Examining Individualized Participatory Approaches to Care for Individuals with Intellectual and Developmental Disabilities

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Background: Patient-centred care plans (PCPs) have been identified as a favourable upstream intervention for community-care populations to improve client outcomes, client and provider experiences, and reduce costly and preventable health service utilization; however, there is limited evidence on implemented approaches.

Aim: Our study aims to address this gap by exploring individualized participatory approaches to care planning as a means to improving health and social care. We intend to understand the key components and impacts of the approach utilized by a community-care organization including the types, features, and factors that support or hinder the use of participatory approaches for developing PCPs.

Methods: Our study utilizes an integrated knowledge translation approach (iKT) and as such involves a collaboration between the knowledge users, PHSS, a provincial community-care organization based out of London, Ontario, Canada, and a Western University research team. Members of PHSS and Western University were involved in all aspects of the research design, starting from developing the research question, creating the interview guide, and recruiting participants. Research team members will be actively involved in the analysis of findings and knowledge dissemination. Using a convergent parallel design, we are conducting a mixed-methods study consisting of two parts: 1) qualitative interviews (n=11) with PHSS staff, and 2) a scoping review. The scoping review will be guided by Arksey and O’Malley’s methodological framework for scoping reviews.

Results: The study is currently ongoing. For the qualitative interviews, we anticipate that the organization’s culture (including their mission and values) and implemented practices that allow for flexibility and adaptability, alongside large support from upper management are important factors that support the utilization of PCPs. It is expected that the benefits of PCPs for persons-supported and their families are inclusivity and the opportunity to lead a full and meaningful life. Moreover, it is expected that PCPs provide motivation for staff to plan and implement the preferences and activities outlined in a PCP. For the scoping review, based on a preliminary search we ran on the MEDLINE (OVID) database, we anticipate finding a small body of evidence that is relevant to our aim. We expect that the literature will demonstrate diversity in the definition of PCPs, community-care services, and implemented practices that are considered person-centred, and participatory. As such, we anticipate that the findings from our scoping review will provide a
wide range of data in identifying types and features of PCPs. Implications: The outcomes of this research project will be utilized to inform PHSS and support the spread of their participatory, person-centred approach to care. The findings will also encourage professionals of an international audience to implement PCP practices for similar vulnerable populations.

**Next Steps:** We believe that this project will demonstrate the link between PCPs and improved standards of care and health equity for community-care clients. As we anticipate a wide variety in many aspects of PCPs in community-care services, future research can focus on developing a framework for PCPs to standardize the patient-centred practices to improve health and social care for community-care clients.