to Adaptation: Families **Raising Adopted Children With FASD in Ontario**

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## Introduction

Existing Fetal Alcohol Spectrum Disorder (FASD) research suggests that the majority of individuals raising children with FASD are adoptive or foster parents (Rowbottom, Merali, & Pei, 2010), but limited research has been conducted on the experience of non-biological families raising children with FASD in Canada (Watson, Coons, & Hayes, 2013). Many adopted individuals with FASD are diagnosed post-adoption (Williams, Dubovsky, & Merritt, 2011), but documentation of prenatal alcohol exposure is extremely difficult to obtain, thus confirming a diagnosis of FASD can be challenging. Ontarian resources are available for parents of adopted children with FASD, but little is known about their actual needs and available resources.

## Methods

Thirty adoptive parents with at least one child with FASD were recruited through FASD support groups across Ontario. Using a mixed-methods approach, informed by the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994), parents completed five quantitative questionnaires and a semi-structured interview. The questionnaire battery included the Parenting Stress Index (Short Form), Family Crisis Oriented Personal Scales, Child Behavior Checklist, Questionnaire on Resources and Stress (Friedrich's Short Form), and the Hope Scale. The interviews were analyzed using Interpretative Phenomenological Analysis (IPA) to gain an understanding of their lived experiences (Lyons & Coyle, 2010). Using a convergent parallel mixed methods design, the quantitative questionnaire data and qualitative interview themes were compared and contrasted (Teddlie & Tashakkori, 2009). Differences in family adaptation factors (i.e., capabilities and resources) were examined.

#### Results

Data analysis is in progress and full results will be available for this poster, but preliminary analysis of interviews reveals both challenges and rewards for families raising adoptive children with FASD. Parents discussed barriers to adaptation including a lack of information about the adoption, a lack of resources available when the adopted children reach adulthood, and a lack of understanding held by some formal supports, but parents also discussed strategies they found helpful including using humour as a coping mechanism, the use of support groups, and picking their battles. To triangulate the qualitative data, each theme will be further substantiated through highly endorsed items throughout the battery of questionnaires (e.g., how parents responded to the question, "When we face problems or difficulties in our family we respond by seeking encouragement and support from friends" on the F-Copes).

## Discussion/Conclusions

The present study will provide a rich, descriptive picture of the experience of raising an adopted child with FASD in Ontario. The results of this study will be used to inform Ontarian adoption agencies and general FASD formal services of the unmet needs of families of adopted children with FASD, as well as which services they consider to be most helpful.

# Support Received by Women With Intellectual and Developmental Disabilities During Pregnancy and Childbirth: A Case Study

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# Objectives

There is a growing number of women with intellectual and developmental disabilities (IDD) in the maternity population. In Ontario, there were 20.3 live births for every 1,000 women with IDD in 2009. Individuals with IDD generally have impoverished social networks, with most experiencing low to moderate levels of social support. However, very few studies have described the social networks that exist to guide women with IDD during pregnancy and childbirth. Indeed, women with IDD are currently a largely invisible maternity population. Our objective is to describe the structure and perceived quality of social support experienced by women with IDD throughout pregnancy and childbirth.

## Methods

We will present two in-depth case-studies selected from a larger grounded theory study which aims to develop a conceptual framework quantifying and qualifying the social support experienced by women with IDD during the perinatal period. Using information-oriented sampling, the cases providing maximal informative content will be selected from the larger sample of participating adult women (18+ years old) with IDD (as confirmed by developmental services agencies) who (a) have given birth in the last five years, irrespective of legal guardian status, and (b) have sufficient cognitive and verbal ability to answer questions about pregnancy and childbirth in an interview setting. Participants will be recruited from developmental services agencies based on service provider knowledge of women meeting the above eligibility criteria. Accessible information packages about the study will be sent to potential participants by association members. Following screening and basic demographic information ascertained through a telephone interview, detailed qualitative data will be collected through one-on-one semi-structured interviews based on a modified version of the Social Support Self Report (SSSR). For the purposes of our research, prompts were added in follow-up to the SSSR questions to elicit detailed qualitative information specific to pregnancy and childbirth. Interviews will be recorded and transcribed verbatim for analysis; content analysis will be carried out by two researchers. For each of the selected cases, we will present emerging themes, along with illustrative quotes, related to the structure and perceived quality of social support received during pregnancy and childbirth.

# Results

We are currently recruiting participants. Results are forthcoming.

## **Discussion/Conclusions**

These cases will offer rich, narrative detail on the sources of formal and informal social supports experienced by women with IDD during pregnancy and childbirth. A limitation to consider when interpreting the data is that our sample will only include women who have sufficient cognitive and verbal ability to remember and relay retrospective accounts of their maternity experience. This population is not homogenous therefore, information will not necessarily reflect the maternity experience of all women with IDD. Nevertheless, this depth of insight has not previously been available on this topic. Such information will be useful to generate hypotheses upon which future research can build. A greater understanding of the social supports available to women with IDD during pregnancy and childbirth will inform development and improvement of services that support women with IDD.

# From Research Into Practice: A Review of the Literature and Examination of Clinical Cases Series Pertaining to the Differentiation of Acquired Brain Injury and Learning Disabilities

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## Objectives

Paediatric acquired brain injury (ABI) is commonly associated with several neurocognitive sequelae that impede children's learning, behavioural and social functioning and, otherwise, success inside and outside of the classroom environment. Despite increasing awareness about the effects of brain injury, misdiagnoses of the neurocognitive impairments that impede learning functioning as learning disorders (LD) is a common clinical challenge. This creates difficulties for students who require assistance, as oftentimes they are mislabelled, are placed in a program not suited to their needs, or do not receive assistance. These difficulties are further exacerbated by the fact that only two Canadian provinces/territories presently acknowledge ABI as an exceptionality within the educational system. As a result, even when students with ABI are appropriately diagnosed clinically, the neurocognitive sequelae that impairs their learning most commonly also results in the formulation of individual educational plans for LDs. The current project informs clinicians, teachers, and front-line workers regarding the differentiation between learning disorders and ABI, provides remediation and compensatory strategies that have been shown to be clinically efficacious for each disorder, and highlights the ramifications that misdiagnoses can have on students emotionally, socially, and behaviourally.

## Methods

A systematic review of the literature was performed examining literature pertaining to the respective clinical presentations associated with LDs and ABI, the neuropsychological instruments pertinent to the differentiation between these two disorders, as well as the strategies that have been illustrated to be clinically efficacious for each type of impairment. Further, a clinical case series involving three clients who had sustained moderate to severe ABIs, but had been previously misdiagnosed with LDs was investigated.

## Results

It is well acknowledged that ABI is highly heterogeneous in the respective cognitive, behavioural, and social impairments that ensued following injury; relative to LDs, the neuropsychological profile reflects widespread limitations with skill sets that are particularly vulnerable to injury depending on the type of ABI (e.g., near-drowning, traumatic brain injury, etc.). Furthermore, while little research has been conducted to contrast these two populations, it is clear that the etiology, onset, and diffusivity of impairment are cardinal features of ABI that impede the successful strategies typically efficacious for those with LDs. Given that LDs are predominately genetic or congenital, these impairments in learning have persisted throughout their development; thus, children have developed a number of compensatory strategies themselves to aid their learning. Moreover, LDs are characterized by reasonable insight and situational specific frustration. Conversely, ABI is associated with abrupt onset, with little opportunity for self-derived compensatory strategies, and is not situation specific. Those with ABI tend to have poorer insight; and their frustration/emotional outbursts may be due to in part to compromised self-regulatory/executive function skills.

# **Discussion/Conclusions**

The differentiation between LDs and ABI is a clinically meaningful distinction that requires maintenance throughout the educational system. Distinct cognitive profiles and clinically efficacious strategies have been identified for both disorders, but the success of these strategies is highly dependent on proper identification. Misdiagnoses or categorizations are associated with poorer outcomes with respect to cognitive, emotional, social, and behavioural functioning.

# Sexual Offender's Perceptions on Early Life Experiences: Role, Gender and Forms of Parental Attachment

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# Background

Sexual offending is considered to be one of society's most deviant and horrific behaviours. However little is known about early life experiences of parental attachment, which may have an effect on the future development of sexually deviant behaviours. Specifically, whether there are differences in gender, parental role, and forms of attachment in early childhood between mother, father and the child. Using a feminist approach through grounded theory, this qualitative study will examine perceived attachment styles of those sex offenders who are currently residing in a medium security treatment facility, using a semi-structured interview. The aim is to better understand the risk factors of sex offenders so that improved clinical strategies can be implemented.

# Purpose

To examine perceived early life experiences, identifying family/social variables in an effort to determine possible risk factors leading to dysfunctional interpersonal relationships or sexual deviance later in life.

**Part one.** Attachment theory was used as a framework to explain offender's perceptions of interpersonal relationships (mother vs. father).

**Part two.** The study was analyzed through a feminist lens, to examine gender and power relations (of mother and father), and how this contributes to the offender's social constructions of gender, norms, and values with respect to gender differences.

# Methodology

Through a feminist lens, this research compared gender roles/power relations, observed by the offender's with respect to their mother and father during early childhood years. Perceived bonding styles between parent-child were also compared by genders.

# Methods

This study was conducted using a semi-structured interview method, through grounded theory. Two male participants with a dual-diagnosis, and a history of engaging in sexually offensive behaviours (with a prior conviction), were randomly selected for interview. Both participants were Caucasian between the ages of 21 and 24 years old, residing in a medium-security treatment facility within the developmental disability sector.

## Results

Part one. Attachment styles:

- Secure attachment-mother-child (both participants)
- Insecure-avoidant attachment-father-child (both participants)

**Part two.** Gender roles/power dynamics (mother/father):

• Drawing on liberal and feminist theories as a framework; exposed family or social variables associated with gender roles, identities, and constructions of power relations, which may pose a significant contribution to their subsequent deviant offense patterns. Please note: The research is in progress, and the above results are current results to date. The estimated completion date of this project is March 30, 2015.

## **Discussion/Conclusions**

The presentation will elaborate on these preliminary results, involving the discussion of grounded theory codes, and specific results related to how early life experiences, and social factors may result in risk factors associated with deviant behaviours in adulthood.

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# The Social Inclusion of a Child With a Severe Developmental Disability in School and the Community

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## Objectives

Children with Developmental Disabilities (DD) are at higher risk of being socially excluded (Solish, Perry, & Minnes, 2010) and can experience low rates of social inclusion, even when they are in integrated settings (Cooney, Jahoda, Gumley & Knott, 2006). Overall, there has been very little research surrounding the social inclusion of children with Severe DD. The Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) Canadian team project, explores the health, wellbeing and social inclusion of school aged children with Severe DD. The GO4KIDDS Social Inclusion study has demonstrated that, in community settings child factors played a large role in children's social inclusion. Children in integrated or mixed settings had higher ratings of social inclusion than children in segregated settings, and more social inclusion occurred when the activities were structured (Carvalho, Bebko, & Perry, 2014). In this poser, we present a case study in order to gain an in depth look at the social inclusion of a child with a Severe DD.

# Methods

"Jack" is an 8-year-old boy with ASD. A case study of his social inclusion in school and the community is presented. Data were collected from multiple sources including interviews with teachers, community leaders, and parents. Trained observers completed direct observations of social interactions in the school and community, providing information regarding the amount of time Jack spent interacting with others. Observers also completed ratings regarding how socially included they believed he was in each setting.

# Results

Jack is in a mainstream, integrated class, and attends a day camp. An interview with his parents gave a positive picture of his inclusion in both school and the community day camp. Jack's teachers also provided a positive description of his social inclusion in the school setting. In contrast, his community leaders reported he had more difficulty being included socially with the other children. Jack engaged in a range of types of play during the observations, including being engaged with adults, proximity play (playing near other children), onlooker (watched other children play), and joint engagement (actively playing with other children). Ratings of Jack's overall social inclusion ranged from completely included to not at all/somewhat included.

# Discussion/Conclusions

A combination of child factors and environmental factors appear to have contributed to Jack's different levels of social inclusion in the school and community. By examining these different child and environmental factors, we can better understand what helps and hinders the social inclusion process for Jack, and children like him, so that specific strategies can be developed to enhance children's social inclusion, regardless of their disability.

# Comprehensive Health Assessments for Adults With Intellectual Disability (ID) in Manitoba

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## Objectives

Researchers, practitioners, and decision makers are working together to determine the feasibility of implementing the Comprehensive Health Assessment Program (CHAP) for adults with ID in Manitoba. The CHAP was designed to help minimize the barriers to access primary health care for persons with ID. Research from Canada and abroad shows that significant health disparities exist between persons with and without ID. Despite poorer health and higher health-care needs, prior research shows that persons with ID experience more difficulty accessing proper health care than the general population. Persons with ID also reportedly have fewer opportunities to engage in health-promoting activities than the general population. As a result, preventable mortalities and comorbidities are more common among persons with ID than those without these conditions or than the general population. Results of the studies conducted in other developed countries show that health checks and Comprehensive Health Assessments can overcome some of the barriers to access proper health care for persons with ID.

## Methods

To address the stated research objectives, we have conducted focus groups and individual interviews with GPs, Nurse Practitioners, formal and informal caregivers of persons with ID. An Interpretive Description design was used for this qualitative study (Thorne, 2008). Interpretive Description is a qualitative methodology grounded in the constructivist paradigm with an aim of generating knowledge useful for the clinical context of applied health disciplines (Hunt, 2009; Thorne, 2008). Qualitative methods Purposive sampling of physicians, nurse practitioners, direct support workers and families who support people with ID in Manitoba were recruited. Data collection was through semi-structured individual interviews and two focus groups. In total, we conducted 24 semi-structured interviews with caregivers and primary care providers. The caregivers consisted of both support workers (n = 13), and family members (n = 6). The primary care providers included general practitioners (GPs) (n = 2), and nurse practitioners (NPs) (n = 3). A total of 18 individuals participated in the focus groups. This sample size was considered sufficient to elicit understandings from important stakeholders in the topic of interest (Thorne, 2008).

## Results

Four main themes were identified from the data. Benefits of implementing the CHAP were identified by every group. Some Barriers were identified, with the majority of them being discussed by the primary health care providers (GPs and NPs). Facilitators for the implementation of the CHAP however were also identified. Some needs were identified that would assist in successful implementation of the CHAP.

## **Discussion/Conclusions**

Overall, in this study we found an overwhelming positive support for implementing CHAP in Manitoba. To overcome the barriers reported in the study, several steps have to be taken including development of training modules for health care professionals, paid support staff and unpaid caregivers; financial incentives for health care professionals and change in regulations to facilitate the implementation of the CHAP in Manitoba. Future studies should evaluate not only the short-term but also the long-term effectiveness of the CHAP for improving health, well-being and continuity of care in people with intellectual disabilities in Manitoba.

# An Examination of the Specialized Support Within the Justice System for Accused With Fetal Alcohol Spectrum Disorder

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## Objectives

There is a growing body of literature that examines the experiences of those with intellectual disabilities involved in the justice system as accused and the challenges they sometimes encounter when involved in the CJS. Current literature has found that individuals with the Fetal Alcohol Spectrum Disorder (FASD) sometimes experience challenges within the justice system, such as difficulties understanding abstract legal concepts as well as communicating with various justice professionals. Although the UN Convention on the Rights of Persons with Disabilities (2006) has created a legislative framework that provides a layout for equity within the justice system for individuals with disabilities as accused, victims and witnesses, there is relatively minimal research that examines the structural constraints of the justice system in effectively supporting accused with the specific diagnosis of FASD. This study examines the current supports and accommodations available in Ontario for persons with FASD when involved with the CJS. In addition, there is a focus on suggestions by key players within the justice system and social service agencies about ways to most effectively address the needs of individuals with FASD within the justice system.

# Methods

In-depth semi-structured interviews will be conducted with approximately 30-40 support workers and justice professionals who work with persons with FASD. More specifically, between 15-20 participants will be professionals who work directly with individuals with FASD such as service support workers or administrators within agencies who support persons with developmental disabilities. The remaining 15-20 participants will be justice professionals who interact with individuals with FASD in a legal setting such as lawyers, police officers and diversion workers. Data will be collected within Ontario jurisdictions.

## Results

Data is currently being collected within Ontario jurisdictions. Although the results of this study are pending, it is expected that there are limits to the traditional, legal accommodations used to support individuals with FASD in accessing justice at the various stages of the CJS, calling for more specialized supports to assist individuals with FASD who have specific needs.

## **Discussion/Conclusions**

This research will help to inform academic and community-based organizations in assisting accused with FASD in navigating their way through the justice system with more ease, resulting in more equitable experiences.

# **Examining the Social Participation of Children With Intellectual Disabilities and Autism Spectrum Disorder in Relation to Peers**

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# Objectives

Participation in social and physical activities promotes physical, emotional, and social well being for children with or without disabilities (e.g., Geisthardt et al., 2002). However, despite the benefits, individuals with disabilities are often excluded from taking part in social activities (Bigby, 2012). Lack of opportunities to participate in activities may prevent exploration of various areas of development (King et al., 2003). Most of the research on activity participation has focused primarily on higher functioning children with disabilities. However, children with severe Developmental Disabilities are often excluded from this type of research because of their complexities and level of functioning. Therefore, the purpose of this study was to report and compare the social participation of children with Intellectual Disabilities (ID) and Autism Spectrum Disorder (ASD) in relation to a Typically Developing (TD) sample.

# Methods

The GO4KIDDS project explores the health, well being, and social inclusion of Canadian schoolaged children (4 to 19 years) with severe ID and ASD. A total of 186 parents of children with ID and 232 of those with ASD completed the Basic Survey. In addition, 210 parents of TD children completed the TD Survey. The surveys include a brief version of The Activities Questionnaire (Solish et al., 2010), which examines the frequency of participation of six types of activities. In addition, there are three questions regarding the child's number of friends, type of friends, and quality of these friendships.

## Results

One-way ANOVAs revealed that the TD group participated in significantly more social activities than the ID and ASD groups. In addition, post hoc analyses revealed that the TD group participated more often in each of the six types of activities than the ID and ASD group. For some social and recreational activities, the ASD group participated significantly less often than the ID group. Ninety-nine percent of the TD group have friends, whereas, 82% of those with ID and 64% of those with ASD have friend(s) ( $\chi^2$  = 89.45, p < .001). In addition, a greater number of children in the ID group had one or more friends than those in the ASD group ( $\chi^2 = 17.46$ , p < .001). The majority of the TD group have average to excellent quality of friendship, while the majority of the ID and ASD group have very poor to average quality of friendship  $(\chi^2 = 216.73, p < .001).$ 

## **Discussion/Conclusions**

Children with ID and ASD in this study were reported to participate in fewer social activities than their TD peers; in addition, those with ASD were participating less often in some social/recreational activities than those with ID. Although majority of children were reported to have friends, those with ASD had fewer friends that those with ID and their TD peers. Furthermore, those with ID and ASD had very poor quality of friendships. These findings indicate the importance of finding ways to encourage and provide opportunities for children with disabilities to become more involved in social activities and build friendships.

# Initial Outcomes of an Emotion Regulation Intervention for Children With Autism Spectrum Disorder

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## Objectives

This research investigated the acceptability and preliminary effectiveness of a manualized cognitive behaviour therapy (CBT) intervention (Secret Agent Society: Operation Regulation; Beaumont & Sofronoff, 2008) for improving emotion regulation (ER) in youth with Autism Spectrum Disorder (ASD).

## Methods

To date, data includes 13 male participants, aged 8 to 12 (M = 10.3, SD = 1.2), who had IQ scores > 80 (M = 108.54, SD = 10.4) and had been diagnosed by regulated health professionals with ASD. Pre- and post-intervention measures included (a) acceptability, reported by parents on the Emotion Regulation Checklist (ERC; Shields & Cicchetti, 1997) and children on the Children's Emotion Management Scale: Anger, Sadness, Worry (CEM; Zeman, Cassano, Suveg, & Shipman, 2010); (b) child psychopathology and adaptive behaviours, reported by parents via the Behavior Assessment System for Children, 2<sup>nd</sup> Edition (BASC-2; Reynolds & Kamphaus, 2006) and the Anxiety Disorders Interview Schedule (ADIS-P-IV; Silverman & Albano, 1996); and (c) treatment response, reported by a blind clinician rater using the Clinical Global Impressions scale (CGI; Guy, 1976), severity (CGI-S) and improvement (CGI-I). Data collection is ongoing as part of a larger controlled trial.

## Results

Children and parents completed all sessions (100%) and reported high satisfaction with the weekly session activities and the program overall. Therapist ratings of session activities and therapeutic alliance with children and parents were also high. Overall treatment integrity was 89.6% across 26 sessions (SD = 9.94, range = 65.4 - 100%). Parents reported significant improvements in children's emotional lability (t = 3.13, p = .005), a reduction in total psychiatric diagnoses (t = 2.80, p = .016) and diagnosis severity (t = 3.39, p = .005) on the ADIS-P-IV, and in internalizing difficulties on the BASC-2 (t = 3.18, p = .008). Blind clinician ratings on the CGI-I indicated that 69% (n = 9) children showed some level of improvement and a significant decrease in mean severity on the CGI-S (t = 3.95, p = .002). Children reported an overall decrease in dysregulation on the CEM (t = 2.14, p = .056) and increase in the ability to inhibit emotional responding (t = -2.32, p = .04.). Updated results are pending.

## **Discussion/Conclusions**

Preliminary outcomes suggest acceptability of the intervention and potential effectiveness in improving ER and decreasing psychopathology in children with ASD. This is an important area for further investigation due to the lack of evaluations of ER interventions for youth with ASD. Longer-term implications may include translation to community-based programs that require efficient, effective, and feasible ER interventions.

# Healthcare Students' Readiness for Interprofessional Learning in the Context of Developmental Disabilities

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# Objectives

Equitable health care is a basic human right that must be accessible and inclusive for all individuals. The world health report 2000 (WHO, 2000) defined "human resources for health" (HRH) as in c lu d in g all individuals engaged in provision of health care services. Health care professionals therefore must be able to respond to both the common and additional needs of children and young people with intellectual disabilities. The purpose of this study was to explore attitudes toward readiness for this shared responsibility through inter-professional learning among groups of healthcare students at four Canadian universities.

# Methods

**Participants.** This cross-sectional study included 594 students in Medicine, Nursing, Physiotherapy, and Occupational Therapy. All students were enrolled in entry-to-practice programs and were at different stages of degree completion.

**Measures.** The 19 item version of the Readiness for Inter-professional Learning Scale (RIPLS) (McFadyen et al., 2005) was included as part of a survey from a larger study examining health, education and parent factors influencing social inclusion of young children with DD (HELPS Inc). The RIPLS is divided into four subscales examining teamwork, positive and negative professional identity, as well as roles and responsibilities. An overall mean readiness score is generated as well. An adapted version of the McGill Inclusive Education Questionnaire (Daniel & Cornish, 2006) was used to rate students' perceived knowledge of and experience working with individuals with DD and perceived level of competence in working with individuals with DD.

## Results

Preliminary analyses indicate that participating students were predominantly female (81%) and there was a broad range in age from 18 to 35 years. Approximately half of the students were in the second year of their degree program. Most participants (56%) had a previous university degree but 32% had entered their program from secondary school. Overall the mean RIPLS scores were quite high (M = 4.10, SD = 0.50; maximum possible score = 5.00) but scores on the RIPLS subscales varied. Internal consistency was excellent (Cronbach's alpha = .90 for the RIPLS with the exception of the roles and responsibilities subscale (Cronbach's alpha = .47). This subscale includes the fewest items (3) and also had the lowest mean score (M = 3.78, SD = 0.69). Analyses will be conducted to examine how students' perceived, knowledge, competence and experience predict RIPLS scores, controlling for gender differences.

# **Discussion/Conclusions**

Successful collaboration requires team members to have a clear understanding of their own professional roles and responsibilities in relation to the focus for joint effort (Villeneuve, 2009). This poster will highlight healthcare students' reported readiness for inter-professional learning and the relative contributions of knowledge, experience and sense of competence to such

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readiness. The implications of these findings will be discussed in relation to entry-to-practice program curricula and the challenges of providing collaborative, inter-professional care for individuals with DD. Limitations of this study and directions for future research will be discussed.

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# The Social Inclusion of a Girl With Severe DD: A Case Study

## Objectives

Children with developmental disabilities (DD) are regularly integrated into mainstream classrooms and community settings. However, while they may be physically present in these environments, they are not always included in activities and are often ignored by their peers (Cooney et al., 2006). As a result, they often participate in social activities with adults (Solish, Perry, & Minnes, 2009). Therefore, it is important to examine the patterns of interaction that occur in school and community settings in order to understand the extent of social inclusion of these children. The Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) project explores the health, wellbeing and social inclusion of Canadian school-aged children with severe DD. One aspect of this study showed that child characteristics were related to children's social inclusion. Children in integrated or mixed settings had higher ratings of social inclusion than children in segregated settings. Finally, social inclusion occurred more frequently when activities were structured (Carvalho, Bebko, & Perry, 2014). The goal of this poster is to present findings from a case study of one child from this sample in order to gain a better understanding of her social inclusion across settings.

## Methods

"Mary" is a 13-year-old girl with Down syndrome. Data were collected through a variety of sources. Mary, her parents, teachers, and community leaders were interviewed. Mary's social interactions at school and in two community settings were observed by trained research assistants, using a coding scheme developed for the GO4KIDDS study.

# Results

Mary attended a public school where she was part of a special education classroom, and was involved in a dance class and camp. Her mother reported that her social inclusion in school was of mixed quality but more positive in her community settings. Three school staff members who were interviewed rated Mary as having social inclusion of mixed quality as well, although she was reported to have a group of friends with whom she socialized. Her community leaders also rated her social inclusion as being of mixed quality. She was reported to participate less than other children in camp but as much as others in dance class. The observational data suggested that Mary participated to the same degree as other children, understood the structure and expectations, and interacted well with the other children. An interview with Mary revealed that she felt that the children at school and in the community were mean to her but that the teachers and community leaders were nice.

# **Discussion/Conclusions**

Mary was a child who took part in school and community activities. Parent and teacher ratings, along with observational data, suggested that she participated and interacted with other children in these settings. However, Mary's perception of her interactions painted a slightly different picture. The diversity of these reports reveals the importance of obtaining information from multiple sources. This allows for a better understanding of children like Mary and is an important step to take in developing strategies to enhance the lives of these children.

# The North Community Network of Specialized Care Skills System Group – An Adaptation of Dialectical Behavioural Therapy for People With Developmental Disabilities Delivered by Videoconference

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## Objectives

The purpose of this presentation is to provide preliminary description of an evidence-based approach to helping people with mild to moderate developmental disabilities achieve goals in their lives by learning skills adapted from Dialectical Behaviour Therapy. People with developmental disabilities residing in Northern Ontario, particularly in remote communities, often find themselves without clinical resources to assist them in overcoming challenging behaviours or challenges related to emotional dysregulation. It is for these people that The Skills System was developed by Julie Brown, MSW.

## Methods

At this point in time, twelve groups of anywhere from 3–5 individuals, in addition to their support staff, attend a 12-week Skills System Group, held once weekly, by videoconference. The Group is taught via videoconference by the principle investigator (Skills Group Leader) and facilitated locally within each smaller group (breakout groups) by trained personnel - professional or paraprofessional. Each Group is two hours in duration and is organized into sections which alternate between teaching via videoconference and smaller in-group discussion. The Skills System is comprised of nine core skills and three skills system tools which helps the participants learn how and when to use the skills. Skills coaches (either paid support staff or caregivers) attend with the participants so that they familiarize themselves with the skills being learned and can provide coaching which facilitates the generalization of the skills to individuals' day to day lives. Most participants attend three cycles of 12-weeks prior to developing mastery in the Skills System. Participants undergo a contracting process prior to entrance in the group and then take part in a brief assessment using standardized psychometric instruments which are re-administered after each 12-week cycle. Retrospective behavioural outcomes will also be included in the evaluation of the project (serious occurrences, visits to the emergency department, hospitalizations, and arrests).

# Results

Preliminary qualitative results will be described and the evaluation project related to this endeavour will be outlined.

# **Discussion/Conclusions**

The North Community Network of Specialized Care Skills System Group, by virtue of its use of videoconference in combination with traditional group discussion, presents a unique and cost effective method of providing an evidence-based method of helping people with challenging behaviour, mental health difficulties, and problems with emotional dysregulation achieve their goals. It represents the preliminary model of a cross sectoral partnership in clinical service delivery.

Clinical/Research Implications & Novelty: No such skills teaching project has ever been undertaken on this scale and delivered by videoconference. The planned evaluation project is intended to demonstrate the effectiveness of the modification in mode of service delivery (hybrid videoconference/breakout group) from the original method outlined in The Skills System Instructor's Guide (Brown, 2011).