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Let's Listen: What do Caregivers Have to say About Reducing Their Child with Autism's Needle Fear and Pain?

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Background: Children with Autism are at greater risk for difficulty undergoing needles due to their needs, including high rates of medical-related phobias, sensory atypicalities, and communication difficulties; all of the aforementioned can lead to poor management of their needle fear and pain, making medical visits complicated and/or traumatic. Despite all these risks and available guidance for neurotypical populations, little is known about how to make needle procedures more comfortable for children with Autism. Stakeholders have yet to be included in developing clinical practice guidelines or resources for managing needle pain and fear in this population.

Objective: To address this gap in the research, an initial needs assessment was conducted by interviewing 20 Canadian caregiver stakeholders. The in-depth and semi-structured interviews aimed to identify the modifications and additions caregivers perceive to be needed for needle fear and pain management protocols to be appropriate, actionable, and accessible for children with Autism and themselves as caregivers. Hypotheses were not generated given the exploratory nature of this work.

Methods: Caregivers reflected on their child's past experiences with needles and answered rating and open-ended questions about the appropriateness of different pain and fear management strategies for their child. Interviews have been transcribed verbatim and are being analyzed using descriptive statistics and inductive thematic analysis.

Results: Data analysis is in progress as of January 2022. Preliminary findings indicate that needle procedures in Canada have been challenging for families with a child with Autism and existing practices have often not been sensitive to and inclusive of children with Autism's needs. In line with the Conference theme, this presentation will focus on the themes identified that relate to inclusion, such as themes of individualized service delivery (e.g., no one-size fit all resource), self-advocacy (e.g., families calling ahead to advocate for child needs), and non-inclusive aspects of existing strategies (e.g., verbal distraction often being ineffective).

Implications: It is imperative to consult with stakeholders to make needle procedures accessible and comfortable for children with Autism and their families. This study has helped to identify how existing needle fear- and pain-reducing clinical practices can be adapted and what additional practices are needed. This knowledge can ultimately help to improve the health of the

Autism population by reducing their risk for painful needles, chronic needle fear, and/or healthcare avoidance.

Exploring a Good Life with People with an Intellectual Disability Using Participatory Audio/Visual Methods

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Objectives: The overarching purpose of my research was to explore the perspectives of people labelled with an intellectual disability (PLWID) on a good life and to create and share knowledge about the conditions that make it possible for PLWID to articulate their vision. The research was situated within the sociohistorical context of the province of Ontario. My main research questions were: 1) What is a good life from the perspectives of PLWID who use various forms of augmentative and alternative forms of communication (AAC) and, what can we learn from past advocacy efforts? What are the possibilities and limitations offered by participatory audio/visual methods for enabling PLWID to articulate their vision of a good life?

Methods: To explore these research questions, I used participatory audio/visual methods and combined approaches from supported decision-making (SDM) to facilitate thinking about and communicating ideas about a good life. A total of five adults identifying as having an intellectual or developmental disability and as facing significant daily barriers to communication took part in the study. A total of nine family members, support workers and friends also took part in the study at various stages and in different capacities. A visual representation of a quality-of-life framework linked to the Convention on the rights of persons with disabilities (Verdugo et al. 2012) served as a springboard to explore a good life with participants.

Results: Collaboratively, a total of 34 video vignettes were produced revealing that participants value participation (arts and sports) and relationships (family and friends). These results also reveal that individualized supports to facilitate thinking, choosing, and communicating ideas about the good, are necessary for meaningful participation in research and for exercising autonomy.

Discussion/Conclusions: The findings of this research indicate the need to continue exploring methodological approaches that facilitate the participation of people with intellectual disabilities and others who face barriers to communication and cognition in research. The research documents how participatory audio/visual methods in combination with strategies drawn from supported decision- making provided practical assistance to people with intellectual disabilities when thinking about and communicating their ideas of the good. At an individual level, cognitive and communicative assistance that is tailored to each participant is a necessary condition for meaningful participation. At a societal level, this research also suggests that deep structural changes are needed to enable the direct participation of people with intellectual disabilities in the design, implementation, and evaluation of supports and services meant to enable their full participation. A few possibilities are explored.

Examining the Effectiveness and Efficiency of Individual Support Plans: A Community-Based Research Project

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Background: Individual Support Plans (ISPs) play a significant role in ensuring that the value-based disability-related goals of international and provincial legislation—promoting human rights and improving quality of life (QOL) outcomes—are brought to fruition. The ISP is a living document that, through person-centered planning practices, guides the day-to-day supports provided to persons labelled with an intellectual and/or development disability (PLWID/D). The quality and standards of care that are received by an individual can be linked to the effectiveness and efficiency of an individual's ISP. Literature has demonstrated that ISPs are most effective when an individual's identified needs and wants are aligned with clearly defined goals, when matched support strategies are used to meet those goals, and when measurement tools to monitor and evaluate individual and team progress toward those goals are in place. Further, ISPs are more likely to demonstrate improved QOL outcomes when the goals capture and promote the following QOL domains: self-determination, personal development, interpersonal relationships, social inclusion, rights, and physical, emotional, and material well-being. Unfortunately, research has demonstrated that the ISP and accompanying processes are often inadequate in meeting the intended purposes of guiding day-to-day supports and practices and improving QOL outcomes. This project aimed to promote the achievement of improved QOL outcomes for PLWID/D supported by Community Living Haldimand through a collaborative examination of their current ISP framework and processes. The goal was to provide recommendations for a new ISP framework shaped by current research on effective and efficient ISPs, and authentically founded in the expressed concerns and recommendations of those who currently are responsible for developing, implementing, monitoring, and evaluating the effectiveness of the organization's ISP.

Methods: In a document analysis, 9 completed ISPs were examined to determine the presence or absence of the components of an effective ISP and the number and types of QOL domains. A Nominal Group Technique (NGT) and participation from Coordinators and Supervisors assisted in capturing culturally sensitive language surrounding QOL and the ISP process. This involved asking participants to provide written responses to questions about how they would define QOL and the 8 QOL domains (noted above), as well as what it means for someone to have a good QOL. The NGT was followed by a focus group that discussed the processes related to the development, implementation, monitoring, and evaluation of ISPs. The final phase involved a questionnaire that was distributed to 180 Direct Support Workers (DSWs). DSWs were asked to rank order their preference for the descriptions and definitions developed through the NGT process and rate their agreement with the description of concerns and recommendations related to the ISP process as identified by Coordinators and Supervisors.

Results: The results of this study are forthcoming.

Conclusions: Recommendations for a new ISP framework included the use of culturally sensitive language and support and training for identified areas of concern (e.g., training on identifying needs and wants and defining goals). A description of the methods used in this study may assist other organizations in the evaluation and improvement of their ISP process.

COVID-19 Pandemic: Parents Find Innovative Ways to Connect with Their Children who Reside in Supported Independent Living Environments

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Objectives: The COVID-19 pandemic has forced individuals with autism spectrum disorder and an intellectual disability (ASD-ID) out of their daily routines, often triggering anxiety and challenging behaviours. With the cancellation or modification to daily supports, parents have experienced difficulties accessing resources. Notably, the environment in which an individual with ASD-ID lives is crucial to their well-being. Unique challenges exist for parents with children residing in supported independent living environments. Social distancing measures often resulted in limiting interactions to ‘virtual visits’, or ‘physical distancing visits’, increasing anxiety for both parents and their adult child. In specific instances, families were no longer allowed to visit their loved ones at all. Therefore, the purpose of this study was to explore the everyday experience of parenting an adult child diagnosed with ASD-ID who were residing in supported independent living environments during the COVID-19 pandemic.

Methodology: Ten mothers (Mage = 60.3 years) of 8 male (Mage = 30.6 years) and 2 female (Mage = 34.5) adult children diagnosed with ASD-ID completed a semi-structured interview (May – December 2020). 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. Non-directive probes were utilized to acquire information on resources, care, and alternative approaches that parents utilized. Inductive thematic analysis was used to analyze the data.

Results: Three themes emerged and were given meaning through participant quotes to expose the realities that parents faced through the COVID-19 pandemic. The first theme, *Visitation Restrictions*, helped to elucidate how parents experienced different challenges when living separately from their child – “I couldn't see him for months because of the rules put out by the Ministry of Health. So, that was a little bit hard for me as a mother.” Parents sought ways to bypass these restrictions - “We just went and sat outside for an hour.” The second theme, *Limitations in Communications*, demonstrated the difficulty parents had communicating with their child - “She can't talk, so I just felt that if I saw her or if she saw me [on video chat], she wouldn't understand why I wasn't there, and I was afraid she would get self-abusive or upset and agitated”. However, some were able to overcome these barriers – “They set up an Instagram for her... they would post pictures of her for me to see.” The third theme, *Need for Emergency Services*, signified the urgency for appropriate services during periods of crisis – “When she left home, ...she was only 15, and there wasn't a place for her (to go) at that time.” Parents laboured to ensure their voices were heard – “We had to advocate for the smallest things.”

Discussion/Conclusion: While restrictions have been put in place to prevent the spread of COVID-19, mothers and their adult children with ASD-ID residing in supported independent living environments have experienced several obstacles to their daily routines. However, mothers have been innovative in utilizing various strategies to adapt to the ever-changing protocols, illustrating profound resilience during this unprecedented time.

When a Seat at the Table is not Enough: A Participatory Action Research Study on Collaborative Partnerships in Ontario Developmental Services organizations

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Objectives: Historically, developmental services (DS) evolved largely guided by the knowledge and direction of non-disabled service providers and the government. However, a human rights approach, as promoted in the UN CRPD, demonstrates the need to shift power toward service users labelled with developmental disabilities (lw/DD) such that they have greater voice, choice, and control over the design, implementation, and evaluation of DS. Unfortunately, little research exists on how service users are participating in Ontario's DS organizations nor how they would prefer to have their voice heard at an organizational level. Existing theories and literature reveal the importance of *collaborative partnerships* where power is shared with service users through participatory decision-making, shared leadership, and opportunities to participate with influence. Addressing this gap, this study explored how service users envisioned collaborating in partnership with DS organizations and what model of collaborative service planning and participatory decision-making best met their goals for inclusion.

Methods: Four self-advocates lw/DD collaborated as co-researchers in all phases of a participatory action research study. The study explored methods of collaborative service planning and participatory decision-making and facilitators of participation service users identified as inclusive and effective in DS organizations. Nine adult service users lw/DD and twelve leaders/managers of eight Ontario DS organizations participated in virtual semi-structured interviews. Thirteen service users participated in two focus groups. Consensus coding and thematic analysis were applied, and results are currently being written.

Results: Findings suggest a model that may meet service users' inclusion goals is a s*trategy* of participation that integrates service users' expertise at each level and stage of the service delivery cycle coupled with an approach to involvement that positions them as experts and partners with the power to effect change. This model consists of the following key elements. At the outer layer is a *supportive organizational culture* including leaders who value it, champion it, and offer multiple means to participate at multiple levels. Service users are viewed as partners and collaborators in designing and planning services and their input is actively sought through consistent means of participation. Within that supportive context, are *methods of participation that are inclusive and influential*. This involves formal methods of participation integrated into organizational planning and decision-making processes. These methods position service users as experts and full members of the group with equal decision-making authority and power to influence change on important topics affecting services. Participation is accessible and involves equipping and education. Methods include a representational body of service users (e.g., advisory council) with representatives on the organization's board. At the centre are *committed and supported members* who are passionate about making the lives of people lw/DD better and the services they use stronger. These members are supported and encouraged to participate.

Discussion: Our findings draw from the experiences and expertise of service users lw/DD to offer key elements of effective collaborative partnerships between service users and DS organizations. This presentation will discuss our collaborative approach to research and the key elements of this model including its consistency with existing literature and unique contributions.