JoDD
Journal on Developmental Disabilities
Volume 30 Number 1, 2025
On-Line First

2023 RSIG Research Day Poster Presentations

*Posters marked with an ** were nominated for a poster award.*

**Research Matters…for Children: Using an Interactive Website to Share Research with Young Disabled Children

Abneet Kaur Atwal & Kathryn Underwood
Toronto Metropolitan University

Objectives: The Inclusive Early Childhood Service System (IECSS) project aims to understand institutional interactions of disabled children and their families. In discussions with the young disabled people on our Youth Advisory Committee, they shared that it was important for us to share our findings with young children in an accessible and engaging way. As a result of these discussions we worked with them to create a website to share research findings with young children.

Method: The IECSS project uses institutional ethnography to analyze institutional interactions and responses to disabled children and their families. During the course of the research project, the research team has produced academic articles, policy briefs, research reports, and presentations. To gain a thorough understanding of the key findings from the project, we went through these items and developed a list of key findings. While engaging in an iterative process, we worked with the young people to decide which findings would be important to share and how to make this information accessible for young children. Further, we worked with an illustrator to illustrate the key ideas that the young people wanted to share.

Results: Through the process of engaging with our youth advisory committee, we created 5 pages to share key findings with young children. These findings include Research matters…for children, Your opinion matters...for children, You matter…for children, Disability matters…for children and Your health and learning matter…for children. Each page on the website is accompanied by an illustration highlighting key ideas from the project and an audio option to listen to the key ideas. Further, the website is available in ASL, English, French, LSQ, and as a storybook to ensure accessibility.

Discussion: In conversation with our youth advisors they have focused on the importance of talking to young children about disability (Davies et al., 2021; Underwood & Atwal, 2019). However, adults tend to be scared to have these conversations (Underwood & Atwal, 2019) and there are limited resources available about disability and childhood that are specifically created for young children. The process of working with young people to create a website for children highlighted the importance of knowledge mobilization aimed at sharing research findings with a wide range of stakeholders, which includes young children themselves. Further, engaging in knowledge mobilization with young people, for young people can support researchers in developing resources that are engaging, informative, and accessible.

Associations Between Age, Anxiety, Cognitive Functioning and Social Impairment with Aggression in Youth with Autism

Ethan Rinaldo & Adrienne Perry
York University

Objectives: Aggression has been observed as a common and impairing behaviour in youth with a diagnosis of autism spectrum disorder. Previous research has indicated that aggression in children with autism is associated with cognitive functioning, age, anxiety, and social functioning, although most samples only include parent-report measures and participants without intellectual disability. Furthermore, there is a lack of research investigating how different aspects of social impairment are associated with aggressive behaviour in youth with autism while anxiety is included in the analyses. The aim of this study was to clarify the relationships of these variables with aggression in a large sample, diverse in age and cognitive level (including youth with intellectual disability), using both parent- and teacher-report measures.

Method: Participants were 1179 youth (age 4-18) with a diagnosis of autism spectrum disorder, with their data coming from the Simons Simplex Collection database that was assembled by the Simons Foundation Autism Research Initiative. Parent- and teacher-report measures were obtained for aggression, anxiety, and social impairment. Univariate statistics were calculated to determine how each variable was associated with aggression and hierarchical regressions were conducted with all variables together to determine which were most predictive of aggression. The hierarchical regressions used measures of IQ, age, social communication, social awareness, social motivation, social cognition, and restricted/repetitive behaviours.

Results: Both parent- and teacher-report measures indicated that anxiety and impairment in social communication were associated with higher levels of aggression while impairment in social motivation was associated with less aggression. Age, IQ, social awareness, social cognition, and restricted/repetitive behaviours all had small or nonsignificant effects depending on whether they were measured by parents or teachers.

Discussion/Conclusions: The findings that social communication impairment and anxiety are more predictive of aggression than the other variables may be explained by a combination of problems engaging in positive social interactions and the distress associated with social situations resulting in aggressive behaviour. It is possible this also explains why social motivation impairment was associated with less aggression, as a decreased tendency to approach others may result in a lower likelihood of aggressing towards them as well. These results indicate the importance of anxiety and social problems, particularly in social communication and motivation, when studying and treating aggression in youth with autism. This should be explored in the context of providing individual therapy as well as creating environments that youth with autism are comfortable in and result in positive social interactions with their peers. Future research should also focus on creating measures of aggression that are more appropriate for use with youth with autism and intellectual disability and should aim to incorporate more data from self-report measures when possible.

**A Qualitative Exploration of Clinicians' Experience Administering the SSDAAT-R

Carly Bumbacco[1], Shelley Watson[1], & Yona Lunsky[2]
[1]Laurentian University; [2]Centre for Addictions and Mental Health

Objectives: The Socio-Sexual Knowledge and Attitudes Assessment Tool-Revised (SSKAAT-R; Griffiths & Lunsky, 2003) was designed to examine the socio-sexual knowledge of people with intellectual/developmental disabilities. It was developed to support the evaluation of sexual education programs, to be used for research purposes, to identify socio-sexual needs for treatment planning, and as part of a comprehensive assessment. Although commonly administered by clinicians, less is known about how clinicians use the SSKAAT-R in their practice with clients. As such, the current study aimed to explore how the tool is utilized by clinicians in their daily work. The current study is part of a larger project aimed at updating the SSKAAT-R.

Method: Semi-structured interviews were conducted with 17 clinicians with experience administering the SSKAAT-R. Clinicians' job titles included psychologist, behaviour analyst, behaviour therapist, behaviour consultant, psychotherapist, case manager, and social worker. The interview guide included questions such as 'In your opinion, what are the strengths of the SSKAAT-R? In your opinion, what are the weaknesses of the SSKAAT-R? and are there specific topics that you believe should be added to a revised version of the SSKAAT-R?' Interview data were coded inductively and analyzed using thematic analysis (Braun & Clarke, 2006).

Results: Using thematic analysis, four themes were identified. Overall, clinicians used the tool in a versatile manner guided by clinical judgment, meaning that many clinicians chose to administer the full scale or select specific subtests related to client needs. Furthermore, clinicians often used the SSKAAT-R to identify client vulnerability or to inform forensic risk assessments. When asked about the two different sections of the SSKAAT-R, both the knowledge and attitudes sections were identified as integral to the tool, but for different reasons. More specifically, the knowledge section of the SSKAAT-R was helpful to identify clients' strengths and skill gaps to inform treatment planning. On the other hand, the attitudes section aided in better understanding their clients' beliefs as part of relationship building and advocacy, or to help understand their sexual behaviour.

Discussion/Conclusions: People with intellectual/developmental disabilities often have gaps in socio-sexual knowledge. As found in this study, clinicians described the SSKAAT-R to be a versatile tool, informing both assessment and treatment to address these gaps. Results from this paper will be used in the development of a revised measure that is responsive to the needs of clinicians and their clients with intellectual/developmental disabilities.

Occurrence, Predictors and Treatment of Mental Health Concerns in Youth with Intellectual Disability with or without Autism

Christina Carrier, Carly Magnacca, Ethan Rinaldo, Jeffrey Esteves & Adrienne Perry
York University

Objectives: Mental health concerns have been noted to be highly prevalent for youth with intellectual disability (ID), with or without autism spectrum disorder (ASD). The purpose of the current study was to examine a Canadian sample of youth with ID, with or without ASD, to determine how many have co-occurring mental health concerns. Further, we explored predictors of mental health concerns, including child sex, age, adaptive functioning, and diagnosis. Finally, we examined the treatment methods used to address mental health concerns, overall, and in subgroups, based on child sex, age, and diagnosis.

Method: The data from the present study came from the GO4KIDDS Basic Survey, a broad survey covering various aspects of the health, wellbeing, and social inclusion of youth with severe developmental disabilities. The sample included 358 caregivers who completed the GO4KIDDS survey on behalf of their child(ren) between the ages of 4 and 20 years ($M = 11.36$; $SD = 3.82$). Chi-square analyses were used to compare the likelihood of overall mental health concerns and treatment modality utilized in subgroups based on child sex, age, and diagnosis. Hierarchical logistic regressions were conducted to explore whether sex, age, diagnosis, and adaptive behaviour were significant predictors of mental health concerns.

Results: Approximately 56% of youth with ID (with or without ASD) were reported to experience mental health concerns. Youth with ID and ASD were significantly more likely to have mental health concerns compared to those with ID alone. In addition, youth who had mental health concerns had higher adaptive functioning than youth who did not. Adaptive functioning and diagnosis were significant predictors of mental health concerns, after controlling for child sex and age. Of the youth who experienced mental health concerns, 80% received some type of treatment, most commonly informal therapies (52%). Males were likely to receive formal behavioural therapies and also non-evidence-based therapies. Older youth (≥12 years old) were more likely to receive medication compared to younger children (<12 years old). Finally, youth with ID and ASD were more likely to receive formal behavioural therapies compared to youth with ID only.

Discussion/Conclusions: More than half of the sample experienced mental health concerns and, while the majority received some type of treatment, many of the treatments utilized are not evidence-based. It is concerning that youth with ID alone are less likely to be receiving evidence-based intervention. Also, many children with severe developmental disabilities are receiving medications, which may be due to low costs and being easily accessible. It is important for parents to be aware of the risks and benefits of the various treatment options as well as have access to evidence-based options.

**Exploring the Self-Diagnosis Experiences of Autistic Women at the Intersection of Gender and Autism

Francis Routledge[1], Yani Hamdani[1,2], Naomi Thulien[1,3], Meng-Chuan Lai[1,2]
[1]University of Toronto, [2]Centre for Addiction and Mental Health, [3]St. Michael's Hospital

Objectives: Autism, commonly diagnosed as Autism Spectrum Disorder (ASD) in medicine, has been heavily researched from a neurobiological perspective and described as a disorder consisting of deficits in communication, interaction, and expression. This biomedical way of understanding Autism has placed emphasis on research involving genetics, co-morbidities, and ways to address biological and behavioural deficits. Less attention has been paid to lived experience perspectives of Autistic people - the profoundly personal and emotional experiences of assessment, diagnosis, and health-related labels. Moreover, male and childhood lenses underlie how Autism is commonly understood and diagnosed. Limited understandings of Autism for non-men contribute to misdiagnosis, under-diagnosis, and diagnosis later in life, leading to consequences for health as well as access to supports and services. As a result, many adults, particularly women, have relied on or arrived at self-diagnosis. The purpose of this study is to explore the self-diagnosis experiences of Autistic women at the intersection of gender and Autism and aims to (1) describe self-diagnosis experiences of Autistic women, (2) examine how understandings of self-diagnosis, gender, and Autism shape their self-diagnosis experiences, and (3) explore the implications for them and their lives.

Methodology: This is a current study, and data collection is ongoing. Up to eight self-diagnosed Autistic women living in Ontario will be recruited to participate in their choice of a virtual interview or open-ended written questionnaire. Using two data collection methods will allow participants to choose a method that aligns closest with their preferences in sharing their lived experiences. The study aims to centre lived and personal experiences to enrich understandings of self-diagnosis through accessible data collection methods. Reflexive thematic analysis will draw on critical Autism studies and intersectionality as a conceptual framework that seeks to challenge underlying assumptions, deficit-based, and pathologizing ways of understanding Autism by exploring power relations and examining the ways intersecting systems of oppression overlap to advantage and disadvantage individuals and groups based on social locations. Qualitative coding will address the research aim to explore the self-diagnosis experiences of Autistic women at the intersection of gender and Autism. This will involve: 1) exploring what constitutes as self-diagnosis, 2) exploring the aims of self-diagnosis, and 3) examining how self-diagnosis, gender, and Autism are represented.

Results: This poster presents the preliminary results of an ongoing critical qualitative study. Preliminary results suggest that examining the self-diagnosis experiences and processes of self-diagnosed Autistic women provides a novel lens for understanding and challenging prevailing representations of Autism and gender and understanding the intricacies of self-diagnosis and its consequences.

Discussion/ Conclusion: Examining the self-diagnosis experience and process of self-diagnosed Autistic women will provide a novel lens for understanding representations of Autism and gender and the intricacies of self-diagnosis. This analysis will provide a critical foundation for creating needed support to address Autism diagnostic barriers, health care apprehension that women experience, and insights into a process undertaken by many Autistic adults who are not clinically diagnosed.

Thematic Analysis of Parents' Perceptions on School Experiences of Their Children with Severe Developmental Disabilities

Sarah Bjornson & Adrienne Perry
York University

Objectives: Education systems across Canada have adopted inclusive education policies for integrating children with Developmental Disabilities (DD) into mainstream schools and classrooms. However, research suggests that parents of children with DD frequently feel more supported by specialized schools and report lower satisfaction with mainstream classrooms. Additionally, parents of children with more severe DD report lower satisfaction with school services. Specific complaints from parents are that they lack choice in educational decisions and must fight for assistive services within schools. Additionally, adequacy of professional services and relationships with service providers have been linked to improved quality of life among families caring for members with DD but schools and educators have not been considered amongst these professional services and service providers. This is a critical oversight considering the significant role that schools play in the lives of all children and their families. The purpose of this research is to investigate parents' perceptions of school experiences for their children with severe DD.

Method: Data were collected through the GO4KIDDS project which was funded by a large team grant previously obtained by the Perry Lab at York University. Participants were 185 Canadian parents (89.9% mothers) ranging in age from 25 to 58 years ($M = 42$) of school-aged children with severe DD. The children were 73.0% male ($n = 138$) and ranged in age from 4 to 19 years ($M = 11.08$). Participants were recruited through websites and agencies providing services for children with DD, intellectual disability, and Autism Spectrum Disorder (ASD). Of these children, 41.1% had DD only ($n = 79$) and 57.3% had an ASD with or without a comorbid DD ($n = 110$). The majority (72.6%) of the children attended a public school ($n = 138$). Within schools, 11.4% of children were placed in mainstream classrooms with minimal assistive services ($n = 21$), 33% were in mainstream classrooms with one-to-one assistance ($n = 61$), and 41.1% were in special education classrooms ($n = 76$). Parents provided brief written responses to open-ended questions (e.g., "please add any comments about your child's school situation"). These responses will be analysed utilizing a Word Association Thematic Analysis method (Thelwall, 2021). Two raters will separately analyze responses to detect and contextualize word associations, so that inter-rater reliability can be determined. Coherent themes will then be established based on terms that have similar meanings or contexts.

Results: Results are pending thematic analysis. It is hypothesized that both positive and negative experiences will be reported within the school system. Specific themes expected to arise are regarding relationships with teaching and assistive staff, assistive services, types of classrooms, and institutional policies and procedures.

Discussion: Children with severe DD are often excluded from DD research. The proposed study will elucidate parental perceptions on the school experiences of these severely affected children. The results of the proposed study could have significant implications for families, schools, and service providers as they interact within the education field. A clearer understanding of the effects of school factors on families could be utilized to improve quality of life for those impacted by DD.

Parental Coping as a Mediator for Stress When Accounting for Child Variables of Children with ASD

Jordana Rotenberg[1], Adrienne Perry[1], Rebecca Shine[2]
[1]Department of Psychology, York University, [2]McMaster Children's Hospital, Hamilton Health Sciences

Objectives: Raising a child with autism spectrum disorder (ASD) comes with its joys but also many challenges, including increased stress among both mothers and fathers (though fathers are less studied). The characteristics of the child and the family can have a significant impact on the stress of parents, but this can be ameliorated by the resources and supports they have. Therefore, it is important to examine the three major areas of a parent's experience of stress: stressors, resources and supports, and parental outcomes (Perry, 2004). In particular, coping strategies and resiliency factors can be used to mitigate the impact of the stressors to produce greater positive outcomes. The purpose of this study is to explore how various methods of coping can mediate and/or moderate the relationship between child variables and parental stress in a large community sample of mothers and fathers of children diagnosed with ASD.

Method: Data were derived from screening assessments conducted at a public agency to determine eligibility for entry into the Intensive Behavioural Intervention (IBI) program. Families were included in the present study based on the child's diagnosis of ASD and completion of Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin et al., 1991) and the Parenting Stress Index – Short Form (PSI-SF; Abidin, 1995) by both the child's mother and father (N = 794 mother-father dyads). Children were between 18 and 83 months (M = 44.0, SD = 13.2) and most were male (84%) which reflects diagnostic ratios seen in ASD. Child variables were assessed using the Vineland Adaptive Behavior Scale (VABS; Sparrow et al., 2005) and the Childhood Autism Rating Scale (CARS; Schopler et al., 2010).

Results: Analyses are in progress but will be reported at RSIG. The degree to which coping mitigates the stressors associated with individual child variables will be analyzed (for mothers and fathers separately) using multiple regression analyses. Various subscales of coping will be examined with emphasis is placed on three types of coping: self-efficacy, passive avoidance, and acceptance.

Discussion/Conclusion: Based on the results of the multiple regression analyses, the present study will illustrate the relationship. between child variables and coping mechanisms on stress of mothers and fathers of children with ASD. Significant results may suggest that particular coping mechanisms should be emphasized for mothers and fathers in order to best mediate stressors associated with their child's diagnosis. This would be helpful for parents themselves and for professionals supporting these families.

Symptoms of Autism Spectrum Disorder in Probands and Siblings in Relation to Parents' Broader Autism Phenotype Traits

Zaina Aloissi & Adrienne Perry
York University

Objectives: Previous research has shown that siblings of children with autism spectrum disorder (ASD) can be at high risk for developing autism as well as other traits, such as features of the broader autism phenotype (Chawarska et al., 2014). The broader autism phenotype is characterized by family members of individuals with autism who may have certain observable traits of autism, but not significant enough to lead to a diagnosis. The goal of this study is to see if certain autistic traits (such as communication and social skills) of children diagnosed with autism and those of their siblings, and of their parents (non-diagnosed with autism) are related.

Method: The Social Responsiveness Scale (SRS) scores of children with autism and their non-diagnosed siblings will be measured and compared to the broader autism phenotype questionnaire (BAPq) scores measured in their parents. It is hypothesized that there will be a strong positive correlation between SRS scores in children with autism vs. BAP scores in parents, and between SRS scores in non-diagnosed siblings vs. BAP scores in parents. Measures will include the social responsiveness scale (SRS) for probands and siblings, and the Broader Autism Phenotype questionnaire (BAPq) for mothers and fathers. The SRS is a 65-item parent report questionnaire assessing social functioning deficits of ASD in youth aged 4 to 18 (Constantino & Gruber, 2005), and the BAPq is is a 36-item self-report questionnaire that assesses the defining features of the broader autism phenotype (Hurley et al., 2007).

Results: The present study involves data analyses of pre-existing data from the Simons Foundation for Autism Research Initiative (SFARI); an initiative aimed at improving the understanding, diagnosis, and treatment of ASD. Specifically, the dataset that will be analyzed comes from the Simons Simplex Collection (SSC), a core project of SFARI, in which researchers collected phenotypic data from simplex families (in which only one child is affected with ASD) (Gotham et al., 2013). In total, the SSC contains data from 2856 probands (the children with autism), 2278 siblings, 2830 fathers, and 2835 mothers. There were 2247 participants whose mother, father, and sibling all participated (Gotham et al., 2013). SSC probands were between the ages of 4 and 18 years, met criteria for autism on the Autism Diagnostic Observation Schedule (ADOS; Hus et al., 2014) and the Autism Diagnostic Interview, Revised (ADI-R; Cholemkery et al., 2016), and had a nonverbal mental age of at least 24 months (Gotham et al., 2013). Children with severe sensory impairments (e.g., blindness or deafness), motor difficulties, genetic syndromes, or medical histories (e.g., birth complications, history of severe nutritional deprivation, low birth weight) were excluded (Gotham et al., 2013).

Discussion/Conclusion: Understanding the correlation between the SRS scores in children with autism and their non-diagnosed siblings, with the BAP scores of their parents, can help provide more accommodating services for both the individual with autism and their family. At this current time, the results of this study are pending.

**Toward an Understanding of Direct Support Professionals who Experienced the Death of a Client During the COVID-19 Pandemic

Ann Hines[1,2], Sarah L. Bernier[1], Sabrina Campanella[1], Yona Lunsky[1], & Nicole Bobbette[3]
[1]Azrieli Adult Neurodevelopmental Centre/CAMH, [2]University of Toronto, [3]Queen's University

Objective: 43% of Direct Support Professionals (DSPs) surveyed throughout the pandemic have experienced the death of a client (Bobbette, Campanella, Hamdani, Thomson & Lunsky, 2022). Public health restrictions in developmental service agencies, isolation and increased workloads limited opportunities for DSPs to participate in traditional rituals related to death, and processing grief. This research explores experiences of DSPs who reported a client death during the COVID-19 pandemic and examines any potential impact on their levels of distress. This knowledge can assist agencies to improve grief-related services and supports for DSPs.

Method: A secondary analysis of a survey on DSPs mental health through COVID-19 pandemic collected at three time points was completed. The total sample (n=2099) included data from time one (T1) in June 2020 (n= 868), time two (T2) in June 2021 (n= 426) and time three (T3) in June 2022 (n= 805). Women were more represented at each time point (n= 738; n= 370; n= 660), and the majority of staff had over 20 years of experience. Descriptive statistics explored the frequency of client death experiences. Relevant demographics included age, gender, level of education, region, work setting, years of experience, mental health barriers and COVID-19 support. The 4-item Patient Health Questionnaire (PHQ-4) score was used to determine whether a relationship exists between client death(s) and distress (using mean differences). The authors engaged in qualitative inductive content analysis to identify key themes related to this phenomenon using responses to open-ended questions related to experiences of a client loss.

Results: Preliminary results indicate that more DSPs experienced client deaths unrelated to COVID-19 compared with COVID-19 only or multiple deaths. Our analysis is ongoing. The PHQ 4 analysis is pending at the time of this abstract submission, as is the qualitative analysis.

Discussion: This exploration helps us to understand the profile of DSPs that have reported the death of a client during this timeframe. Understanding the profile of DSPs experiencing client death by using this data may help create opportunities for grief support for DSPs and increase accessibility to mental health supports while acknowledging and validating the DSP experience. We can continue to explore potential impacts of age, years of experience, gender, and educational level as they relate to managing as a professional while balancing the human experience of grief in this relational field.

Limitations: Although the survey asked about whether a client death occurred, there was no specific question about the experience of the DSP related to those deaths. We drew on answers from other questions that include mention of death for the qualitative analysis which does impact the quality of the analysis. Issues of complicated grief due to isolation protocols may have also impacted distress level at various time points.

Reference:

Bobbette, N., Campanella, S., Hamdani, Y., Thomson, K.,& Lunsky, Y. (2022). Recognizing the Mental Health Needs of Direct Support Professionals: An Essential Workforce 2022 Update.