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

2021 RSIG Research Day Oral Presentations

Being Men and Women "The Right Way" and Staying out of Trouble: Gender Identity and Performance Among Adults with Intellectual Disabilities in Ontario Canada

Alan Santinele Martino
Carleton University

Objectives: To date, little attention has been paid to how people with intellectual disabilities develop and make sense of their gender identities (Björnsdóttir et al. 2017; Fitzgerald and Withers 2011; O'Shea and Frawley 2020), including how structural factors shape the very possibilities for multifaceted identities to exist within this social group. This gap is partly due to how people with intellectual disabilities are commonly de-sexualized and infantilized in ways that assume discussions about gender and sexual identities to be irrelevant (Björnsdóttir et al. 2017; Fitzgerald and Withers 2013). To address this gap, this presentation attends to how adults with intellectual disabilities make sense of their gender identities based on the "gender habitus" (Krais 2006) acquired in their lives. The gender habitus, which people acquire through socialization, shapes how individuals navigate the social world as gendered social actors.

Method: Drawing on semi-structured, in-depth interviews with 46 adults with intellectual disabilities (33 men and 13 women) in Ontario and building on the theoretical concept of "gender habitus," I explore participants' understandings of what it means to be a man or woman. To be eligible, participants had to be at least 18 years old, self-identify as having an intellectual disability, have a clear understanding of their legal guardianship status, live in Ontario, and have an interest in sharing their romantic and sexual experiences. Combining a larger sample size and a comprehensive eligibility criterion allowed me to access a diverse sample, including men and women of different ages. The data was examined from a critical-constructivist framework (Guba and Lincoln 1994) using thematic analysis (Aurini et al. 2016).

Results: Participants commonly experienced gender-segregated spaces, faced surveillance, and were taught limited understandings of gender. Failing to perform gender "the way right way," as some participants articulated, sometimes resulted in punishment and further surveillance in their lives. Unsurprisingly, many participants have striven to follow the limited gender roles offered to them. They often reported a shared belief that men and women are entirely different and that their roles differ within intimate relationships. However, for participants, it is not just a matter of drawing on dominant stereotypes. Instead, they have been actively taught simplistic formulas for being a 'good' man or a woman by people around them, which did not prepare them for real-life situations, much less for exploring the richness of gender identities.

Discussion/Conclusions: People with intellectual disabilities can sometimes be offered an extremely limited "menu of options" regarding gender identity and performance. Not only that, but they were also held accountable to heteronormative and de-sexualized ways of being a man or a woman by fear of landing into trouble with family members and direct care workers. The notion of "gender habitus" is useful for us to understand these sexualities as embodied gendered practices uniquely shaped by the intersections of disability, gender, and sexuality.

Coffee Talk: The Right to be an Artist

*Christina Yarmol**
York University

Objectives: The proposed presentation draws from my dissertation research entitled, The Right to Be an Artist: Operationalizing Studio Art Practices for People with Cognitive and Intellectual Disabilities that examines the practical, philosophical, fiscal and social policy realities of people over the age of 21 years with IDDs who want to live as artists in the community as a means of citizenship and life enhancement. The study strives to understand the importance of art practice in the lives of adults with IDDs to learn what they require in the studio to achieve their artistic goals.

Method: The multi-methods qualitative study weaves narrative inquiry and arts-Informed methodologies into an intricate tapestry employing methods such as review of literature, face-to-face interviews, observation, collaborative artwork, art creation, and the researcher's personal experiences as an artist, researcher and educator. It examines the everyday subjective conscious experience of artists form Creative Village Studio (CVS), an urban studio located in west end Toronto that is run by Community Living Toronto. The study drawings from 16 artists with IDDs artists' perspectives and includes interviews with three volunteers, three parents, three instructors and the site's facilitator who support the participants' art-making to learn how to operationalize studio practices and discover the conditions that make the studio a success for the participants.

Results: The presentation will outline ways in which studio staff, a social services agency and parents can provide a supportive environment for artists with IDDs to participate in art making. A series of handmade books holding the researcher's arts-based research responses, images of the artist-participants' artwork, and a co-created project of participants' portraits created in conjunction, one of the study's artist-participants Evelyn van Duffelen will be shared. This digital presentation will demonstrate that art creation at this studio is not simply about a social services day program but how art creation can be a vocation and lifeline for study's artists.

Discussion/Conclusions: The exhibition presents an example of how art practices, knowledge of artists with IDDs and artwork can be publicly commended, credited, and celebrated.

****2021 Recipient of the Student Award for Excellence in Research***

"We had to Shift and Shift": The Impact of COVID-19 Social and Physical Distancing Measurers on Direct Support Workers Supporting Adults with Intellectual and Developmental Disabilities in Rural Ontario

Anna Przednowek, Sharon Desormeau, & Sara Ouellette
Nipissing University

Objectives: To date, there is limited understanding of the impacts of COVID-19 and associated social and physical distancing measures on direct support professionals (DSPs) working in residential and community settings supporting adults with intellectual and developmental disabilities (I/DD). There has also been little acknowledgement of the innovative ways that direct support workers, agencies and communities have been responding to these situations, especially in often under-resourced rural settings. The perspectives of DSPs need to be investigated and included. Therefore, the purpose of this study is to explore the impacts COVID-19 and the associated public health measures and subsequent organizational policies and practices on the working conditions, care practices with, and care relations between DSPs and service users with I/DD.

Method: An instrumental case study of an agency supporting persons with I/DD was employed. In-depth interviews were conducted with 15 key agency staff, direct support workers, and family members of service users with intellectual and developmental disabilities. Preliminary data analysis was informed by feminist theories of political economy, ethic of care and critical disability which attend to the relationship between care or social reproduction (Duffy, 2011), capitalism and the market processes, and the role of states (Armstrong, 2010); and ensures that explanations of social and material worlds begin with disability (Kelly, 2013). The research integrates these with a feminist ethic of care framework, which uses a relational approach to understand vulnerable and oppressed people (Tronto, 1993).

Results: DSPs reported changes in their working conditions in a multitude of ways including having to change jobs, reduced/changed working hours, and increased uncertainty in the working conditions such as last minute and on-call work shifts. DSPs also reported engaging in technology related training that enabled them to pivot to remote service delivery. Finally, DSPs discussed the impact of these changes in their working conditions on their own wellbeing and the continuity of care and quality of services being provided to the people they support.

Discussion/Conclusion: This research highlights the impact that COVID-19 and associated public health measures are having on the working conditions of DSPs working in a rural Ontario setting. The preliminary findings of this study also highlight the importance of understanding the care relations between staff and the service users they support, and how these are shaped by organizational polices and practices. Understanding the experience of DSP's through a care relation lens is novel and contributes to the broader care theory scholarship (Armstrong, 2010; Duffy, 2011) which highlights the interrelation between conditions of work and quality of service/support delivery. Employing a relational lens warrants the inclusion of the perspectives of service users with IDD about the impacts of COVID-19 on their support delivery and the conditions of their everyday lives, which will be taken up by the authors in the next phase of the study.

COVID-19 Pandemic – Parenting an Adult Child with Autism Spectrum Disorder and an Intellectual Disability

Kirsten Penrose, Nadine Minott, Kelly Carr, Patti Weir, Nadia R. Azar, Chad A. Sutherland, & Sean Horton
University of Windsor

Objectives: COVID-19 has altered everyone's lives, creating uncertainty regarding the 'new normal' we will experience in the future. Precautions to prevent the spread of COVID-19 include the closure of schools, recreation facilities, businesses (cafés/theatres), and public places (parks), as well as the cancellation of social events. Throughout the COVID-19 pandemic, individuals have been confined to their homes, which created drastic changes to the everyday life of adults with disabilities as well as the mothers who maintain the role of primary caregiver. During these unprecedented times, where many support services have been cancelled or severely altered, it is important to understand the immediate and future needs of these caregivers. Therefore, the purpose of this study was to explore the everyday experience of parenting an adult child diagnosed with autism spectrum disorder and an intellectual disability (ASD-ID) during the COVID-19 pandemic.

Methodology: Ten mothers (M_{age} = 49.5 years) of adult, male children (M_{age} = 25.5) diagnosed with ASD-ID completed a semi-structured interview (35 to 90 minutes; April - October). Nine of the adult children co-resided with their mothers and one resided in an alternative living arrangement. A strengths-based perspective, which emphasizes abilities and resources, was utilized in this study to counter the traditional deficits-based perspective that focuses on impairment, weakness, and pathology. As such, non-directive probes were utilized to acquire information on resources, care, and alternative measures that otherwise might not be mentioned. Inductive thematic analysis was used to analyze the data.

Results: Three themes emerged, accompanied by seven subthemes, and were given meaning through participant quotes. The first theme, *Parenting Through a Pandemic*, included: (1) *talking to their child about the virus* - "I really felt [virus] was scary. But [child] doesn't understand that.", (2) *disruption to routine* - "it's been a huge, huge adjustment for [child] because he's used to going to a day program every day.", and (3*) social isolation* - "But he is isolated, totally isolated in a way, he's not with anybody." The second theme, *Resilience*, encompassed: (1) *adaptive strategies* - "We've altered the activities, like he's been doing some baking. And I got some activities, educational activities to work on, manipulatives and things to keep him occupied." and (2) *finding silver linings* - "We're all spending more time together…So, for me, I'm enjoying having this dinner at the table every night, like we don't usually have that." Finally, the third theme, *Future Considerations*, consisted of: (1) *financial hardship* - "[funding] still another issue. It's never enough to get me through the year." and (2) *parental recommendations* - "I think that where there should have been more support, is in places of mental health for families, it's hard enough to be in the home."

Discussion/Conclusion: The COVID-19 pandemic has forced mothers to provide around-the-clock care for their adult children with ASD-ID, while maintaining their other family and employment obligations. While the COVID-19 virus has produced obstacles, mothers have utilized various strategies to compensate for the changes in available services and programs, illustrating great perseverance during this unprecedented time.

Suicidality Among Individuals with Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder in Ontario, Canada

Kelly D. Harding[1,2], Katherine Flannigan[1], Amanda Ewasiuk[3], Dorothy E. Badry[1,4],Carly McMorris [5], Kathy Unsworth[1], Jocelynn L. Cook[1,6,7]

[1]Canada Fetal Alcohol Spectrum Disorder Research Network, [2]Laurentian University, [3]CASA Child, Adolescent and Family Mental Health, [4]University of Calgary, [5]University of Calgary, [6]University of Ottawa, [7]The Society of Obstetricians and Gynaecologists of Canada

Objectives: Individuals with prenatal alcohol exposure (PAE) and Fetal Alcohol Spectrum Disorder (FASD) experience significant mental health concerns, including suicidality (i.e., ideation, attempts, and deaths). Despite the high rates of suicidality documented within this population, the heterogeneity of this experience has not been investigated in Canada. The aim of the current study was to ascertain: 1. the prevalence of suicidality among individuals assessed for FASD in Ontario; 2. the demographic profile of individuals in Ontario assessed for FASD who experience suicidality; and 3. the demographic factors that may increase the risk for suicidality among these individuals.

Methods: Data for this study were obtained from the Canada FASD Research Network's National FASD Database. The database includes clinical and diagnostic information from individuals in Canada who are assessed for FASD. As part of a larger project examining suicidality among individuals with PAE and FASD across the country, a subset of data was analyzed for individuals residing in Ontario. Suicidality in this study was defined as previous suicide attempt(s) and/or suicidal ideation.

Results: The total number of participants in this sample was 144. Participants had a mean age of 13 years (SD = 7.7, range = 0 to 49) and 43.8% were female. Almost one-third (n = 45; 31.3%) of participants experienced suicidality; among these individuals, the mean age was 14.8 years (SD = 7.3) and 42.2% were female. Most participants who experienced suicidality were living with biological parent(s) (n = 12, 27.3%), other family members (n = 9, 20.5%), or in adoptive homes (n = 9, 20.5%). Sixty percent of participants experiencing suicidality were diagnosed with FASD. After controlling for multiple comparisons, there were no statistically significant differences in suicidality based on sex, living situation, or diagnostic factors. However, there was a significant age group difference, X2(2, 144) = 10.68, p = .005, with adolescents 13- to 17-years old experiencing the highest rate of suicidality (n = 18, 47.4%), which was significantly higher than that found in children 0-12 years (n = 17, 20.5%); the rate among adults 18 years and older fell in between (n = 10; 43.5%). Although differences in suicidality based on living situation were not statistically significant, two-thirds (n = 6, 66.7%) of participants living in institutional settings (i.e., group home, custody, or hospital in-patient) experienced suicidality, which was notably higher than those living in other settings.

Discussion: We found an overall endorsement of suicidality in 31.3% of the study sample, with individuals in adolescence and those living in systems-based placements demonstrating markedly higher risk. The prevalence rate found in this study is similar to findings published in other recent studies, both in the United States and Germany. These findings speak to the urgent need for screening, early identification of risk factors, timely intervention specific to mental health and suicidality, and broad suicide prevention initiatives across the lifespan for individuals with PAE and FASD.