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# 2023 Research Day Oral Presentations

## Objective Structured Clinical Examinations (OSCE) with Individuals with IDD as Simulated Patients Early in Medical Education

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**Objective:** Individuals with Intellectual and Developmental Disabilities (IDD) face unique physical and mental health needs. Yet, they are medically underserved and face numerous barriers. Furthermore, often medical professionals do not receive adequate training early in their careers serving individuals with IDD. This study aimed to address this gap by developing and implementing an Objective Structured Clinical Examinations (OSCE) with individuals with IDD as patient educators (PEs) for first and second-year medical students.

**Methods:** This was a pilot observational study, with first- and second-year medical students (n=25), participating in a virtual OSCE with individuals with IDD as PEs. The students were recruited from the Queen's University medical program (Kingston, Ontario, Canada). The PEs (n=5) were recruited across Ontario. Also, senior medical students and medical residents were recruited across Ontario (n=5) to assess all student-PE interactions as objective observers (OOs). The OSCE was conducted over Zoom and consisted of five virtual stations back-to-back. The stations' simulated scenarios were prepared by our research team together with the PEs and included real PE experiences with healthcare, adjusted to ensure anonymity. Demographic information was collected from every participant in the study. During the OSCE, OOs assessed student's performance using a Prediger scale. Prior to and following the completion of the OSCE, the students completed a self-report scale and a Prediger scale. After the OSCE, the students participated in a semi-structured interview to collect qualitative data. The demographics data and assessment scale scores (self-report scale and Prediger scale) were analyzed using descriptive statistics and effect size using Cohen D (d) analysis. The qualitative data was analyzed using NVivo with two independent reviewers. The analyzed data was used to determine whether the OSCE had a beneficial effect at improving comfort, communication skills and competency of medical students interacting with patients with IDD.

**Results:** Students reported a significant large effect size ($d > 0.8$), comparing their post-OSCE to their pre-OSCE scores (Self-report: $d = 1.96$, $p < 0.0001$; Prediger: $d = 1.34$, $p < 0.0001$). OOs reported a significant large effect size when comparing their assessments to the students' pre- and post-OSCE Prediger scores (pre-OSCE: $d = 1.86$, $p < 0.0001$; post-OSCE: $d = 0.79$, $p = 0.0013$). Prior to this OSCE, 80% of students reported not having an experience interacting with a person with IDD. Qualitative analysis yielded the following common themes: positive experience, perspective changes, and development of personal awareness.

**Discussion/Conclusion:** Most medical students reported not having experiences interacting with individuals with IDD. As a result, these students tended to rate their skills much lower, compared to the ratings provided by more experienced medical trainees (OOs). Then after the OSCE, these students rated themselves significantly higher and reflected positively on this experience, mentioning several self-realizations and changes in perspective. Thus, this study should encourage educators, curriculum developers and researchers to include individuals with IDD into medical education. This is a necessary change because of the unique experiences of individuals with IDD which cannot be accurately portrayed by other populations.

## Creating Study Materials for Qualitative Research with Advisors who are Neurodiverse

*Rebecca Hansford[1], Alyson Mahar[1], Virginie Cobigo[2], & Hélène Ouellette-Kuntz[1]*
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**Objective:** Individuals with intellectual or developmental disabilities (IDD) are more likely to experience worse cancer outcomes due to cognitive and communication challenges, increased social risks, and structural stigma, bias, and ableism. Breast cancer is a leading cancer among Canadian women. Our team recently documented worse survival among those with IDD relative to the general population across cancer stages, emphasising the need to examine factors beyond stage, such as cancer treatment. This research is a component of my dissertation project that will explore breast cancer treatment among people living with IDD using a convergent mixed methods design. My dissertation includes an integrated knowledge translation component, as advisors who are neurodiverse have been consulted to develop study materials. Advisors will also be consulted to disseminate the project findings in 2024.

The objective of this study component was to develop informative and accessible recruitment flyers, information letters, consent forms, and interview guides for cancer patients living with IDD who participate in the qualitative component of my dissertation research. This presentation will include my thoughts and lessons learned from this experience.

**Methods:** This project involved working with Open for Cognitive Accessibility (Open), headed by Dr. Virginie Cobigo. Through Open, I received training in Easy Read. Subsequently, advisors were recruited with flyers describing the work required for the study. I then met virtually with each of the advisors separately to receive feedback and guidance on the recruitment flyer, information letter, consent form, and interview guide. Advisors were emailed the materials before each meeting to ensure sufficient time to review the materials. Practice interviews were conducted to improve my skills and experience in interviewing adults who are neurodiverse.

**Results:** Including advisors who are neurodiverse allowed for lived experience context to inform the development of study materials. These meetings greatly enhanced the current version of the materials. For instance, the updated information letter described the research process more clearly, and a section for interview accommodations was added to the consent form. In particular, questions in the interview guide were greatly improved, including adding questions focused on reflection "Thinking now about your treatment, did you feel like you were involved in making treatment decisions". Advisors also provided clear feedback following the practice interview.

**Discussion/Conclusion:** Inclusive research is a vital component of conducting research with individuals living with IDD. Involving advisors in the development of study materials improved the quality and accessibility of the study materials. Further, their inclusion helped the focus of the project to remain on empowering cancer patients living with IDD. The practice interview was imperative for my gaining experience in following the interview guide while ensuring that interviewees felt comfortable describing their lived experiences. This experience has opened my eyes to the importance of inclusive research. I hope to speak to the value of including advisors living with IDD throughout research projects.

## Distilled, Tailored and Consultative Pedagogy in a Course Where People with Intellectual Disability Learn to Share Their Knowledge

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**Objective:** To operationalize a range of research findings about teaching new skills for people with intellectual disability into a course where they are expected to learn how to share their insights and knowledge for the purpose of taking on a leadership role in their organization (applied research).

**Methods:** This was a pilot course on leadership developed for a non-profit organization that supports people with intellectual disability. The NPO aims to bring more of their clients into paid roles in their organization and ideally roles involving leadership (this is a form of stakeholder engagement).

Course took place over 3 months with online and in-person elements. Highly interactive methods and regular adjustments rooted in engaging the stakeholders (course participants with ID) in learning but also shaping the process of learning.

Sample: 9 course participants; 18 to 30 years of age; mix of men and women, range of diagnosis/severity but all could communicate verbally or with talking mats; English and French speaking from across Canada.

This was *in vivo* or fluid/dynamic applied research in the sense that we did multiple iterations (during the course) to the format, content and teaching tools based on trial and error, and listening to the participants' experiences and feedback.

The approach was highly tailored to the group as a whole, but also each individual learner as we tried out different approaches and gauged comprehension and what kind of scaffolding was required.

**Results:** Successes: The course tools and content that were successful will be discussed and shown using slides and video footage from the course (with permission).

Areas for Improvement: Things we learned how to do better next time are also discussed and shown in video (about theme, content, tools and schedule).

**Discussion/Conclusion:** We developed a set of 6 core insights that we believe can help anyone who wants to design a course that would be suitable for adult learners with intellectual disability.

We also address how concepts like "leadership" need to be unpacked when it comes to people with intellectual disability – what is it really that we want them to learn and how can professors/teachers find a good balance between optimistic expectations and a course that sets people up for failure.

## SOL Express in the Time of COVID: Reflections from a Creative Arts Participatory Research Project

*Madeline Burghardt*[1]*, Andreas Perez* [2]*, & Kathleen Woo*[2]
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**Objective:** The purpose of this participatory research project was to explore people's experiences of participating in a creative arts program that utilized an online format during the Covid-19 pandemic.

**Methods:** With the onset of Covid-19 pandemic restrictions in March 2020, Sol Express, the creative arts group of L'Arche Toronto, moved its programming to an online format. In a response to a call by the editors of *Research in Social Science and Disability* to explore issues arising for disabled people due to the pandemic, Sol Express participants and creative facilitators decided to collaboratively design and carry out a participatory research project to explore the impact of the online format on individuals and on the group as a whole. A research team was established, consisting of two Sol Express members, four creative facilitators, and one academic who is a friend of the group. The research team designed and carried out the project, which consisted of four online Zoom sessions to which five more members of Sol Express were invited. In the larger online sessions, we explored the positive and negative features of an online format for a creative arts project. Participants were encouraged to use a variety of media, such as drawings, crafts, artefacts, music, and verbal sharing to explore fundamental questions such as 'what was good about doing Sol Express online?' and 'what was hard about doing Sol Express online?' Following the larger exploratory sessions, the research team gathered online to summarize what we had heard and to discuss themes. One team member, Madeline, was assigned to write up the findings. The paper was circulated and revised, after which the large group met to validate the findings and to finalize the paper.

**Results:** Findings indicate that there are both positive and negative consequences of online programming. Positive features include allowing people who live far away to join the group, thus increasing the program's geographic reach; people gain technological and problem-solving skills; and people have at least some connection with each other during a difficult time. Negative features include the lack of physical contact and connection resulting from online formats; the 'targeted' approach of online technology that prevents casual conversation and is particularly limiting for people with visual impairments; and the fact that online formats 'lose' people in the community who do not have adequate support to help them get connected. We also learned that participatory research can be an inclusive and empowering process!

**Discussion/Conclusion:** Our findings indicate that while online formatting is useful in situations where people cannot physically access programs and allows connection over large distances, it does not replace the energy and comradery that results from in-person contact. Online programs may 'lose' people who are inadequately supported or are unable to manage the technology, thus excluding them from otherwise beneficial programs, and making it difficult for program organizers to know who is missing from community-based programs.

## A Clinical Fellowship in the Psychiatry of Developmental Disabilities: The Importance of Training in an Underserved Area.

*Sarah O'Flanagan, Georges Loba-Gutierrez, & Rob Nicolson*
*Western University*

**Objective:** Although psychiatric disorders occur at a higher rate in people with Developmental Disabilities (DD), the lack of training opportunities in medical school and residency with this population has led to most clinicians feeling inadequately trained to assess and treat such patients. This study examined the impact of a Clinical Fellowship in the Psychiatry of DD in the Developmental Disabilities Program in the Department of Psychiatry at the Schulich School of Medicine & Dentistry at Western University which was designed to increase the capacity of psychiatrists in this area.

**Methods:** The fellowship utilizes a novel learning approach, leveraging the expertise in DD across the Schulich School of Medicine & Dentistry at Western. The fellow completed three-month rotations in interdisciplinary clinics in neurology, developmental pediatrics, genetics, and rehabilitation medicine. Also, rather than spending blocks of time in psychiatry, the fellow spent four days each week throughout the academic year in two psychiatry clinics, one for children and one for adults with developmental disabilities. This model allows the fellow to see the same patients multiple times over the year, allowing them to develop expertise in the ongoing management of mental health problems in people with DD. Surveys regarding the role and the impact of the fellow were completed by supervisors at the completion of the fellowship and a semi-structured interview was completed with the fellow at the completion of training.

**Results:** Data was analyzed and coded using grounded theory methods. 3 main themes emerged: The fellow provided psychiatric expertise in non-psychiatric clinics, reducing wait times to see a psychiatrist. The fellow provided education specific to DD and Mental Health to students and inter-disciplinary clinicians and teams across all clinics.

Having a fellow in clinic provided reciprocal opportunities for learning for everyone involved.

Supervising physicians reported overall that having a Clinical Fellow in the Psychiatry of Developmental Disabilities was extremely beneficial to their clinics and their patients. They, and the fellow also reported that the longitudinal, multi-disciplinary approach was critical to training the fellow.

**Discussion/Conclusion:** The purpose of the fellowship was to increase the number of physicians with expertise in DD. Based on the results from our first fellow we have achieved this goal, although continuation of the fellowship will allow us to collect more data. Based on the results from this study, the longitudinal model is integral to training, as is the participation in inter-disciplinary clinics.

## Reflecting on the Co-Production Process of a Peer-Led Support Program Developed with and for Newly Diagnosed Autistic Women

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**Objective:** Coproduced research, where decision making power is shared between researchers and community members, has a long history outside of autism research. Involving community members in the generation of new knowledge is often considered important to ensure research findings are impactful and to reduce the knowledge to research practice gap. Yet, genuine research collaborations between non-autistic researchers and autistic partners are rare. There is also little consensus about what coproduction is, or the most effective coproduction methods with autistic partners. Finally, the extant literature often does not reflect on the tensions that can arise throughout coproduced research processes, which can impact participant and research outcomes.

This presentation will highlight our current study focused on the development of a virtual peer-led support program co-developed *with* and *for* newly diagnosed autistic women. We will review various models of collaborative research practices, our key methodological learnings, and the infrastructure needed for effective and supportive coproduction based on our ongoing work within an interdisciplinary, neurodiverse team.

**Methods:** Our team is composed of autistic self-advocates, clinicians, and researchers. We acknowledge the intersecting identities of our team members. Adopting a critical and reflective stance, we will provide a brief overview of the history of coproduced research, review relevant examples of partnerships within autism research, and position our own team's values and methods.

**Results:** Several important considerations for effective collaborative research with non-autistic and autistic partners, including practical communication strategies to encourage candid collaboration and foster mutual respect within a neurodiverse team and virtual working environment, will be outlined. We will discuss how our methodology requires flexibility as we encounter and adapt to cultural (e.g., traditional views of autistic people as passive participants in research vs. active research partners) and structural barriers (e.g., institutional hiring practices) that have impacted our work within a neurotypical-dominated research and clinical space.

**Discussion/Conclusion:** Following the principles of 'nothing about us without us', the autistic community has fought for their rightful inclusion in research partnerships. There is growing interest in participatory and collaborative methods in autism focused research, which carries the potential to improve the translation between research and practice. Authentic co-production, however, is a time and resource intensive endeavor and requires careful reflection and intentionality to be delivered to a high standard.

## Burnout of Direct Support Workers of Adults with Intellectual and Developmental Disabilities: A Systematic Review

*Katelyn Soucie-Vukmanich & Rosemary Condillac*
*Brock University*

**Objective:** Burnout literature is growing and suggests that a multitude of work, client, and personal stressors increase burnout levels of direct support workers (DSW) who support adults with intellectual and developmental disabilities (IDD). However, previous systematic reviews indicate that burnout research is inconclusive due to varying research methods and limited study and result replications and that burnout levels for this population are average (Skirrow & Hatton, 2007). To our knowledge, there is no updated burnout trends for DSWs of adults with IDDs. The purpose of this presentation will be to report the current trend of DSW burnout as measured by the Maslach Burnout Inventory (REF), review variables which were consistent correlates of burnout across studies and report the current gaps in the literature.

**Methods:** This systematic review followed the PRISMA guidelines and methods of Skirrow and Hatton (2007) to report on correlations and predictors of burnout in DCWs working with adults with IDDs. A Boolean string was inputted into PsychINFO and Medline on March 30, 2021, to search for articles to include in the review based on a predetermined list of inclusion and exclusion criteria such as being published between January 2004 and December 2020, clientele were adults with IDDs, research participants were 80% or more DSWs, and more. Following extraction of the correlations, effect sizes, and burnout scores, comparisons of correlations, meta-regression intercept analyses, visual analyses were completed to compare the results from Skirrow and Hatton (2007) to the current results.

**Results:** Meta-regression intercept analyses show significant increases in risk of burnout when measured by emotional exhaustion ($p < .001$; 95%CI [-1.790, -.571]) and personal accomplishment ($p < .001$; 95% CI [0.553, 1.443]) scores, and significant decreases in risk burnout as measured by depersonalization scores ($p = .008$; 95% CI [0.103, 0.685]). Additionally, when Canadian studies from the current sample were examined separately, higher risks of burnout were found for emotional exhaustion and depersonalization, with lower risks of burnout for personal accomplishment when compared to both Skirrow and Hatton's (2007) and the current samples average coefficients. Finally, it was found that 0% of demographics, 60% of client-related, 76% of workplace-related, and 50% of personal characteristics showed consistent significant results across studies in the current sample.

**Discussion/Conclusion:** The presentation will discuss the findings which suggest that risks of burnout measured by emotional exhaustion and personal accomplishment are rising, while depersonalization is improving since the initial systematic review by Skirrow and Hatton (2007) and that work-related variables remains the most consistent significant correlated variable group with high risk of burnout.

## A Visual Inquiry into the Social Support Networks of Adults with Intellectual and Developmental Disabilities Using Eco-Maps

*Anna Przednowek & Leanne Ganter*
*Nipissing University*

**Objective:** While there is an active call to include people with intellectual and developmental disabilities (IDD) in research, they continue to be underrepresented in research about issues central to their everyday lives (Park & Hutton, 2018). The exclusion of persons with cognitive differences from research is an ethical issue that can align with lack of accessibility to research participation. Researchers have a responsibility to include diverse voices in research, especially those hard-to-reach populations who may experience a number of access needs. While eco-maps as a practice and research tool have been effective in mapping out social relations with caregivers (Rempel et al., 2007) and youth (Rogers, 2017), we propose that that they may offer an additional benefit of creating greater access to research participation for persons with cognitive differences who may benefit from information being presented in a visual way. Following the work of Boxal & Ralph (2009), we position that the inclusion of people with IDD in research through the use of visual methods such as eco-maps can help create greater access to research participation and thus help to address the issue of research exclusion/inclusion. The following presentation will discuss the use of eco-maps as a visual tool used to map out social relations in the lives of people with IDD and and reflect on eco -maps as an access promoting tool used to create greater access to research participation.

**Methods:** An eco-map is a social work assessment tool that involves the process of mapping out a person in their environment (McGoldrick, 1985). It facilitates the opportunity to map out social relations in a visual way (Carpenter-Aeby et al., 2007) and helps to bridge the practice-research gap (Harold et al., 1997). Eco-maps align with feminist methodology (Mercier et al., 2004) to study the everyday life, care and social relations with person with IDD. To date, eco-maps as a research tool have been adapted for research with caregivers (Rempel et al., 2007) and youth (Rogers, 2017) but have not been utilized with persons with IDD. The following study centered the perspectives of adults with IDD (n=27) over the age of 21, about the conditions of their everyday life and care in rural and urban Ontario under austerity. The semi-structured interviews were supported by the visual mapping of the availability, quality and access to informal and formal supports such as agency support, families and communities by person with IDD. The interviews and eco-mapping were also supported by participant observations.

**Results:** The use of eco-maps created generated a snapshot of social supports and services for adults with IDD at a particular time and place. The visual mapping also facilitated greater access to research participation for many of the adults with IDD who participated in this study. Participants were engaged and many required fewer verbal prompts to map out and discuss the presence and quality of support and services in their life.

**Discussion/Conclusion**: The study did not set out to evaluate the effectiveness of the use of eco-maps as a visual research method, but rather eco-maps were utilized as a visual aid and an access promoting tool to help facilitate semi-structured interviews about the supports and services in the lives of persons with IDD. While the use of visual eco-map supported active engagement in research by participants with IDD and facilitated sharing of rich narratives for the participants involved, the semi-structured interview and visual mapping do not facilitate access to participation for all person with IDD, especially those who experience visual impairments or those who do not communicate verbally. Further, while the researcher was prepared to address access to research participation for persons experiencing a variety of impairment related access needs, it is possible that some individuals experiencing visual impairments or those communicating through non-verbal means might have self-selected not to participate in the study when they read the information letter. Future research should evaluate the effectiveness of eco-maps as visual and access promoting tools.