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

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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Abstract

Person-centred plans have been identified as an upstream approach to addressing the inequities experienced by individuals with intellectual and developmental disabilities. However, little evidence on implemented approaches exists. This integrated thesis consists of two studies exploring individualized participatory approaches to care within community-care services, guided by an integrated knowledge translation approach. The first study is a scoping review aimed to identify individualized participatory approaches to care in the literature. The second study is a qualitative descriptive study utilizing semi-structured interviews with community-care staff (n=11) to understand an operationalized person-centred planning approach. The scoping review provides insight into the variability of care planning approaches while the interviews highlight key features of an operationalized approach that has led to positive impacts on the persons-supported and care professionals. These studies provide evidence to fill the gap between theory and implementation, supporting the spread of person-centred plans within community-care organizations across Canada.

Keywords: person-centred care, community care services, intellectual and developmental disabilities, care planning, participatory approaches, integrated knowledge translation

Summary for Lay Audience

Person-centred care has received significant support to involve the individual in decisions regarding their care. This typically involves discussions between the person and care professionals to understand the person's wants and needs and effectively respond to them. There has been notable movement towards person-centred care approaches, such as person-centred planning. Person-centred plans (PCPs) have been identified as a promising approach for individuals with intellectual and developmental disabilities, to fully understand a person's care needs as well as life goals. PCPs are meant to move beyond health care to encompass social care, facilitating a goal-setting process for individuals to live meaningfully, engaging in activities that they enjoy.

This thesis consists of two studies, a scoping review and a descriptive study. The scoping review was conducted to identify relevant literature on PCPs to understand the features and resulting impacts of these approaches to care. The descriptive study aimed to understand how PCPs are practiced in a community-care organization and the impacts of their approach from the perspective of care professionals.

The findings from the scoping review revealed huge variability in how PCPs can be practiced within organizations. There was no clear consensus on how to implement PCPs and a lack of studies showcasing the impacts of these approaches. The descriptive study identified the importance of centralizing services around the individuals they serve, which can be facilitated through PCPs. It also revealed positive impacts on the individuals themselves and the care professionals.

The studies illustrate that PCPs have the potential to improve health and social care for vulnerable populations. The findings from this research can support organizations in implementing similar approaches to PCPs. It is important that future research explores how PCPs have been implemented in other organizations and the perspectives of persons-supported and their families.

Co-Authorship Statement

Both studies included in this thesis are part of a larger project, designed by the primary investigator [Dr. Maria Mathews], co-investigator [Dr. Shannon L. Sibbald], and members of the PHSS leadership team [Brian Dunne and Donnie Antony]. The primary researcher of this thesis, MD, was brought onto the project to facilitate the scoping review and interviews with PHSS staff.

Chapter 2 – Scoping Review

The scoping review protocol was written by MD. MD then worked with a librarian researcher [Roxanne Isard] to develop a primary search strategy. Data collection was completed by MD and Gillian Young and the resulting data was analyzed by MD. The manuscript will be submitted in the summer of 2023 to the Journal of Intellectual & Developmental Disability.

Chapter 3 – Qualitative Descriptive Study

Recruitment was completed by MD with support from the leadership team at PHSS. Data collection in the form of semi-structured interviews was conducted entirely by MD. Data analysis was conducted by MD, SLS, and Jasmine Dzerounian (an additional member of the research team). The manuscript will be submitted in the summer of 2023 to the Journal of Intellectual & Developmental Disability.

Final Thesis

The manuscripts were drafted by MD with feedback from SLS and an advisory committee. The final version of the thesis was completed by MD and approved by SLS and an examination committee.

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List of Abbreviations

CSNs: Complex Support Needs

IDs: Intellectual Disabilities

IDDs: Intellectual and Developmental Disabilities

iKT: Integrated Knowledge Translation

MCCSS: Ministry of Children, Community and Social Services

PCC: Person-Centred Care

PCPs: Person-Centred Plans

QoL: Quality of Life

Chapter 1

1 Introduction

This first chapter presents a brief introduction to the topics of this thesis highlighting the issues that sparked the research project. Specifically, I discuss the health and care of individuals with intellectual and developmental disabilities, patient engagement, person-centred care, and the community-care sector.

1.1 Background

Intellectual and developmental disabilities (IDDs) are defined as lifelong conditions that develop before the age of 18 and are characterized by limitations in intellectual (IQ ≤70; ± 5 points for error) and adaptive functioning (American Psychiatric Association, 2013). Adaptive impairments are further defined as deficits in "personal independence and social responsibility" that do not "meet developmental and sociocultural standards" (American Psychiatric Association, 2013, p. 33). An adaptive impairment impacts "at least one domain of adaptive functioning – conceptual, social, or practical" abilities – requiring the individual to need support in "one or more life setting" (American Psychiatric Association, 2013, p. 38).

Patient engagement practices in health care have emerged as a strong recommendation and critical element in disability research for improving healthcare quality for populations with IDDs (Purbhoo & Wojtak, 2018; Sullivan et al., 2018). Patient engagement practices (often known as patient and public involvement in the United Kingdom) include sharing, consulting, deliberating, and collaborating with patients, their families, and healthcare practitioners (Health Quality Ontario, 2017; Purbhoo & Wojtak, 2018). For the purpose of this study, patient engagement is defined as the partnering of clients, their families, and professionals to collectively understand the client's values, needs, experiences, and goals to cooperatively respond to their needs, wishes, and requests (Health Quality Ontario, 2017). These practices can aid in developing the knowledge, confidence, and skills of clients, helping them to participate in their care planning and improve their overall care experience (Health Quality Ontario, 2017; Purbhoo & Wojtak, 2018; Sullivan & Heng, 2018). Further, it provides the

opportunity for care services to centre around clients, leading to higher quality care that is effective, timely, and equitable (Dhala & Tepper, 2018). Better care can result in less demand on health and social care systems and improve resource utilization and distribution in the long run (Sullivan et al., 2018).

The population of individuals who experience disability worldwide is approximately 15% (World Health Organization, 2021), while the population of individuals living with IDDs makes up approximately 1% (315, 470) of the Canadian adult population (Durbin et al., 2019; Morris et al., 2018). There is a complex mix of etiological factors related to IDDs, including environmental, genetic, infectious diseases, and complications during birth (Boat & Wu, 2015; Katz & Lazcano-Ponce, 2008). Of those Canadians ages 15 and above who report being formally diagnosed with a developmental disability or disorder, only 25% describe their health as "good" or "very good" (Health Canada and the Public Health Agency of Canada, 2021). This coincides with the complex health issues this population often face, differing in prevalence, progression, severity, and manifestations compared to the general population (Kamalakannan et al., 2021; Sullivan et al., 2011). Individuals living with IDDs experience health challenges that vary across their lifespan in regard to severity and type, illustrating an intersection of health disparities (Forrester-Jones et al., 2021; Rowland et al., 2014; Sullivan et al., 2018). As physical and mental health care needs and preferences are linked to age, development, social support, and the environment (Forrester-Jones et al., 2021; Sullivan et al., 2011), health challenges are usually unique to each person. This highlights the importance of person-centred care, which should entail co-designed care plans that place the person at the centre of their care service to align care and support with their needs, wants, values, and beliefs (Cramm & Nieboer, 2017; Purbhoo & Wojtak, 2018). Finding and receiving appropriate, specialized, and high-quality care for this population can be difficult (Rowland et al., 2014; Sullivan et al., 2011; Todd et al., 2020). Sullivan et al. (2018) relate this to the lack of understanding of the needs of individuals with IDDs at both a population and individual level, which may also be due to the lack of population-based research (Todd et al., 2020). Moreover, this can result in the escalation of symptoms and illness, leading to "ineffective monitoring of preventable conditions and missed opportunities to promote health and well-being" (Bobbette et al.,

2019, p. 2507). Person-centred care and patient engagement practices can be utilized side-by-side to develop individualized health and social care plans for individuals living with IDDs and complex medical conditions (Purbhoo & Wojtak, 2018). This highlights a variety of approaches in which professionals can collaborate with their clients to enhance the journey toward achieving an individual's health and social goals (Martin et al., 2016; Potvin et al., 2019).

Individuals with IDDs and the Community-Care Sector

Seventy-five percent of Canadians ages fifteen and above who report being formally diagnosed with a developmental disability or disorder also report receiving help with at least one daily living activity such as preparing meals (Health Canada and the Public Health Agency of Canada, 2021). In addition to relying on family members or informal caregivers for support, this population commonly utilizes community-care services (Lin et al., 2019). Community-care refers to community-based health and social care services, including community support services, supportive housing, personal care services, and social care that assists individuals with daily activities such as in-home care (Humphries, 2015; Kuluski et al., 2017; Purbhoo & Wojtak, 2018). These services can typically range from support for daily living skills such as help to get up in the morning and preparing meals, to more complex medical and intimate personal care. This can include helping someone use the bathroom and taking medication. As well, it may involve social care support to access education and engage in meaningful activities such as paid or unpaid employment and other lifetime goals such as finding a loving partner (Lin et al., 2019; Purbhoo & Wojtak, 2018).

PHSS Medical and Complex Care in Community (previously known as Participation House Support Services) is a provincial community-care organization based out of London, Ontario, Canada that utilizes a person-centred, participatory model of care (PHSS, 2023). The organization employs individual service agreements and person-centred plans (PCPs) to tend to each individual under their care, providing a road map of services and support with options tailored to individual needs and capacities. This study will describe the evidence base for individualized participatory care in community-care and work with the organization PHSS Medical and Complex Care in Community (PHSS)

to further examine their use of individual service agreements and PCPs for individuals living with IDDs and complex medical conditions.

Note About Terminology

It is important to consider the use of inclusive and respectful language when researching individuals with disabilities. As there have been major evolvements in disability language, researchers within the field have been left questioning whether to use person-first or identity-first language, causing tensions in academia (Andrews et al., 2022). This thesis utilizes identity-first language with person-first constructs, guided by Dunn and Andrews (2015) and Andrews et al.'s (2022) examinations of the evolution of disability language. There are differences in preference noted in the disability literature when it comes to person-first (e.g., person with a disability) versus identity-first language (e.g., disabled person) and there is no clear consensus (Crocker & Smith, 2019). Preference on language may change throughout an individual's life as it is connected to their identity, which develops over time (Andrews et al., 2022; Botha et al., 2021; Crocker & Smith, 2019). As such, it is my understanding that there is no solution for all and person-first as well as identity-first language can be used in academic writing (Andrews et al., 2022; Crocker & Smith, 2019).

It is noted that in community-care, the terms 'persons', 'people', or 'person-supported' are preferred over 'patient' as it directs focus on the individual rather than the medical conditions they may experience (Crocker & Smith, 2019). There has been an effort to remove the term 'patient' from this project to support the language used in community-care and PHSS's philosophy. However, the literature is filled with widely recognized terms including 'patient engagement' and 'patient-centred' that do not support the preferred language. The term 'client' is also widely used in the literature, though the Latin root of the word 'cliens' can be described as a follower (Shevell, 2009). This contradicts our project and the aim to empower individuals with IDDs. As such, the terms 'person', 'person-supported', 'individual', and 'people' are used wherever possible. Language is an important topic within disability research as it can influence how a person feels about themselves, perpetuate ideologies, and impact care (Botha et al., 2021; Crocker & Smith, 2019); it is further unpacked in chapters 2 and 3.

1.2 Research Question and Objectives

The goal of this research was to gain an understanding of individualized participatory health and social care models for individuals living with IDDs and complex medical conditions within community-care. This research answered the following question: How do individualized participatory approaches to care planning play a role in improved health and social care for individuals living with intellectual and developmental disabilities?

This project addressed the following four objectives:

1. To identify the types and features of participatory approaches used to develop care plans for individual persons with IDDs and medically complex needs who receive community-care services;
2. To identify factors that support or hinder the use of participatory approaches for developing care plans for persons-supported in the community-care sector;
3. To understand the effectiveness and impact of participatory approaches to developing individual care plans in the community-care sector; and
4. To understand the key components and impacts of the individualized participatory individual service agreement/PCP approach utilized by PHSS.

Using a convergent parallel design to answer the research question and objectives, the project had two studies (Creswell, 2014). The first study was a scoping review that aimed to identify types and features of participatory approaches used to develop plans as well as identify factors that support or hinder the use of participatory approaches for developing care plans for the identified population in the community-care sector. The second study was a qualitative descriptive study consisting of semi-structured interviews with PHSS staff that aimed to understand the key components and impacts of the individualized participatory individual service agreement/PCP approach used in the PHSS model of care.

1.3 Rationale

Ninety-two percent of Canadians ages 15 and above who report being formally diagnosed with a developmental disability or disorder also report a co-occurring disability

(Health Canada and the Public Health Agency of Canada, 2021). This population is regarded as being among the most vulnerable populations due to their complex health issues (Bobbette et al., 2019), and they face challenges accessing timely and appropriate health care that fit these health needs (Durbin et al., 2019; Sullivan et al., 2011). Yet, despite these needs, according to Sullivan et al. (2011), this population is poorly supported by the Canadian healthcare system, as well as healthcare systems abroad in other high-income countries including Australia, the United Kingdom, and the United States. Lin et al. (2019) further argue that there is a lack of healthcare support because of fragmented health systems. Due to problems with the availability and accessibility of appropriate care, missed opportunities to promote health and manage symptoms contribute to poorly managed chronic conditions (Bobbette et al., 2019).

There is limited literature focusing on already implemented individualized participatory approaches for individuals living with IDDs and complex medical conditions. Additionally, there is a lack of primary sources centring on the impact of such practices, as well as the availability of supports. It is important to map existing literature and identify already implemented approaches for this population as it is a strongly recommended practice in this field of care (Purbhoo & Wojtak, 2018; Sullivan et al., 2018). Moreover, it is salient to provide evidence on already implemented individualized participatory care practices to determine how to best move forward in supporting the improvement of health services. The rationale behind the methods chosen is further explained in chapters 2 and 3.

These studies are part of a larger project led by Dr. Maria Mathews called *Achieving the quadruple aim: An assessment of a participatory approach to develop individual patient-centred care plans for community-care services* that responds to PHSS's request for evidence on their model of care. Specifically, they requested researchers from Western University to provide evidence on the effectiveness and scalability of their person-centred approach to promote and expand their services. The larger project consists of three studies: (1) the Components and Impacts Study, (2) the Context Study, and (3) the Scoping Review. The Components and Impacts Study consists of semi-structured qualitative interviews with PHSS persons-supported (or their family) and PHSS staff. The qualitative interviews with the PHSS staff are included in this thesis

project. The Context Study involves semi-structured qualitative interviews with administrators of community-care organizations in Southwest Ontario. The third component is the scoping review, which is also included in this thesis project.

1.4 Impact of COVID-19

While this thesis did not focus on the impacts of COVID-19 and the resulting government restrictions, I acknowledge that COVID-19 may have had an impact on the research process and findings. COVID-19 had a significant impact on the community-care sector due to the vulnerable health needs of the population they serve (Navas et al., 2021), and this was reflected in the interviews. As such, future research should explore the impacts of COVID-19 on these studies and PCPs.

1.5 Structure of Thesis

This thesis takes on the form of an integrated thesis, also known as an article-based thesis. This type of thesis differs from a traditional monograph format as it is presented in a manner that contains an introduction, one or more manuscripts suitable for publication, and an integrated discussion (Lewis et al., 2021). An integrated thesis was chosen due to the opportunity the integrated discussion chapter presents. This chapter is typically characterized by high-level analysis and interpretation of the findings, forming a connection between the manuscripts to create broader implications and meanings (Lewis et al., 2021).

This first chapter established the importance of person-centred care for individuals living with IDDs and complex conditions and introduced the context under which this research took place. Chapter 2 is a scoping review examining the state of evidence on individualized participatory care plans for individuals living with IDDs and/or complex care. Chapter 3 is a qualitative study that utilizes semi-structured interviews with community-care staff to gain a better understanding of PHSS's approach to PCPs. As this is an integrated thesis, chapters 2 and 3 are presented in an article-based format as separate manuscripts which can be presented on their own. It is important to note that both chapters rely on similar evidence. Chapter 4 presents the integrated discussion, tying the two manuscripts in chapters 2 and 3 together. The fifth chapter concludes the thesis with a summary of the research and implications of the findings.

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Chapter 2

2 Individualized Participatory Care Plans for Individuals with Intellectual and Developmental Disabilities (IDDs): A Scoping Review

This chapter presents a scoping review that examined the state of evidence worldwide on individualized participatory care plans for individuals living with intellectual and developmental disabilities and/or complex care. An introduction to the research topic begins the chapter, followed by details of the research process, results, and discussion. The review aimed to answer the overall question: How do individualized participatory approaches to care planning play a role in improved health and social care for individuals living with intellectual and developmental disabilities?

2.1 Background

Ninety-two percent of Canadians aged 15 and older who have a developmental disability also report a co-occurring disability (Health Canada and the Public Health Agency of Canada, 2021). Comorbidities and chronic diseases (e.g., chronic pain, diabetes, cancer, and heart disease), as well as early onset dementia, are highly prevalent among individuals with intellectual and developmental disabilities (IDDs) (Havercamp & Scott, 2015; Sullivan et al., 2018; Todd et al., 2020), defined as lifelong conditions characterized by limitations of intellectual (IQ $\leq$70; $\pm$ 5 points for error) and adaptive functioning that develop before the age of 18 (American Psychiatric Association, 2013). This population often has additional complex needs that vary in severity and manifestation, distinctly differing from others in the community (Sullivan et al., 2018). Substandard quality of care, limited social networks and social support, and systemic barriers have been identified as factors limiting the quality of life of people living with disabilities (Forrester-Jones et al., 2016; Havercamp & Scott, 2015; Sullivan et al., 2018; Todd et al., 2020). These challenges present the necessity of specialized support from health and social care systems to address each individual's diverse needs. Roughly three in five (57.9%) individuals with intellectual disabilities also experience difficulties with communication (Shady et al., 2022), presenting challenges to having their needs understood (Havercamp & Scott, 2015; Sullivan et al., 2018). This calls for systems that

partner with individuals in all aspects of their care to understand their individual needs and wants to plan appropriate care and support (Lindblad et al., 2017). An integrated streamlined approach to care delivery is essential to ensure that each individual's needs are met (Lin et al., 2019; Purboo & Wojtak, 2018).

Community-care services are a common support for this population as the sector addresses both health and social care issues (Lin et al., 2019), including but not limited to support for daily living, in-home care, respite services, and supportive housing (Humphries, 2015; Kuluski et al., 2017; Purbhoo & Wojtak, 2018). The social care aspects of community-care services aim to address adaptive impairments, providing individuals with domestic support such as cleaning, meal preparation, and social interaction (Purbhoo & Wojtak, 2018). Community-care services also provide person-centred care (PCC) in a unique approach that addresses the individual's health and social care needs (Wojtak & Stark, 2016). PCC is most commonly highlighted as a critical practice of high-quality care (Cramm & Nieboer, 2017; Dhalla & Tepper, 2018; Jo Delaney, 2018). The 2011 Canadian guidelines for primary care of adults with IDDs emphasize PCC, defined as placing the person at the centre of all care to assess their needs for support effectively and communicate their decisions regarding care (Sullivan et al., 2018). PCC involves a partnership between the person-supported, their family, and professionals to put forth the individual's voice in the organization and delivery of services (Cramm & Nieboer, 2017; Lindblad et al., 2017). This approach has been associated with a variety of positive perceived benefits, including improved care experience, overall person-supported outcomes, increased levels of satisfaction for caregivers and persons-supported, and lower cost of treatment contributing to the sustainability of care systems (Cramm & Nieboer, 2017; Purbhoo & Wojtak, 2018; Sullivan et al., 2018).

One approach to PCC is person-centred plans (PCPs), generally detailed as an outline of an individual's desires and goals for the year including individually tailored services and supports to meet their needs and enhance their capabilities (Dingwall et al., 2006; Ministry of Children, Community and Social Services, 2021; Sanderson, 2000). In Canada, PCPs typically focus on the social well-being of individuals rather than health, providing an opportunity to dream, aspire, and live a meaningful life as defined by the

individual (Dingwall et al., 2006). It is important to note that healthcare may be included in PCPs if physical health and well-being goals are included in the individual's aspirations (Ministry of Children, Community and Social Services, 2021). PCPs are unique and vary across community-care services, depending on organizational factors, governmental regulations, and the individual to guide the process (Dingwall et al., 2006).

Given the ambiguous nature of PCPs, we chose a scoping review as an effective approach to examine the state of the current literature on PCPs (Arksey & O'Malley, 2005; The Joanna Briggs Institute, 2015). We chose a scoping review to map the present evidence of individualized participatory approaches to care for individuals with IDDs. It was also hoped that a scoping review would aid the research team in understanding characteristics of the types, features, and factors that support or hinder PCPs, and to understand the effectiveness and impact of participatory approaches to developing individual care plans in the community-care sector.

We conducted preliminary searches utilizing determined keywords on MEDLINE (Ovid) and PubMed. The search yielded approximately 1,244 articles (including duplicate and ineligible citations), revealing many opinion articles that highlight the importance of utilizing individualized participatory approaches to care planning. This search made it unclear as to what aspects of the evidence inform practice in Ontario (as PCPs are mandated in Ontario within community-care organizations). Further, while literature reviews on similar topics do exist, a large portion of the ones identified in the preliminary search were outdated. These combined factors led the research team to opt for a scoping review as opposed to a systematic review. Scoping reviews are an effective approach to identifying evidence that informs practice and research gaps on a given topic (Arksey & O'Malley, 2005; Munn et al., 2018; The Joanna Briggs Institute, 2015). Systematic reviews are often used to inform guidelines and current or new practices, and to produce conclusions to guide clinical decisions (Munn et al., 2018; Peters et al., 2020).

Terminology

'Patient-centred' is a widely recognized term within the health care literature. While this terminology is generally accepted, Kumar and Chattu (2018) outline the similarities and differences between 'patient-centred' and 'person-centred'. Typically,

‘patient-centred’ emphasizes the empowerment of the individual to make medical decisions (Kumar & Chattu, 2018). On the other hand, ‘person-centred’ highlights decision-making in what Kumar and Chattu (2018) term “nonmedical issues” to focus on the person as a whole (p. 488). This strongly aligns with our research in person-centred planning, as it recognizes the individual’s uniqueness through their goals and preferences (Kumar & Chattu, 2018). The term ‘client’ is extensively used in disability and community-care literature to describe the individuals who utilize and receive community-care services. Shevell (2009) explains that the root of ‘client’ comes from the Latin word ‘cliens’, which refers to a follower, or someone who requires protection. This contradicts our aim to empower individuals with IDDs to take greater control over their care, support, and services, and therefore we have chosen to use the terms ‘persons’, ‘people’, ‘individual’, or ‘person-supported’.

Moreover, disability literature highlights the ongoing debate between person-first and identity-first language (Crocker & Smith, 2019). Preference varies from person to person and can further change throughout an individual’s life as language is strongly aligned with identity development for individuals living with disabilities, as well as culture and time (Botha et al., 2021; Crocker & Smith, 2019); as such, there is no consensus (Dunn & Andrews, 2015). We chose to use identity-first language and person-first constructs to place emphasis on the person rather than their disability (Crocker & Smith, 2019). This decision was guided by Dunn and Andrews (2015) and Andrews et al.’s (2022) examinations of how disability language has evolved. Andrews et al. (2022) illustrate that the use of both person-first and identity-first language can be appropriately used within scholarly writing as both approaches aim to destigmatize disability. Person-first language (e.g., person with a disability) was introduced to recognize disability as a neutral characteristic and shift away from the perspective of disability as a medical issue that requires a cure (Dunn & Andrews, 2015). On the other hand, identity-first language (e.g., disabled people) views disability as a positive attribute, highlighting community and diversity by focusing on systemic issues and sociocultural experiences (Dunn & Andrews, 2015). Language is a significant part of disability culture and is an important consideration for researchers within the field who desire to promote health equity and social inclusion for individuals living with disabilities.

2.2 Methods

We created a scoping review protocol to provide structure prior to starting the review. This scoping review was guided by the Joanna Briggs Institute (JBI) Reviewer's Manual 2015: Methodology for JBI Scoping Reviews and Arksey and O'Malley's (2005) methodological framework for scoping reviews. Arksey and O'Malley (2005) propose a framework of six steps: (1) identify the research question, (2) identify relevant studies, (3) select studies, (4) chart the data, (5) collate, summarize, and report the results, and (6) partake in a consultation exercise. Step six of the framework is considered optional and is to be conducted in parallel rather than at the end of the study (Arksey & O'Malley, 2005). This stage can provide value if the right stakeholders are engaged and contribute to the work whether it be through the identification of additional sources or by bringing their unique perspectives to the table (Arksey & O'Malley, 2005). This study is part of a larger project (detailed in Chapter 1) guided by an integrated knowledge translation (iKT) framework. iKT involves collaborative research conducted between researchers and knowledge users with the potential to create more relevant and practical research findings (Kothari et al., 2017). As such, researchers and PHSS Medical and Complex Care in Community (PHSS), the knowledge users, formed a partnership that entailed a collaboration throughout the research process; this is the rationale behind our inclusion of Arksey and O'Malley's (2005) sixth stage. The reporting of the details of our scoping review was guided by Tricco et al.'s (2018) Preferred Reporting Items for Systemic Review and Meta-Analyses (PRISMA) Extension for Scoping Reviews (PRISMA-ScR) Checklist, Peters et al.'s (2020) guidance on conducting scoping reviews, and Arksey and O'Malley's (2005) scoping review framework.

2.2.1 Scope of Research

The aim of the scoping review was to examine the state of the evidence for and identify any gaps within individualized participatory approaches to health and social care for individuals living with IDDs and complex medical conditions. To accomplish this goal, the scoping review focused on three questions:

1. What are the types and features of participatory approaches used to develop care plans for individual persons with intellectual and developmental disabilities and medically complex needs who receive community-care services?
2. What factors support or hinder the use of participatory approaches for developing care plans for persons-supported in the community-care sector?
3. What is the effectiveness and impact of participatory approaches to developing individual care plans in the community-care sector?

2.2.2 Search Strategy and Information Sources

We developed a primary search strategy for published literature (Appendix A) with the help of a research librarian from Western University. We created the search strategy by identifying four key concepts and keywords, which were modified throughout four iterations. We developed the strategy for the PubMed database (including MEDLINE [Ovid]). Once we created the primary search strategy, we used a similar strategy to search for articles in the following databases: CINAHL, ERIC, Social Work Abstracts, Embase (EBSCOhost), and Social Services Abstracts (ProQuest).

The review also included additional citations identified from hand-searching reference lists of pertinent articles and tables of contents of relevant journals. We conducted a separate search for grey (unpublished) literature on Google on January 14, 2023.

2.2.3 Eligibility Criteria

We used the following inclusion and exclusion criteria to guide the identification of relevant studies:

Inclusion Criteria

We included articles in the English or French language if they were about:

1. Participatory or co-design approaches (involving persons-supported and/or family) to care planning at the individual (rather than program) level;
2. Care for adults (18 years or older in terms of age as opposed to legal status);
3. Specific for individuals with IDDs and complex medical conditions (individuals who require extensive support for aspects of daily living);

4. Community-care services setting (including day programs and psychiatric group homes).

Exclusion Criteria

We excluded articles if they were:

1. Specific to acute care substitution home care, palliative care, psychiatric facilities, addiction rehabilitation facilities, short-term support programs, or institutional long-term care;
2. Age-related medical conditions (including, but not limited to dementia and Alzheimer's disease);
3. Specific to active support.

While active support is similar to PCPs, it is not the same and the research team determined that it was important to differentiate the two approaches. Active support is similar to PCPs in the aim of improving the quality of individuals' lives (Beadle-Brown et al., 2012; Bigby et al., 2019; Sanderson, 2000). However, active support places emphasis on expanding the individual's opportunities for participation in meaningful activities (Harman & Sanderson, 2008). Harman and Sanderson (2008) point out that 'meaningful' does not mean that these activities are important to the person-supported. This is where person-centred planning and active support differ. PCPs work to discover what is important to the person-supported and create action plans to pursue these goals (Sanderson, 2000).

2.2.4 Study Search and Selection

We completed the final search on September 2, 2022, utilizing the six databases yielded 675 references. One member of the research team collated and uploaded all identified literature into Covidence. Once duplicates were removed, 505 abstracts remained for screening. The hand-searching of reference lists and tables of contents identified six articles and the search for grey literature pinpointed six sources included in this review.

The first author, MD, alongside another graduate student [GY] who conducted interviews with PHSS persons-supported (or their families) as a part of the larger project

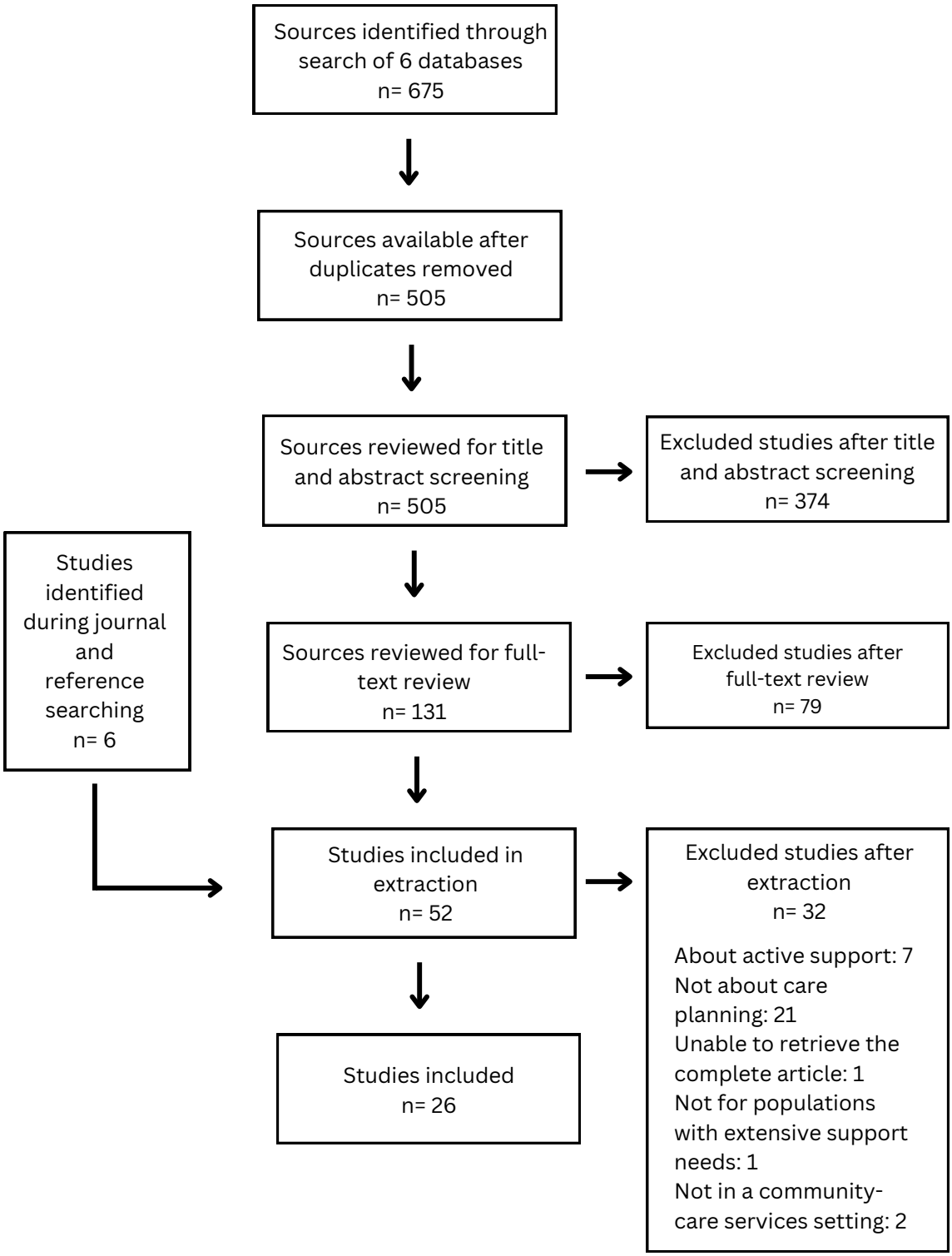
(detailed in Chapter 1) took on the role of reviewers. Given GY's contribution to the larger project and her understanding of PCPs, GY was invited to partake in this review. The two reviewers [MD and GY] ran a pilot screen where they independently screened 10 titles and abstracts and discussed conflicts before continuing with the screening process. During this initial phase, the ambiguous nature of the topic and our initial eligibility criteria produced many conflicts. The eligibility criteria were discussed with a third reviewer [MM] to further specify and define the criteria. Once the refined criteria were determined, the reviewers continued screening the remaining articles. One hundred and thirty-one studies met the criteria during the initial title and abstract screening phase and moved to the full-text review, 374 studies were excluded. For any conflicts, the two reviewers discussed their opinions and if they still disagreed, a third reviewer was consulted. After a full-text review of these studies, 79 articles were excluded, leaving 52 studies for data collection. A PRISMA flow diagram detailing the study selection process can be referred to in Figure 1.

2.2.5 Data Collection

Two reviewers [MD and GY] independently extracted data from the selected studies. Western and PHSS research team members designed the data extraction template to address the three research questions. We first created the extraction template when the scoping review protocol was written but modified it after two rounds of pilot testing occurred. In each round of a pilot test, two reviewers extracted information from five articles and then met to discuss the data from each article to ensure data accuracy and reliability. The researchers then went on to extract data from the remaining articles, utilizing the extraction template to facilitate data collection. The extraction template included: study purpose and design, data source/collection, name and description of program/intervention, the vocabulary used to label 'person-centred care', program setting, program target group, inclusion and exclusion criteria (if applicable), comparison groups (if applicable), participant details, outcomes, conclusions, and any additional thoughts/comments from the reviewer. Once each reviewer had completed data collection, the two independent extraction tables were combined into a master extraction sheet. During this stage, comments about ineligibility were reviewed and discussed between the two reviewers and a third member [MM]. This led to the exclusion of seven

Figure 1

PRISMA Flow Diagram



active support articles and 25 additional articles due to a combination of several factors including the quality of evidence and the ineligibility, based on several criteria. The six articles identified from hand-searching reference lists and tables of contents were also included in the data collection stage.

2.2.6 Summarizing the Data

Using the final extraction table, MD organized the data based on the study's three research questions into summary tables, which aided in the identification of recurring themes and key findings. MD presented the results to the entire research team, including PHSS research team members as part of Arksey and O'Malley's (2005) consultation exercise and true to an iKT approach. During this stage, PHSS research team members provided insights on the results that are highlighted in the discussion section.

2.3 Results

2.3.1 Study Characteristics

A total of 32 sources (26 articles and six grey literature sources) were included in this study for analysis (refer to Figure 1 for details on the exclusion process), including empirical research using qualitative methods (n=11); opinion pieces (n=5); literature review articles (n=5); quantitative methods (n=2); mixed (qualitative and quantitative) methods (n=2); and evaluative research (n=1) (Table 1 below, Table 2 found in Appendix A). The reviewers labelled opinion pieces based on BioMed Central (BMC) Medicine's (2023) definition: editorial-style articles that discuss the impact of a new intervention or research, in this case, PCPs, without the use of original research. The articles included were published between 1996 and 2022. The top number of articles were published in the Journal of Intellectual and Developmental Disability (n=3), followed by the Journal of Applied Research in Intellectual Disabilities (n=2), the Journal of Intellectual Disability Research (n=2), Health and Social Care in the Community (n=2), the British Journal of Learning Disabilities (n=2), the Journal of Intellectual Disabilities (n=2), and Research in Developmental Disabilities (n=2). The largest number of articles were published in England (n=6), the USA (n=6), and Australia (n=4).

The oldest study, published in 1996, lists individuals with 'mental retardation' as their focus. The term 'mental retardation' was previously used in medical settings but has

been mostly extinguished from current literature and is no longer accepted as inclusive and respectful language (Lin et al., 2019). Three studies focused on individuals with complex care needs, two studies concentrated on individuals with disabilities, and ten studies either exclusively focused on individuals with intellectual disabilities or listed this population as one of the target groups. Two studies concentrated on individuals with IDDs and four studies either exclusively focused on individuals with learning disabilities or listed this population as one of the target groups. In this thesis, the term 'developmental disabilities' is used as it is the term used in Ontario legislation (Lin et al., 2019), the province we conducted the research. This differs from definitions in the United Kingdom, where 'learning disabilities' is used to describe a similar population (Lin et al., 2019). The remaining four articles did not specify any target population. Table 1 displays a complete chart of the frequency of study characteristics. Table 2 presents the studies' characteristics and Table 3 (Appendix A) summarizes the data collection sources and main findings.

Table 1

Scoping Review Study Characteristics and Frequency

Characteristic	Category	Frequency
Country	England	6 (23.08%)
	USA	6 (23.08%)
	Australia	4 (15.38%)
	The Netherlands	3 (11.54%)
	New Zealand	2 (7.69%)
	Scotland	2 (7.69%)
	Denmark	1 (3.85%)
	Canada	1 (3.85%)
	Ireland	1 (3.85%)

Characteristic	Category	Frequency
Journal Published In	Journal of Intellectual and Developmental Disability	3 (11.54%)
	Journal of Applied Research in Intellectual Disabilities	2 (7.69%)
	Journal of Intellectual Disability Research	2 (7.69%)
	Health and Social Care in the Community	2 (7.69%)
	British Journal of Learning Disabilities	2 (7.69%)
	Journal of Intellectual Disabilities	2 (7.69%)
	Research in Developmental Disabilities	2 (7.69%)
	Patient Education and Counseling	1 (3.85%)
	Scandinavian Journal of Disability Research	1 (3.85%)
	Home and Community Health Special Interest Section Quarterly	1 (3.85%)
	Current Opinion in Psychiatry	1 (3.85%)
	Intellectual and Developmental Disabilities	1 (3.85%)
	Mental Retardation	1 (3.85%)
	Cochrane Database of Systematic Reviews	1 (3.85%)
	Journal of Vocational Rehabilitation	1 (3.85%)
	Mental Health Today	1 (3.85%)
	Learning Disability Today	1 (3.85%)
	American Journal on Mental Retardation	1 (3.85%)
Study Design	Qualitative Methods	11 (42.31%)
	Opinion Piece	5 (19.23%)
	Review	5 (19.23%)
	Mixed Methods	2 (7.69%)
	Quantitative Methods	2 (7.69%)
	Evaluation	1 (3.85%)

Characteristic	Category	Frequency
Study Target Population	Exclusively focused on individuals with intellectual disabilities or listed this population as one of the target groups	10 (38.46%)
	Exclusively focused on individuals with learning disabilities or listed this population as one of the target groups	4 (15.38%)
	Individuals with complex care needs	3 (11.54%)
	Individuals with disabilities	2 (7.69%)
	Individuals with intellectual and developmental disabilities (IDDs)	2 (7.69%)
	Individuals with mental retardation	1 (3.85%)
	No specification of the target population	4 (15.38%)

2.3.2 Types of Individualized Participatory Approaches Used to Develop Care Plans

The most common names used to describe individualized participatory approaches were: 'person-centred planning' or 'person-centred care planning' (Table 4 found in Appendix A). Other terms used to describe the approaches were: 'making action plans (MAPs)'; 'person-directed planning (PDP)'; 'consumer-directed care'; 'self-directed care (SDC)'; 'personal plans'; 'lifestyle planning'; 'whole life planning'; 'individual support plans (ISPs)'; 'planning alternative tomorrows with hope (PATH)'; 'personal futures planning (PFPs)'; and 'essential lifestyle planning (EFPs)'.

Purpose of Planning

Care planning had different purposes (Table 4). In two articles, PCPs were used for financial planning, which Friedman (2018) refers to as "budget authority" (p. 31). Financial planning facilitates budgeting for future activities and goals, engaging persons in decisions regarding financial management (Collings et al., 2016; Friedman, 2018).

In two articles, PCPs were used to identify appropriate personnel and referred to as "employer authority" by Friedman (2018, p. 31). Employer authority PCPs involve the person-supported in decision-making when it comes to who supports them, including

recruiting, hiring, and supervising responsibilities (Friedman, 2018; Ritchie, 2015). Engaging persons-supported in personnel decisions allows them to choose the attributes and skills of their supporting staff (Friedman, 2018; Ritchie, 2015).

Six grey literature sources described the purpose of PCPs as the planning of services to facilitate goals (Administration for Community Living, 2021; Community Living London, 2022a; Community Living London, 2022b; National Quality Forum, 2020; Tondora et al., 2020; PACER's National Parent Center on Transition and Employment, 2022), including future goals (Hagner et al., 1996; Parsons & Theobald, 2004), interaction and social roles (e.g., community participation) (Kaehne & Beyer, 2014; Ritchie, 2015; Vlaskamp & van der Putten, 2009), physical well-being (Herps et al., 2016; Kaehne & Beyer, 2014), employment (Kaehne & Beyer, 2014), and housing (Kaehne & Beyer, 2014; McCausland et al., 2022).

As part of the *Getting a Life Project* Kaehne and Beyer (2014) specified that community activities and previous work experience were not prominent topics of discussion. In contrast, McCausland et al. (2022) noted that 66.9% of PCPs had one or more goals related to participation in the community and Claes et al. (2010) specified the focus on community participation and presence.

Settings

Ten articles and a majority of the grey literature found detailed program and intervention settings in home and community-based services; sixteen articles did not specify a setting (Table 4). The description of these services ranged from small and large group homes, publicly funded community agencies, family homes, human service agencies, and communal living.

2.3.3 Features of Individualized Participatory Approaches Used to Develop Care Plans

Meeting Topics and Number of Goals

The topics discussed during planning meetings or included in the plans varied (Table 4), however, it was clear that the person-supported was almost always placed at the centre (Martin et al., 2016; Parsons & Theobald, 2004). In Hagner et al.'s (1996) exploration of whole-life planning for the transition from school to "adult life" (p. 160),

the authors specify that the time and location of the meeting were decided by the individual. The topics discussed during meetings were typically the same. Parsons and Theobald (2004) describe the discussion of the following topics: a person's life story, dreams and nightmares, and any challenges the person may face. Hagner et al. (1996) note that an agenda is set for each meeting and typically includes discussions around a person's life domain structure, what they currently do, their likes, dislikes, and future goals. While the range of topics reflects what was identified in the grey literature (Administration for Community Living, 2021; Community Living London, 2022b), Collings et al. (2019) point out that some individuals did not want to discuss intimate information during planning meetings, such as sexuality and intimate relationships.

The number of goals in each plan varied, McCausland et al. (2022) note a mean of 8.55 goals and Vlaskamp and van der Putten (2009) note a range of one to four goals, while Herps et al. (2016) described plans that ranged from one to eleven goals. However, Herps et al.'s (2016) analysis also notes that 86.1% of plans had goals, while 13.9% did not include any goals. The content of the plans analyzed by Herps et al. (2016) specified resources, with service-based resources being cited more than informal supports. Sometimes natural resources, specifically the individual's roles and responsibilities were also included (Herps et al., 2016).

Preparing for Person-Centred Meetings

The process leading up to care planning illustrates some similar features in training (Table 4). Yamamoto et al. (2014) state that counsellors attend workshops to learn how to understand goals and needs of the persons-supported. Persons-supported are also invited to attend and participate in workshops to learn about the goal-setting and planning process (Yamamoto et al., 2014). Robertson et al. (2006) describe the process leading up to the implementation of person-centred planning including the training of facilitators and managers. Espiner and Hartnett (2012) mention the involvement of an outside trainer who designed and facilitated training for staff who were taking on a new facilitator role. Training topics ranged from communication skills, identifying community resources and services, problem-solving, and the values of PCC (Espiner & Hartnett, 2012).

Meeting Participants

The most common identification of who was involved in the planning was family (Table 4). Family members were frequently involved in meetings although Espiner and Hartnett (2012) note that it could be difficult to involve family members if they lived far away. Collings et al. (2019) note that some persons-supported preferred to be more independent and not have family involved in the person-centred planning process. Friends were infrequently involved in the planning meetings, though Parsons and Theobald (2004) and Ratti et al. (2016) highlight the significance of the involvement of friends. Hagner et al. (1996) noted that friends may not take the process seriously. Other participants mentioned in studies include neighbours, case managers, social workers, teachers, and volunteers (Hagner et al., 1996).

Meeting Leaders

The individuals who led the planning meetings varied (Table 4). Hagner et al. (1996) list several different leaders, including special education teachers, social workers, adult service program managers, and outside consultants. Robertson et al. (2006) noted that leaders were either people with intellectual disabilities, unpaid volunteers, or paid support staff.

Meeting and Goal Documentation

Three articles and two grey literature sources noted the documentation of meetings and goals (Table 4). Watchman et al.'s (2021) research on psychosocial interventions within social care settings found that staff complete both an "intervention diary" and "behaviour change tool" following each meeting (p. 167). Hagner et al. (1996) and PACER's National Parent Center on Transition and Employment (2022) describe a different approach with chart paper being used to record details pertaining to the meeting. Martin et al. (2016) did not specify how documentation of meetings and plans was practiced but noted it as a key element of the planning process. Moreover, Tondora et al. (2020) emphasize the importance of documentation of the PCPs to ensure that revisions and evaluations of the plans can be made, further, to verify that the plan is following person-centred values.

2.3.4 Supports of Individualized Participatory Approaches for Developing Care Plans

Table 5 (Appendix A) contains the extracted information relating to the supports of participatory approaches identified by the studies, this is displayed alongside the studies' citations.

Staff and Person-Supported Relationship

A strong relationship between staff and the person-supported is integral to the person-centred planning process (Table 5). Martin et al. (2016) describe the supports of person-directed planning as a mix of the right people with the right attitudes that carry out the right actions. The right people are noted by Lakhani et al. (2018) as a combination of a trusting relationship with staff, the involvement of family, and a strong social support system. The meeting leader and support staff's roles were important facilitators of individualized participatory approaches (National Quality Forum, 2020; Ratti et al., 2016). Engen et al. (2019) describe the staff as being the centre of supporting individualized care. Specifically, a trusting, high-quality relationship between staff and the person-supported was cited as a vital support (Collings et al., 2016; Collings et al., 2019; Dowling et al., 2007; Engen et al., 2019). Building rapport through an ongoing process of getting to know the individual can enable an environment where the persons-supported feel comfortable sharing their goals and aspirations, increasing the capacity of the staff to support the individual effectively (Collings et al., 2016; Collings et al., 2019; Engen et al., 2019; Lakhani et al. 2018; Martin et al., 2016; National Quality Forum, 2020).

Staff Characteristics

Care professionals are at the centre of providing person-centred services, and as such their attributes and characteristics have been identified as important enablers of individualized participatory approaches (Table 5). Characteristics mentioned in studies include warmth, openness to ideas, and a range of skills in areas such as emotion, communication, facilitation, and planning (Collings et al., 2016; Collings et al., 2019; Engen et al., 2019; Espiner & Hartnett, 2012; National Quality Forum, 2020). Staff's competence and experiential knowledge of resources and the sector were identified as important to persons-supported (Collings et al., 2019; Dowling et al., 2007; Lakhani et

al., 2018; National Quality Forum, 2020). Moreover, collaboration was a significant factor highlighted throughout the literature. This includes the staff's ability to work effectively in a partnership with the person-supported and the willingness to engage in ongoing listening and learning (Dowling et al., 2007; Engen et al., 2019; Espiner and Hartnett, 2012; Parsons and Theobald, 2004; Ratti et al., 2016). The staff's perceptions of the capability of the person-supported, alongside their positive, motivating, and enthusiastic personality were identified as facilitators of person-centred choice-making (Cardol et al., 2012; Dowling et al., 2007; Martin et al., 2016).

Informal Social Supports

Informal or natural supports can play a significant role in the individualized participatory planning process (Table 5). Espiner and Hartnett (2012) note the importance of supporters to discuss with and share goals. Dowling et al. (2007) identify these additional supporters (external or paid and unpaid staff) as informal social supports. Family is also an important source of support and is identified by Collings et al. (2019) and Lakhani et al. (2018) as natural supporters of the process. Hagner et al. (1996) describe the positive effects of family at meetings to aid in giving prompts and sometimes rewording questions to help with communication with the person-supported. Collings et al. (2016) report similar findings, highlighting that social support networks can take on the role of advocates, supporting a person-centred approach. Although McCausland et al. (2022) note varying levels of family involvement, they (along with Claes et al., 2010) acknowledge the resulting positive impacts when family plays a stronger, more integral role.

Organizational Culture

Organizational culture plays an important role in supporting individualized participatory approaches to planning (Table 5). These approaches to care planning must be embraced throughout all organizational levels (Ratti et al., 2016), including the engagement of internal and external stakeholders (Dowling et al., 2007; Kaehne & Beyer, 2014; National Quality Forum, 2020). Ratti et al. (2016) specify that services and staff should be committed to the implementation, which may involve a lengthy and unpredictable process (Collings et al., 2016; National Quality Forum, 2020; Vlaskamp &

van der Putten, 2009). Similarly, Fleming-Castaldy (2013) acknowledges choice and control as a continuum. The organization can display support by providing staff with the correct tools and resources to enable and promote person-centred planning (Heller, 2002; Parsons & Theobald, 2004). Hagner et al. (1996) recommend the use of monitoring and evaluation by the organization to ensure that a person-centred approach is implemented and fully embraced (Kaehne & Beyer, 2014; National Quality Forum, 2020). Monitoring and evaluation can also aid organizations in verifying that policies support service delivery to offer opportunities for self-direction and choice-making (Fleming-Castaldy, 2013; Heller, 2002; Lakhani et al., 2018). However, Kaehne and Beyer (2014) note that person-centred planning approaches do not guarantee an improvement in choice-making. Rather such an approach needs to be supported by accessibility to options and resources (Kaehne & Beyer, 2014), such as assistive technology (Heller, 2002). Ritchie (2015) notes that creativity may be required to make opportunities accessible to individuals. Heller (2002) recognizes the stress that staff may experience as a result of responding to behaviours that challenge; support from the organization for staff can increase staff motivation and job satisfaction.

Importance of Communication and Teamwork

The importance of good communication in facilitating participatory approaches for care planning was noted multiple times throughout the literature (Collings et al., 2016; Martin et al., 2016; McCausland et al., 2022; National Quality Forum, 2020; Ottmann & Mohebbi, 2014) (Table 5). Collings et al. (2016) highlight communication as an important support within PCC (between the care professional and person-supported); effective communication allows individuals to articulate the support they want/need. Parsons and Theobald (2004) suggest that a visual communicative approach may be effective in breaking down communication barriers between staff and supported individuals. McCausland et al. (2022) also highlight that familiarizing persons-supported with new activities through visual methods can support the planning process, facilitating the uptake of new activities.

Martin et al. (2016) identify documentation as a key component to support planning as it is used to record plans and outcomes. Documentation can act as a reminder

of the plan and motivate the individual to continue working towards their goals (Espiner & Hartnett, 2012). Espiner and Hartnett (2012) describe accessibility as proximity and readability, and suggest providing personal copies of plans to individuals, using computer programs to create a combination of visual and textual material, or utilizing a more visual method such as scrapbooking.

Communication is also integral to teamwork which supports a participatory approach (Claes et al., 2010; Martin et al., 2016). Martin et al. (2016) specify that members can work in collaboration to communicate effectively with persons-supported.

Capacity of the Person-Supported

The capacity of the person-supported to engage in planning is mentioned in two articles (Ottmann & Mohebbi, 2014; Ritchie, 2015) (Table 5). Ritchie (2015) notes the individual's confidence, skills, and ability to make decisions as a support to participatory planning.

2.3.5 Hindrances of Individualized Participatory Approaches for Developing Care Plans

There were five key hindrances identified in the literature that provide resistance to individualized participatory approaches for developing care plans. Table 5 contains the extracted information relating to the hindrances of participatory approaches as identified in the studies.

Inflexible Services Do Not Align with Person-Centred Approaches

Offering flexible support and services is ideal to enable and support person-centred approaches (Table 5). Claes et al. (2010) and Heller (2002) found flexible services to be difficult to provide in traditionally large systems. Collings et al. (2016) acknowledge that inflexible services may lead to unmet needs and pose barriers to individuals with complex support needs.

Lack of Time

A lack of time was cited multiple times as a barrier to individualized participatory approaches to care planning (Table 5). Robertson et al. (2006) note that the time to develop and construct a PCP varies. Vlaskamp and van der Putten (2009) specify that time is needed to build a trusting and meaningful relationship between persons-supported

and staff. As discussed previously, the staff-person-supported relationship is a significant support. Moreover, Watchman et al. (2021) found that staff may require practice to embrace and properly facilitate individualized participatory approaches to planning. The authors note that a participatory approach may present as a difficult task at the beginning, requiring additional time for staff to practice, and use time effectively to facilitate plans (Watchman et al., 2021). Parsons and Theobald (2004) similarly state that time is needed to practice the person-centred planning tools, prepare the person-supported for planning, complete the plan, and conduct a follow-up. Increasing the roles and expectations of staff by introducing a new approach should also come with the additional time needed for staff to adjust. Parsons and Theobald (2004) state that the time requirements for the planning process may impede on staff's other work and duties.

Support Staff

Staff shortages in the community-care sector can hinder the implementation of individualized practices (Engen et al., 2019) (Table 5). McCausland et al. (2022) found that inadequate staffing was a barrier in 29.2% of the plans analyzed.

Collings et al. (2019) found that a change in facilitator without notice or agreement from the person-supported suggested a lack of respect towards the person-supported. Similarly, McCausland et al. (2022) identified unfamiliar staff as a barrier in approximately 30.8% of the plans analyzed.

Capacity of the Person-Supported

A person-supported's capacities were identified as a challenge to person-centred planning approaches (identified by the persons-supported themselves) (Table 5). McCausland et al. (2022) found that the person-supported was the most commonly identified barrier in 46.7% of the plans analyzed. Persons-supported may have mental health difficulties such as anxiety and behaviours that challenge, which may hinder their ability to participate and fully engage in care planning (McCausland et al., 2022). A person-supported's lack of self-confidence, feelings of being overwhelmed, health concerns and changing health status were also potential challenges to the process (McCausland et al., 2022; Ottmann and Mohebbi, 2014).

Balancing the Person-Supported, Organizational, and Staffing Needs and Policies

PCC requires a balance between the person-supported, organizational, and staff needs and policies (Table 5). Cardol et al. (2012) note that staff express a desire to provide PCC but find it difficult to implement such practices. Specifically, strict health and food restrictions were identified as a factor that can hinder staff's ability to provide person-centred support (Cardol et al., 2012). Staff found that at times there could be an imbalance between a person-supported's desires and their care needs, which may cause difficult and frustrating situations for staff and less than ideal care (Engen et al., 2019). Further, staff were uncertain about how to resolve conflicts between healthcare needs and PCC values and respect for a person's autonomy (Cardol et al., 2012). These findings are supported by Engen et al. (2019) who found a difficult balance between organizational practices and individualized care needs, specifically in situations when behaviours that challenge are displayed. Moreover, unrealistic goals and expectations may create difficult situations for staff to diffuse (Claes et al., 2010).

2.3.6 Impact of Individualized Participatory Approaches to Developing Care Plans

Parsons and Theobald (2004) reported that they received exceedingly good feedback on their person-centred planning pilot from persons-supported and staff. Vlaskamp and van der Putten (2009) also reported positive feedback on individual support plans regarding the impact on individuals and staff. Table 6 (Appendix A) summarizes the impact of participatory approaches.

Quality of Life

Person-directed planning can empower individuals to attain a satisfying quality of life (Fleming-Castaldy, 2013) (Table 6). One study included in Ratti et al.'s (2016) review noted that participants who partook in person-centred planning had a six times greater improvement in quality-of-life scores, compared to those who engaged in controlled traditional individual support plans. Similarly, Robertson et al. (2006) note that PCPs can enhance the quality of life of individuals with intellectual disabilities. Fleming-Castaldy (2013) specifies that increasing personal control and an individual's ability to self-manage can contribute to increased quality of life. On the other hand, Ratti et al. (2016) included three studies in their review that reported no significant effect on self-

reported life satisfaction and Claes et al. (2010) identified one study that found a decrease in life satisfaction.

Satisfaction with Care

Ottmann and Mohebbi (2014) highlight that persons-supported appreciated opportunities to coordinate their own care (Table 6). Further, the authors found high levels of satisfaction with PCC and services (Ottmann & Mohebbi, 2014). Parsons and Theobald (2004) note similar feelings from persons-supported, individuals were proud of the plans they co-produced and wanted to display them. Hagner et al. (1996) report that five individuals enjoyed the planning process, wanted to further engage in another planning meeting, and were pleased with the outcome. Moreover, Fleming-Castaldy (2013) mentions higher satisfaction that comes with consumer direction, specifically in decision-making regarding finding the appropriate personnel. This mirrors similar outcomes noted by Espiner and Hartnett (2012) who reported that seven out of ten adults with intellectual disabilities were happy with the facilitation and outcome of their PCP. In the same study, one adult emphasized feelings of frustration, resulting from the inaction and lack of support toward their goals (Espiner & Hartnett, 2012). Overall, Espiner and Hartnett (2012) highlighted that nine out of ten participants reported a positive experience with the facilitation process.

Participation in Society

Participation in the community was a common theme addressed in studies (Table 6). Person-centred planning can provide a good foundation for facilitating and increasing community participation (including economic and social participation and group activities), specifically for individuals with intellectual disabilities and complex needs (Claes et al., 2010; Collings et al., 2019; McCausland et al., 2022; Ratti et al., 2016). Fleming-Castaldy (2013) noted that self-directed support, which can be facilitated through person-centred planning, can empower the person-supported to participate in society.

Social Connections

Collings et al. (2019) state that person-centred planning does not consistently facilitate social connections for those who made it a goal (Table 6). Similarly, Ottmann and Mohebbi (2014) found that almost half of the participants felt lonely and a third of participants reported they did not have what they deemed to be a 'good' social life. Watchman et al. (2021) note positive impacts on social interaction, mirroring Robertson et al.'s (2006) findings of an increase in social activity, including visits to and from friends. For those who did not have a PCP, Robertson et al. (2006) found a 23% decrease in the size of an individual's social network. For those who did have a PCP, the size of their social network significantly increased (Robertson et al., 2006), mirroring Claes et al. (2010) who noted an improvement in social networks, including closer contact with family and friends.

Ratti et al.'s (2016) review reported that social relationships were more positively influenced compared to other categories they analyzed. However, the review also identified studies that provided inconclusive evidence on the improvement of social relationships and networks from person-centred planning for individuals with intellectual disabilities (Ratti et al., 2016).

Health Impacts

An improvement in health through the reduction of negative behaviours (e.g., distress and agitation) was reported by several studies (Table 6). Watchman et al. (2021) and Vlaskamp and van der Putten (2009) noted positive impacts on mood and level of alertness (as reported by staff) and a reduction in distress and agitation for individuals who partook in the person-centred planning process; Claes et al. (2010) also noted a reduction in challenging behaviour. Additionally, an improvement in communication and an increase in confidence and happiness were recorded (Claes et al., 2010; Ratti et al., 2006). Robertson et al. (2006) noted a significant increase in hyperactivity which was measured using the Strength and Difficulties Questionnaire Hyperactivity Subscale. Meanwhile, Ratti et al. (2016) found no improvements in health, behaviour, and adaptive functioning.

2.3.7 Effectiveness of Individualized Participatory Approaches to Developing Care Plans

Table 6 contains the extracted information relating to the effectiveness of participatory approaches as identified in the included studies alongside the studies' citations.

Achieving Stated Goals

McCausland et al. (2022) reported that an average of six goals were achieved, with an average of two goals either still in progress or not attained (Table 6). Watchman et al. (2021) note that 32% of goals were met in cycle one of their study, with 43% exceeding expectations. Further, in cycle two, 35% of goals were met, with 37% exceeding expectations (Watchman et al., 2021). Watchman et al. (2021) suggest that this process of setting and achieving goals is more likely to be successful for participants living in small group accommodations (three residents or less) compared to those living in larger group homes. Ottmann and Mohebbi (2014) reported that a third of individuals were not fully occupied with activities of their choice.

Process: Increased Person-Direction and Choice-Making

Fleming-Castaldy (2013) reports that opportunities for self-direction can increase independence (Table 6). Kaehne and Beyer (2014) found that person-centred planning can increase the opportunities for individuals to express their preferences and desires, enabling opportunities for person-direction. However, they note that person-centred planning approaches do not guarantee an improvement in choice-making which needs to be backed by resources and accessibility to options (Kaehne and Beyer, 2014). This mirrors Friedman (2018) who reported that 64.86% of plans for people with IDDs offered participant direction, further participant direction was only available to 12.1% of the applicable population. Heller (2002) emphasizes the need for resources to support person-centred planning, however, resources were not found to increase self-determination. Ratti et al. (2016) included six studies that recorded the impact of PCPs on empowerment and self-determination. Three out of six studies noted a positive impact while the other three studies suggested a limited impact (Ratti et al., 2016).

Lack of Outcomes

Claes et al. (2010) note a lack of reporting on the evaluation of outcomes related to PCPs (Table 6), which may be due to the lack of a clear definition of PCPs as there are complex components that are difficult to define. The National Quality Forum (2020) proposes multiple frameworks in which person-centred planning could be evaluated, however, they note that a standardized method does not exist. These frameworks are as follows: Personal Outcome Measures from the Council for Quality and Leadership, the Functional Assessment Standardized Items, NCI Aging and Disabilities Indicators, goal attainment measures (such as the one developed by the National Committee for Quality Insurance), the National Center on Advancing Person-centred Practices and Systems (NCAPPS) Indicators, and the National Core Indicators (National Quality Forum, 2020).

2.4 Consultation Exercise

The consultation exercise mostly confirmed the findings from the scoping review, consultants were not surprised by many aspects of the results including the main features of PCPs and the lack of evidence on the impacts and effectiveness of such approaches. Upon initial presentation of the included studies' characteristics, PHSS's associated consultant was surprised by the lack of evidence on operationalized practices (i.e., the impacts). The consultant went on to explain that it is surprising that organizations (i.e., government bodies) still decide to implement PCPs without the evidence to support their decision-making.

One key issue brought up during the exercise is the lack of discussion surrounding 'dislikes' during planning meetings. While the consultants did not find this result surprising, it was noted that this is an issue within care as persons-supported are often afraid of coming forward with negative ratings due to fear of being discharged. This also brought up the issue of 'power' within a care relationship and how the shift towards empowering persons-supported is important so that individuals can freely discuss care issues without a negative reaction from the care professional. Fisher et al. (2018) highlight that persons-supported may not bring up care issues due to a number of reasons including a lack of comfort in raising concerns. An individual's reluctance to share their care concerns is not widely discussed in the literature, rather articles highlight individual

concerns of care professionals dismissing health concerns, but not broader care issues (Dang et al., 2017).

Moreover, consultants discussed issues surrounding documentation of the care planning process. Many found it interesting and surprising that there are sparse details on the documentation process. However, they did mention that Ministry funding does not outline a lot of rules for documentation. Consultants also found it surprising that funding was not brought up throughout the literature as a hindrance to care planning approaches.

2.5 Discussion

The aim of this scoping review was to examine the state of the evidence (including gaps) on individualized participatory approaches to care planning for individuals living with IDDs and complex medical conditions. The review revealed a small number of articles (26) that met this study's inclusion criteria. While there were 11 studies that used qualitative methods, these studies mostly focused on the process leading up to the care planning meeting and the facilitation of the meeting itself rather than the impacts and effectiveness of the services and programs. Only one article evaluated an existing program, illustrating a substantial gap in evidence on the evaluation of the impacts of individualized participatory approaches to care planning for individuals with IDDs.

The first research question aimed to understand the types and features of participatory approaches used to develop care plans. The literature revealed the ambiguous nature of participatory approaches, displaying high variability in the types and features. Additionally, there was no consensus on the purpose, processes, and participants involved in care planning. The lack of a centralized definition of 'person-centred planning' as well as 'intellectual and developmental disabilities' could be one of the reasons why there is high variability in the literature. When screening articles, specifically in the full-text review stage, reviewers found it difficult to differentiate person-centred planning from decision-making and self-directed care. As seen in Figure 1, an additional 32 articles were removed after data extraction and charting due to these difficulties.

Legal age and determined age of adult status was a factor in the screening process. There were a handful of articles that had various groups of participants who ranged in age from mid-teens to mid-20s. As our inclusion criteria included those who are ages 18 and older in terms of legal age, these studies were included. We suspect that such age ranges in research are chosen due to the difference in legality for individuals with IDDs. Moreover, individuals with IDDs are often in high school until the age of 20 and make the transition to community-care support services at a later age.

Moreover, while this study used the American Psychiatric Association's (2013) definition of IDDs, it is not used universally by all service systems. For example, in the United Kingdom, the term 'learning disabilities' is used to note similar conditions to 'developmental disabilities' in Ontario, Canada (Lin et al., 2019). While the search strategy did include the term 'learning disabilities', this difference in terminology is one example of how inconsistent definitions could be a factor in the sparse number of articles found.

The second research question was to identify factors that support or hinder the use of participatory approaches for developing care plans. The most common supports were the staff and person-supported relationship, communication and teamwork, staff characteristics, informal social supports, and organizational culture. The most common hindrances were a lack of time, support staff, and the challenge of balancing the person-supported, organizational, and staffing needs and policies. The lack of mention of funding as a support or hinder was surprising to our research team and the professionals consulted. Although finances were mentioned as a purpose of some planning meetings, funding is an important part of facilitating activities and goals and a lack of funding can be a significant barrier to carrying out PCPs. This may link back to the variability in purpose of PCPs and may suggest that PCPs are not formally linked to resource allocation.

The third research question sought to better understand the effectiveness and impacts of participatory approaches to developing individualized care plans. The scoping review illustrated limited evaluation of implemented individualized participatory care planning practices. Combined with limited evaluation are the scarce details on

documentation. This finding likely reflects the recent uptake of PCPs as well as the variation in the goals and processes. Moreover, it may suggest that PCPs remain a paper exercise that checks off a legislative box, where documentation has become an end in itself, an idea that was echoed during the consultation exercise. There is a need for more clarity of required documentation to assess whether organizations are meeting the Ministry mandate and to facilitate the evaluation of services.

The findings also revealed limited empirical evidence demonstrating the impact of PCPs. Kaehne and Beyer (2014) suggest that PCPs do not guarantee an improvement in choice-making, however, we argue that individualized participatory approaches to care planning is the ethically correct approach to take. Public involvement and participation of persons in care environments are rooted in consumer activism (Longtin et al., 2010; Frank et al., 2019). This started as the consumer's basic rights to be informed, to safety, to choose, and to be heard (Longtin et al., 2010). Elinor Ostrom was a driver of this movement, Ostrom first started exploring co-production and public involvement in the 1970s as important aspects of services (Williams et al., 2020). Since then, both concepts have evolved and gained significance, taking on important roles in service delivery and research (Frank et al., 2019). The roots of person involvement in care settings lie in the right to choose. Even though PCPs may not improve choice-making, involving individuals in their care plans is the right thing to do as it is important to respect an individual's right to make decisions.

2.5.1 Implications

Our findings do not suggest whether individualized participatory approaches to care planning improve health and/or social care for individuals living with IDDs or complex care needs. As such, our findings have implications for further research on the impact of PCPs and the evaluation of operationalized participatory care planning approaches. Moreover, our findings suggest that future research should look at measuring the effectiveness of PCPs as there is currently no standardized method by which services can effectively evaluate their PCPs and programs. If the impacts are as positive as is suggested by the opinion articles, it is important that evidence is produced to support the widespread implementation of individualized participatory care planning approaches.

Further, positive evidence can encourage funding; we believe a lack of funding can significantly hinder the implementation of activities and goals.

As the population of individuals with IDDs have complex care needs and are more vulnerable to the negative impacts of COVID-19 compared to the general population, further research must be conducted to explore the impact of the COVID-19 pandemic on this population and the impact it had on PCPs. Further, since COVID-19 restrictions in countries such as Canada were prolonged for the community-care population compared to the general public, many individuals were socially isolated for extended periods, which may have had a negative impact on the health and social well-being of the population.

2.5.2 Limitations

As our scoping review searched six databases, our findings do not encapsulate the entirety of the literature on individualized participatory care planning approaches for individuals with IDDs. While we concentrated efforts on developing a search strategy that consisted of keywords used in different countries, it is possible that relevant articles were not found. Moreover, our inclusion criteria were limited to articles published in the English or French language. As such, we are unsure if relevant articles exist in other languages. It is important to note that individualized participatory approaches to care planning may be taking place across the world, however, these practices may not be researched and therefore, were not included in this study.

2.5.3 Study Strengths

This scoping review used an iKT approach, which proved to be a strength of this study during the scoping review process, specifically data analysis and the consultation exercise. Having healthcare leaders as partners in this study was beneficial during the research process. The experts in the research team supported a deeper understanding of the findings throughout the research process, including study selection, data collection, and data analysis. Moreover, the consultant group identified important differences in the literature when compared to their own experiences, this revealed issues that are not thoroughly detailed within the literature.

A strength of this study is the breadth of the scope of literature. The three objectives guided the scoping review to identify relevant details surrounding the types and features, supports and hinders, and effectiveness and impacts of individualized participatory approaches to care planning. These were chosen to identify details that would facilitate a better understanding of PCPs and paint a fuller picture of these approaches. Although literature reviews have been conducted and are identified in this study, many of them are outdated. This scoping review provides an updated scope of the literature and identifies ongoing gaps in knowledge.

2.6 Conclusion

Our scoping review demonstrates that there is limited literature on PCPs and the impacts of such approaches to care planning. This illustrates that there is very little known about the effectiveness of PCPs and the process of translating planning meetings into activities or the achievement of goals. Further research is needed to understand how PCPs are operationalized in practice. These findings lead to a need for research to understand the process and impacts of PCPs from the perspectives of care professionals and persons-supported at community-care organizations. Descriptive studies of the approach are needed to evaluate the effectiveness of PCPs. Moreover, research should focus on how PCPs have been incorporated into care in Southwestern Ontario. With that, our study leaves the question: do person-centred plans truly have a meaningful impact?

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2.8 Appendix A: Scoping Review Summary Tables

Scoping Review Data Summary Tables

Table 2

Characteristics of Included Studies

Author, year	Country	Journal/Source type	Study aim(s)/Source purpose	Study design	Program Setting	Program Target Group
Administration for Community Living (ACL), 2021	USA	Website	Describes person-centred planning	N/A	Living in the community	Older adults or persons with a disability living in the community
Cardol et al., 2012	The Netherlands	Patient Education and Counseling	Explore the role of professional caregivers in supporting people with mild or moderate intellectual disability (ID) who also have diabetes in communal living arrangements.	Empirical: Qualitative	Communal living arrangements, community housing	Individuals with mild or moderate ID who also have diabetes and support workers who work with people with IDs who have diabetes.
Claes et al., 2010	USA	Journal of Intellectual and Developmental Disability	This study aims to review the current status of effectiveness research, describe person-centred planning (PCP) effectiveness in terms of outcomes or results, and discuss the effectiveness of PCPs in relation to evidence-based practices	Review	N/A	N/A
Collings et al., 2019	Australia	Journal of Intellectual & Developmental Disability	Examine the perspectives of people with ID who are engaged in National Disability Insurance Scheme planning and what they believe what composes a successful planning process.	Empirical: Qualitative	N/A	Individuals with IDs

Author, year	Country	Journal/Source type	Study aim(s)/Source purpose	Study design	Program Setting	Program Target Group
Collings et al., 2016	Australia	Journal of Intellectual & Developmental Disability	To explore the research evidence on support planning for people with complex support needs (CSNs).	Opinion piece (labelled by reviewers)	N/A	People with CSNs
Community Living London, 2022	Canada	Website	Describes person-centred planning and goes into specifics about the types of plans/services the organization provides	N/A	Community care	Persons with a disability
Community Living London, 2022	Canada	Website	Description of person-centred planning	N/A	Community care	Individuals with a developmental disability
Dowling et al., 2007	England	Journal of Intellectual Disabilities	Review the literature on practices and policies on person-centred planning for learning disability services in England	Review	Learning disability services in England	Individuals with learning disabilities in England
Engen et al., 2019	Denmark	Scandinavian Journal of Disability Research	Studies how care for people with IDs is practiced in Denmark.	Opinion piece (labelled by reviewers)	Accommodation units in Denmark	Individuals with IDs
Espiner & Hartnett, 2011	New Zealand	British Journal of Learning Disabilities	To understand elements of the approach to facilitation of person-centred planning of an organization.	Empirical: Qualitative	Group home (4 individuals)/residential setting (1-2 individuals)	Individuals with IDs
Fleming-Castaldy, 2013	USA	Home & Community Health	Advocate for policies that enable control, choice, and a higher quality of life. The study also aimed to examine the relationships between personal assistance services and life satisfaction.	Opinion piece (labelled by reviewers) – and personal story	N/A	N/A
Friedman, 2018	USA	Intellectual and Developmental Disabilities	Examine if and how states permitted participant direction in Medicaid Home and Community Based Services (HCBS) 1915(c) waivers for people with IDDs	Empirical: Quantitative	Home and community-based services (HCBS)	Individuals with IDDs
Hagner et al., 1996	USA	Mental Retardation	Explore and describe the person-centred planning process as part of the	Empirical: Qualitative	N/A	Individuals with mental retardation

Author, year	Country	Journal/Source type	Study aim(s)/Source purpose	Study design	Program Setting	Program Target Group
			transition from school to adult life, including details on implementation, participants, and the kind.			
Heller, 2002	Residential settings and outcomes for individuals with intellectual disabilities	Current Opinion in Psychiatry	Examine the impact of residential settings on individuals with IDs to promote a high quality of life.	Review	Ranging from family homes, institutional settings, small and large group homes, and supported living	Individuals with IDs
Herps et al., 2016	The Netherlands	Journal of Intellectual Disability Research	Explore what domains of quality of life (QoL) are associated with Individual Support Plans (ISPs) goals and objectives, what support resources are referenced for achieving the goals and objectives, and how domains and resources are related to demographic characteristics	Empirical: Quantitative	N/A	Individuals with intellectual disabilities
Kaehne & Beyer, 2014	England	Journal of Intellectual Disability Research	Investigate the use of person-centred planning in the context of transition planning as there is a lack of evidence that person-centred planning positively influences outcomes.	Empirical: Qualitative	Transition care from school	Young people with IDs
Lakhani et al., 2018	Australia	Health and Social Care in the Community	Synthesize findings from the literature on self-directed models of health and social support (disability support policies).	Review	Social support services	People with disability
Levack et al., 2015	New Zealand	Cochrane Database of Systematic Reviews	To assess the effects of goal setting and strategies to enhance the pursuit of goals on improving health outcomes in adults with acquired disability participating in rehabilitation.	Review	N/A	Individuals (after 16 years of age) with acquired disabilities: arises during a person's adult life (after 16 years

Author, year	Country	Journal/Source type	Study aim(s)/Source purpose	Study design	Program Setting	Program Target Group
						of age). Musculoskeletal disorders, brain injury, chronic pain, mental health conditions, and cardiovascular disease.
Martin et al., 2016	Canada	Journal of Applied Research in Intellectual Disabilities (JARID)	Examine how key elements in person-directed planning (PDP) contribute to successes in planning.	Empirical: Qualitative	Board-governed, publicly funded community agencies.	Administrators in community agencies, individuals with IDDs
McCausland et al., 2022	Ireland	Journal of Intellectual Disabilities	Combine quantitative analyses with qualitative case studies of individuals with severe-profound ID to assess the impact of PCPs on community participation.	Empirical: Quantitative & qualitative	Disability service	People with severe-profound disability
National Quality Forum, 2020	USA	Report	Provide critical guidance for providers of home and community-based services (HCBS) to meet person-centred planning expectations	N/A	Community living, health and human service	Individuals living with disabilities, multiple chronic conditions, and who require living in community and institutional settings
Niven et al., 2020	England	British Journal of Learning Disabilities	Explore the experience and quality of life for people with learning disabilities and/or autism 10 years after the Cornwall facility moved them out of inpatient (hospital) settings into home care in the community.	Empirical: Qualitative	Home care in the community	People with learning disabilities and/or autism, discharged from long-term care in Cornwall, England.
Ottmann & Mohebbi, 2014	Australia	Health and Social Care in the Community	Report the outcomes of a stepped capacity-building-focused self-directed care (SDC) project for older Australians with complex care needs.	Empirical: Qualitative & Quantitative	Aged care service options	Older people with complex care needs
PACER's National Parent Center	USA	Website	Description of person-centred planning.	N/A	Human services' agency	Families of children, youth, and young adults with disabilities

Author, year	Country	Journal/Source type	Study aim(s)/Source purpose	Study design	Program Setting	Program Target Group
on Transition and Employment, 2022						
Parsons & Theobald, 2004	Scotland	Mental Health Today	Evaluate Car-Gomm's pilot program on person centred-planning.	Evaluation	N/A	Individuals with people with learning disabilities, mental health issues, homeless clients, Somali women refugees, and people with human immunodeficiency virus (HIV) and acquired immunodeficiency syndroms (AIDS).
Ratti et al., 2016	England	Research in Developmental Disabilities	Evaluate the effectiveness of PCPs on outcomes for individuals with ID across the age range.	Empirical: Qualitative	N/A	N/A
Ritchie, 2015	England	Learning Disability Today	To inform on Turning Point's approach to person-centred support, ensuring people with learning disabilities are involved in decision-making.	Opinion piece (labelled by reviewers)	N/A	People with learning disabilities
Robertson et al., 2006	England	American Journal on Mental Retardation	To provide evidence on the effectiveness of the implementation of person-centred planning in improving the life experiences of people with IDs.	Empirical: Qualitative	Group home, living with informal carer, locally based hospital unit, independent living, and respite.	Individuals with IDs
Tondora et al., 2020	USA	Report	To provide a resource on person-centred planning and set a framework of competencies.	N/A	Human service agencies	Individuals with disabilities, older adults with support needs and are utilizing long-term services, and people with

Author, year	Country	Journal/Source type	Study aim(s)/Source purpose	Study design	Program Setting	Program Target Group
						behavioural health-related needs.
Vlaskamp & van der Putten, 2019	The Netherlands	Research in Developmental Disabilities	Evaluate the effectiveness of an Individual Support Program (ISP) developed for individuals with PI(M)D	Empirical: Qualitative	Residential facility	Individuals with profound and multiple intellectual disabilities (PI(M)D)
Watchman et al., 2021	Scotland	Journal of Applied Research in Intellectual Disabilities (JARID)	Aims to identify the effectiveness of psychosocial interventions in social care settings as well as explore the use of photovoice methodology to develop dialogue about dementia.	Empirical: Qualitative	Social care settings including: living alone with limited outreach from social care, small group home, larger group home, and generic care home.	Individuals with an ID and dementia and their support staff
Yamamoto et al., 2014	USA	Journal of Vocational Rehabilitation	Discuss the needs and present key components of a model that supported people with IDs in their transition to and participation in postsecondary education (PSE). The study highlights how one vocational rehabilitation (VR) agency assumed a leading role in the transition of students with IDs into post-secondary education through participation in a model demonstration based on three evidence-based practices: interagency team processes, person-centred planning, and provision of essential post-secondary education supports.	Opinion piece (labelled by reviewers)	N/A	Individuals with IDs

*Intellectual disability (ID); person-centred plans (PCPs); complex support needs (CSNs); randomized controlled trials (RCTs); quality of life (QoL)

Table 3

Data Collection and Main Findings of Included Studies

Author, year	Data source/collection and participant details	Main finding(s)
Cardol et al., 2012	Semi-structured interviews: 13 professional caregivers of individuals with mild or moderate ID who also have diabetes.	Caregivers want to provide person-centred care but struggle with engaging and involving persons-supported. Staff are unsure how to balance person-centred care and respect for autonomy when it conflicts with health needs.
Claes et al., 2010	Literature review: Published on the Web of Science between 1985 and January 2009. 15 studies including: 11 quantitative and 4 qualitative.	The study came to five conclusions: 1) Person-centred planning reaches a small minority of service users; 2) PCPs may be a paper exercise; 3) Flexible supports are needed to support PCPs and is difficult in large traditional systems; 4) Social isolation and the absence of relationships may be counter-productive in a PCP process; 5) Too much optimism may lead to unrealistic goals, unsuccessful outcomes, or unrealized expectations.
Collings et al., 2019	Focus groups: 9 adults with ID living in a National Disability Insurance Scheme trial site. Participants: mid-late 20s and one person in their mid-60s; five individuals lived independently, four lived in their family home with parents; almost all individuals were engaged in paid or voluntary work roles, majority worked part-time.	The National Disability Insurance Scheme planning has the potential to increase social and economic participation of people with ID. The planner's role is an important support in the planning process and can significantly impact the results and benefits of the process.
Collings et al., 2016	N/A	The proper supports and planning need to occur to accurately and effectively implement support planning for individuals with IDs and CSNs.
Dowling et al., 2007	Scoping review. Databases searched: Assia, Amed, Age Info, Age Line, Care Data, Best Practice, Cochrane, Cinahl, King's Fund, and PsychINFO. Forward citation was carried out using Web of Science specifically for papers that were included in this study. Materials from the voluntary sector, professional organizations, and governmental organizations were identified using a search on the websites of Modernization Agency, the National Council for Voluntary Organizations, and the National Elctronic Library for Learning Disability (BILD). A grey literature search was conducted using Google. Relevant journals were hand searched and reference lists were checked. Data extraction utilized a framework method.	This review identified many facilitators and barriers of person-centred planning. Many barriers of implementing person-centred planning are presented from previous service delivery models.

Author, year	Data source/collection and participant details	Main finding(s)
Engen et al., 2019	This study looked at two empirical studies: qualitative and ethnographically inspired studies of professional practices in accommodation units for people with IDs in Denmark (observational study & individual interviews and focus groups)	The staff is at the centre of facilitating individualized care and support; they must have professional competencies including emotional and relational skills and attentiveness to help with conflicting interest situations. Forming a trusting relationship is vital and is a delicate, ongoing process.
Espiner & Hartnett, 2011	Semi-structured interviews and questionnaires. Perspectives of adults with IDs, their family, caregivers and/or advocates, and key staff. Individual interviews with adults with IDs. Questionnaire for supporters and key staff focusing on the design and content of the plan, facilitation of the meeting, learning gained by the adults with IDs, personal learning of supporters and key staff, and the organizational support they have received. 3 groups of participants. Group 1 (adults): 10 adults with ID who participated in planning with the new facilitation approach (5 males and 5 females). 3 individuals had retired from work and were in the "normal" retirement age, 7 were of working age, 4 in paid employment, and 3 satisfied with their current job. This group's living situations included: living with another person, on their own, or in a residential home with one other person or a group (up to 4 people). Group 2 (supporters): Family, caregivers and/or advocates of the 10 adults with ID. Group 3: Key staff involved in the adults with ID's lives through support and service delivery and have also attended the planning meeting.	The new facilitation approach had been a positive experience for 9/10 participants. This approach enhances a sense of ownership, increased involvement, and motivated adults to view their plans as a living document. Supporters and staff agreed that the approach allowed for a better understanding of the adults' goals and aspirations that could then be translated into aligned supports and services. The study further showcases the importance of skilled facilitation in creating the personal plans and supporting adults with IDs in their goals.
Fleming-Castaldy, 2013	N/A	By enabling opportunities for self-direction, specifically in policies, services can support and increase independence.
Friedman, 2018	Analysis of the waivers from 46 states and the District of Colombia. Descriptive statistics to calculate trends. 111 Medicaid HCBS 1915(c) waivers from CMS Medicaid.gov website: frequency of participant direction, expenditures directed towards participant-directed services, and the types of participant direction allowed by states (i.e., employer and/or budget authority). The study also used states' goals for the number of participants to be involved in participant direction as a metric to examine state priorities.	The majority of waivers allowed for participant direction illustrating a paradigm shift in home and community-based services; however, the policies and number of services that allow for participant direction do not directly reflect the paradigm shift. Approximately one fifth of services allowed for participant direction.

Author, year	Data source/collection and participant details	Main finding(s)
Hagner et al., 1996	Purposeful sampling process, participant observation, in-depth interviewing, and document analysis. 108 individuals with mental retardation (ages 14-21), 6 were chosen for an in-depth participant observation. 18 individuals with mental retardation per community.	The study emphasized that implementation issues need to be closely monitored and evaluated to ensure that wide-scale implementation holds the same integrity.
Heller, 2002	Review of empirical and review articles: Published between March 2001 and March 2002. Published in peer-reviewed English language journals. Including articles from Australia, USA, Ireland, and UK.	The article identified that the trend towards community-based housing is increasing. Services vary in their quality but key features for positive outcomes include: home-like architecture, use of assistive technology, organizational policies promoting person-centred planning, and staff characteristics.
Herps et al., 2016	Document analysis of individual support plans using stratified sampling. Eight service provider agencies that provide 24-hour residential care to people with all levels of IDs. 209 plans for persons with ID from 8 residential Dutch service provider organizations were analyzed including 104 males and 105 females aged 20-83.	To enhance individual support plan practices, service contracts should be separate from goal plans. All forms of resources should be emphasized, including service-based, and natural supports. Three implications for individual support plan related policies: 1) Need for service providers to understand what constitutes a plan, having standards and administration requirements can make them less person centred; 2) All areas of quality of life should be included; 3) There is a shift to using individualized blended resources rather than using one resource to maximum capacity.
Kaehne & Beyer, 2014	Documentary analysis of 44 PCPs, transition review meeting records of young people with IDs, and telephone interviews with all families participating in the program	The study confirms Claes et al.'s (2010) suspicion that even the best PCP process may remain a paper-based exercise. Services need to embrace person-centred transition reviews as a vital part of their service planning.
Lakhani et al., 2018	Systematic review of data published between October 2014 and April 2016. Three databases (MEDLINE, CINAHL and Web of Science) were searched for research and review articles. Findings were mapped into either: key areas determining service user engagement, or service users' informed decision-making. 927 articles were found and was reduced to 131 after title and abstract screening, then 24 after full-text review.	A flexible approach to self-direction is needed to match varying settings. Self-direction has the potential to provide individuals with IDDs more choice and control to align services with their needs and aspirations.
Levack et al., 2015	Systematic review of randomized controlled trials (RCTs), cluster-RCTs and quasi-RCTs. 39 studies involving 2846 participants total.	The evidence is not conclusive and of low quality when it comes to goal setting and the impact on adults with acquired disability participating in rehabilitation. The evidence appears to favour positive effects for psychosocial outcomes (i.e. health-related quality of life, emotional status, and self-efficacy). Due to study limitations, there is uncertainty regarding these effects.

Author, year	Data source/collection and participant details	Main finding(s)
Martin et al., 2016	Participatory action research (reflective stage of the study). Researchers worked with three planning teams from different community service agencies using participatory action research techniques. Participants were broken into 2 groups and met twice each. The first meeting: Free List and Pile Sort activity to brainstorm ideas related to the 3 components of the person-directed planning framework. Second meeting: The Socratic Wheel exercise & Five Whys and Hows exercise (provide a summary of elements, rate the importance of each element, and understand why those elements were important to success). Five community agencies and 24 participants: 4 adults with IDDs, 2 natural supporters, 14 agency staff members, 3 principal investigators, and 1 project coordinator.	Common elements underlie the success to person-directed planning approaches; different elements contribute to the success due to the individual nature of the approach. Three elements not identified in the person-directed planning framework were highlighted: empowering the person, communication, and documentation.
McCauslan d et al., 2022	Quantitative analyses and qualitative case studies. Dataset containing the Planning Alternative Tomorrows with Hope (PATH) data of 169 service users who had completed and reviewed their plan. Mean participant age was 50.1 years, ranging from 21 to 93 years. Phase 2 had 7 individuals with severe-profound level of ID.	PCPs may provide a good basis for planning community participation for adults with ID and with the right support it may provide opportunities for people with CSNs to improve their level of community participation.
Niven et al., 2020	Semi-structured interviews on QoL and measures of current activity levels (Guernsey Community Participation & Leisure Assessment - measures of quality of life). Participants previously had been on the Community Learning Disability team or the Intensive Support Team. 15 participants were former in-patients of learning disability assessment and treatment units in Cornwall at the time of their closures in 2007. Only 1 participant self-reported, therefore informants were utilized instead: 3 parents, 12 team leaders/service managers and 3 included support workers/care staff. Participant's ages ranged from 35-67, and clients included 2 female and 13 male. Of the 15 clients two individuals had no comorbid mental health or neurodevelopmental diagnosis, 13 had a range of comorbidities: autism spectrum disorder, psychosis, affective disorder, epilepsy, and personality disorder.	People with complex conditions with a history of placement breakdowns and past institutionalization can be transitioned into the community safely and successfully although it may be difficult for them to achieve a satisfactory QoL on a long-term basis. This study highlights the need for a person-centred, proactive approach to discharge planning to better ensure successful transition and integration into the community.
Ottmann & Mohebbi, 2014	Multi-methods longitudinal comparative cohort study. Non-randomised prospective longitudinal comparison study with one intervention group (over 10 months) and one comparison group. The study also used 56 semi-structured interviews and 4 survey tools: Adult Social Care Outcomes Toolkit (ASCOT), self-perceived health scale, eight-item Personal	Holistic support and mentoring have the potential to increase older people's sense of choice and control over their care services, facilitating and contributing to a better outlook on life. A stepped approach has the potential to build older persons capacity to self-direct their care.

Author, year	Data source/collection and participant details	Main finding(s)
	Wellbeing Index, and the Australian modified version of the extensions to the UK-focused User Experience Survey For Older Home Care Service Users and Younger Adults. A total of 185 participants (98 in the intervention and 87 in the control group) including older people and carers who were recruited at baseline. Eleven months later, 109 participants (59 in the intervention and 50 in the control group) completed the repeat measure.	
Parsons & Theobald, 2004	Pilot program evaluation. 15 facilitators took apart in two review days to reflect on the pilot, evaluate its progress, and plan the full implementation.	Feedback from staff and clients was positive regarding the person-centred planning pilot study. Carr-Gomm continues the rollout of their program with a commitment to training staff more before starting to work with clients.
Ratti et al., 2016	Systematic review. Databases searched: PsycInfo, Embase, CINHAL, PubMed, Web of Science, Scopus, and Medline (published between 1990 and 2014). Manual searches of reference lists as well. 16 papers were included in this study: 7 quantitative, 5 qualitative, 4 mixed methods published between 1992 and 2014. The studies were published in the UK, US, New Zealand, and Canada. A total of 598 participants across age range 8-84 yrs old with various levels of ID (mild to severe).	There is good quality evidence on a small scale that PCPs can have a successful impact on many different outcomes for individuals with IDs. With implementation there comes many challenges and the application of PCPs on a wider scale is still unknown.
Ritchie, 2015	Utilizes a case study example.	Supporting people to take control of their own lives is also supporting them to play a part in society. Staff are responsible for helping individuals get as much as they can out of their lives, helping them represent themselves to the wider world, and helping them play as big a part in the community as they can. The skills, confidence and abilities needed to make more decisions in their own lives are equally as important when it comes to playing a bigger part in the community.
Robertson et al., 2006	Four sites in England over a 12-month period. Data was collected at 3-month intervals for 2 years. At the start of the project data collected included: age, gender, ethnicity, ability, and additional impairments (residential and community) using Part 1 of the Adaptive Behavior Scale (ABS), psychiatric status using the PAS-ADD Checklist, syndromes associated with IDs, challenging behaviour using the Learning Disabilities Casemix Scale, residential history (for those living in supported accommodation only); and existing arrangements for individual planning. The participant's postcode was also collected to measure economic level of the neighbourhood (using the English Indices Deprivation). Every 3 months	Person-centred planning is a step in the right direction that builds on existing services. Further, person-centred planning can enhance the QoL of people with IDs.

Author, year	Data source/collection and participant details	Main finding(s)
	data collected include: current scheduled day activities; physical activity using the Health Survey for England; community-based activity using the extended version of the Index of Community Involvement; social networks using the Social Network Map, contact with family and friends, use of hospital-based services, health checks, community-based service receipt using the Client Service Receipt Inventory, and person-centred planning activities. Every 6 months data collected includes: all of the above information and information from key informants on health problems; medications prescribed; behavioural and emotional strengths and difficulties using the Strengths and Difficulties Questionnaire; risks, accidents and injuries using an adapted version of the Risks Scale, and changes in the level of choice experienced by participants. There were 93 participants total from 4 different sites ranging from people with a high level of CSNs to people with living semi-independently with minimal support, full range of IDs. Average age was 40.25 (16-86): 61% male, 91% of participant's ethnicity was white. 62% lived in a group home, 27% living with informal carer, 7% locally based hospital unit, 3% independent living, 1% respite.	
Vlaskamp & van der Putten, 2019	Five units at one residential facility participated, the training program took place over 2 years beforehand. Researchers collected the individuals support plans of all participating clients. The study conducted semi-structured questionnaires using the Questionnaire Evaluation Strategies (QES). 23 clients and 41 professionals (direct support staff) of a residential facility in the Netherlands: 27 support staff from the living unit, 9 support staff from day services centers, and 5 physical therapists.	Individual supports plans have benefits on staff work and clients. Time is a significant barrier, specifically as building meaningful relationships is an ongoing process and a long-term process.
Watchman et al., 2021	Mixed-method participatory action study using individualized goal-setting theory. Semi-structured interviews (at 3 different periods during each cycle) with support workers and photovoice (enabled researchers with an ID to capture information). Opportunistic sampling and the Bespoke behaviour change tool and intervention diary were used. Neuropsychiatric Inventory Questionnaire (NPI-Q) completed by staff who supported participants with the interventions. Cycle 2 (only), researcher and social care staff collaboratively completed the Quality of Life in Advanced Dementia (QUALID) instrument. Participants with ID and dementia completed the goal attainment (pictorial) scale.	The opportunity for participants to select interventions provided them with respect and care, shifting the control to the participant with ID. Staff's claims that the interventions benefited participants were corroborated by the behaviour change tool and the number of goals met.

Author, year	Data source/collection and participant details	Main finding(s)
	16 participants with ID and dementia and 22 social care staff (across 11 sites). There were 5 co-researchers with ID.	
Yamamoto et al., 2014	In the first year 27 students were supported by project-funded educational coaches to pursue inclusive social and academic opportunities at three community colleges. Only 20 students continued with the program.	The partnership between the Hawai'i vocational rehabilitation agency and the Dual Enrollment with Individualized Supports Project (DEIS) provided opportunities for assessment and program strategies to aid individuals with IDs transitioning to postsecondary education, in which PCP tools were used.

*Intellectual disability (ID); person-centred plans (PCPs); complex support needs (CSNs); randomized controlled trials (RCTs); quality of life (QoL)

Table 4

Extracted Details of Types and Features Related to Individualized Participatory Care Planning Approaches

Author, year	Types of PCPs	Features of PCPs
Claes et al., 2010	Approach to individual program planning with a focus on the fundamental changes in the lives of people with IDDs. Develop collaborative, goal-oriented, and individualized programs focused on community presence and participation, positive relationships, respect, and competence.	N/A
Collings et al., 2019	National Disability Insurance Scheme planning provides an opportunity for individuals to think about and then achieve their life goals.	Some individuals did not want to discuss intimate information in the planning sessions but was important to their lives and plans. Some individuals did not want to have their parents/family present to be more independent.
Collings et al., 2016	Support planning is the process through which the value of funding for an individual is decided. Used to assist disability users to assess whether the support they receive is conducive with their goals.	Formal meeting ("planning conversation") when supports are determined.
Espiner & Hartnett, 2011	N/A	There were no wider social circle individuals (friends) at the meetings. An independent trainer (from an organization with expertise in service design and evaluation of the quality of services to adults with ID) was hired to design and facilitate training for staff who had been appointed roles as facilitators. The training program was used to ensure that the person's voice was being captured in the plans. Training content included: values in being person-centred, facilitation skills, problem solving, group dynamics, effective communication skills, accessible communication formats, networking and identifying community resources, and the acknowledgement of planning as a process.
Friedman, 2018	A majority of the waivers allowed budget authority (the participant manages their budget) and employment authority (allowing the participant to recruit, hire, supervise, and direct the staff who provide their supports).	N/A
Hagner et al., 1996	N/A	The focal individual took charge of the planning process (setting time and location). Meeting leaders: special education teacher, social worker, adult service program manager, and an outside consultant.

Author, year	Types of PCPs	Features of PCPs
		Meeting topics: established an agenda for a meeting and emphasized three rules: a) equal participation from everyone, b) comments should be positive, and c) “don't hold back, don't limit dreaming”. Included asking questions and recording information on chart paper. First meeting: life domain structure, what the individual does, likes and dislikes, and would like to do in the future. First planning meeting lay a foundation for future meetings but resulted in few clear plans. Meeting attendees: family members were very involved. Meetings were focused on "grown-up" topics, and case managers asked friends to leave if they were not being serious.
Herps et al., 2016	Physical well-being was the most often stated domain of goals (114 individual support plans, 63.3%). Not all individual support plans included goals, goals were found in 180 (86.1% of the individual support plans analyzed).	Number of goals varied from 1-11. Presence or absence of goals were related to the organization (not to any client characteristic). Resources were specified in a majority of individual service plans (service-based resources listed more often than informal supports). 25.9% of all goals included service-based and natural (individual's roles and responsibilities in working towards quality of life-related outcomes) resources.
Kaehne & Beyer, 2014	N/A	Meeting topics: School education (most common), health, paid job, skills/competencies, college, welfare benefits, evening/weekend job, relationships, housing, individual budgets and direct payments. There was not much discussion on work experience and community activities.
Martin et al., 2016	Person-directed planning: approach that empowers the individual while facilitating goal setting based on what the individuals wants and the empowerment of individuals with IDDs to make decisions about their own lives.	Three elements not explicitly in the person-directed planning framework were identified: empowering the person, communication, and documentation.
McCauslan d et al., 2022	66.9% (139/169) included at least one community participation goal in their PCP. A majority (62.1%, 105/169) also identified a holiday in a community setting as a goal, and 17.8% (30/169) identified a social goal that took place in both community and non-community places. Goals related to family (68%, 115/169) and personal independence (62.7%, 106/169), included independent living activities, decorating bedrooms and outdoor spaces, public transport and travel. Social goals within service-run facilities were identified by three-quarters of participants (74.6%, 126/169), making these goals more common within	Most of the group had family involvement in the person-centred planning meeting and had ongoing contact with family who also contributed to the implementation of goals. Mean number of goals (of all types) included in PCPs was 8.55 (SD 1⁄4 4.06, n 1⁄4 168).

Author, year	Types of PCPs	Features of PCPs
	planning alternative tomorrows with hope (PATHs) than community-based social goals. 49.7% (84/169) included a 'holiday (service)' goal, which was a short break/holiday at the organisation's holiday home in the west of Ireland.	
Parsons & Theobald, 2004	Making Action Plans (MAPs): a collaborative approach to helping the person review their life story, their nightmares, dreams, and the challenges they face. Planning Alternative Tomorrows with Hope (PATH): starts with a vision of where the individual wants to be and works backwards to identify what it takes to get there. Personal Futures Planning (PFP): oldest person-centred planning tool involving a circle of people who support the individual and looking at their life and strengths now. ELP: essential lifestyle planning - a more detailed planning approach, gathers information about what is and what is not working in the person's life now, what is important to the person and what support they need to have these elements present or absent from their life.	The person is at the center, family and friends are "full partners", the plan reflects the person's capacities, there is a shared commitment to action that recognizes a person's rights, there is continual listening, learning, and action. Not all individuals wanted a plan.
Ratti et al., 2016	Person-centred planning has the aim to build a lifestyle based on choices, preferences, shared power, rights, and inclusion.	Five key features: 1) the person is at the centre; 2) family members and friends are partners in planning; 3) the plan reflects what is important to the person, their capacities and what support they require; 4) the plan results in actions that are about life and reflect what is possible, not what is available; 5) the plan results in ongoing listening, learning, and further action.
Ritchie, 2015	Supporting people to take control of their own lives is also supporting them to play a part in society. Helping individuals get as much as they can out of their lives, but also supporting them to play as big a part in the community as they can. It includes individuals helping to choose who supports them, what they want out of a support worker, what attributes they want, what activities they want the person to be familiar with and what that means.	N/A
Robertson et al., 2006	N/A	Person-centred planning development was introduced to the organizations by external consultants. These consultants provided support to develop policies, procedures, and practices to implement PCPs over two years. Training was provided to facilitators and managers (facilitators were paid outreach support staff, people with IDs, and unpaid volunteers).
Vlaskamp & van der	Interaction and social goals/roles appeared as an important domain to persons-supported.	Four individuals had only one goal, nine individuals had two goals, seven individuals had three goals, and three individuals had four main

Author, year	Types of PCPs	Features of PCPs
Putten, 2019		goals. Short-term goals were mostly focused on gathering knowledge, the mean number of short-term goals was 10.
Watchman et al., 2021	The goal-setting intervention strategy was developed by Locke et al. (1981). This included personalized goals set by participants in Cycle 1 and collaboratively agreed on with social care staff in Cycle 2.	Documentation: staff completed the behaviour change tool and an intervention diary following each intervention.
Yamamoto et al., 2014	Person-centred planning: assist people to plan their lives and supports.	Participants took part in workshops to learn about goal setting and planning. Vocational rehabilitation counsellors also attended workshops to understand clients' goals and support needs.

*intellectual and developmental disabilities (IDDs), person-centred plans (PCPs)

Table 5

Extracted Details of Supports and Hindrances Related to Individualized Participatory Care Planning Approaches

Author, year	Supports	Hindrances
Cardol et al., 2012	The caregiver's perceived severity of diabetes and their perceptions of the capability of the person-supported are factors that impact the support provided. Clarifying the person-supported's wants can help plan for autonomy and partial self-management.	Caregivers wanted to be person-centred in their support but found it difficult with restrictions (i.e., food intake) and struggle with involving the person with ID. Staff are unsure what to do when person-centred care and respect for autonomy conflict with caring for the person-supported's health.
Claes et al., 2010	Teamwork and involvement of the person and their family were identified as important. Flexible support is needed to make PCPs work and is frequently difficult in large traditional service systems.	The absence of relationships and social isolation may hinder the PCP process. There may be too much optimism surrounding which may lead to unrealistic goals, unsuccessful outcomes, or unrealized expectations.
Collings et al., 2019	For planning preparation participants had support for their initial planning meeting (family members). Being prepared would have been better and result in less anxiety. Trust was created through planner skills, communication and sector knowledge, and warmth and openness attributes. Plans should be able to respond to changing lives. A trusting relationship between the participant and support planner was an important facilitator of planning if they were going to share their goals and aspirations (only possible if the planner was able to respect their goals and understood who the person is). Planners should be well informed about the system and what is out there. The person-supported wanted to develop a relationship with their planner that evolved over time so they could discuss what worked and what didn't with someone who they felt understood the goals and aspirations. The planner's role is an important facilitator in the planning process and can significantly impact the results and benefits of the process. Planners should listen to individuals and respect their opinions, rather than assume that their carers or advocates knew best.	Having a new planner assigned to the person-supported without prior notice or agreement demonstrated a lack of respect towards them.
Collings et al., 2016	Support planning for this group requires professionals and services to commit to a lengthy process to build trust and provide intensive support. High-quality relationship between worker and individual is consistently	The inflexibility of services and systems result in unmet needs and barriers to people with CSNs. National Disability Insurance Scheme criteria must be met before receiving an individualized funding package

Author, year	Supports	Hindrances
	cited as an element of good practice (including trust and respect). The support planner's skills (communication skills and rapport) are important to properly support the individual.	and the opportunity to document goals and needs. Some individuals have had limited supports previously and will be unable to articulate what supports they need, a lack of support networks may hinder advocacy for the individual.. Many carers are overwhelmed and confused by the National Disability Insurance Scheme information.
Dowling et al., 2007	Multi-level engagement across agencies/organizations may be a support of person-centred planning. Informal social supports are an important component of person-centred planning. A positive relationship between staff and client is a facilitator of person-centred planning. Staff with negotiation skills for negotiating access to services is a support.	A challenge may lie in the responsibility of encouraging person-supported's participation.
Engen et al., 2019	Establishing a good and trusting relationship between staff and person (an ongoing process), staff sensitivity, responsiveness, and ability to interact with persons in a partnership were important elements. Staff characteristics are an important factor as the staff is at the centre of facilitating individualized care and support. Professional competencies include emotional and relational skills and attentiveness; further, staff having a common understanding of behaviours that challenge and taking the time to get to know the person-supported can facilitate individualized support.	Time, intensity, and shortage of staff caused barriers to ideal practices of individualized care, especially in the morning. Staff shortages can lead to multitasking, creating barriers for individualized care. It can be difficult to balance between institutional practices and adapting to a person's individuality and needs, specifically when behaviours that challenge are exhibited. Situations where there are differences in a person-supported's understanding/desires and their need for care and treatment can cause difficult situations for the staff that are frustrating and can also lead to care that is not ideally individualized.
Espiner & Hartnett, 2011	9/10 adults indicated that their facilitator opened a space where they felt acknowledged and listened to. One adult expressed frustration as their aspirations/goals had not been acted on. Supporters and key staff also expressed the supporters were listened to. Individuals appreciated the supporters at their meetings. The accessibility of the plan (readability and proximity) was a support of motivation and acted as a reminder of the plan, specifically personal copies. Scrapbook format was associated with great ownership of the plan. Computer-generated formats (with text and pictures) were popular and were found to be easy to read. There is importance in skilled facilitation in creating plans and supporting adults with IDs in their aspirations.	Difficulty in attendance at meetings was expressed due to family living far.
Fleming-Castaldy, 2013	Choice and control in services (offered in a continuum) can support the process, agencies should make sure opportunities for choice and self-direction are integrated into service delivery.	N/A

Author, year	Supports	Hindrances
Friedman, 2018	N/A	Only 1/5 of services allow for participant direction (education, family training and counseling, individual goods and services, and financial support services were the categories that allowed for participant direction the most). There is a disconnect between the number of services that are allowed to be participant directed (by state) and the goals of each state in the number of participant directed services (policies do not reflect goals of participant direction). The proportion of each waiver that allowed participant direction varied widely.
Hagner et al., 1996	Family members were very involved and can support by providing prompts and rewording questions to aid the individual's understanding.	Some facilitators did not enforce the rule of avoiding negative comments, resulting in some meetings that were negative. Additionally, not all family members were positive and supportive (specifically when it came to community inclusion).
Heller, 2002	Degree of support from staff and the quality of support were important factors that impact resident outcomes. Further, organizations that promote individualization and person-centred planning are associated with positive outcomes. Organizational support is important for staff due to the stress of dealing with behaviours that challenge (i.e., increasing job satisfaction and motivation, organizational policies promoting individualization, and use of assistive technology). Organizational features that promoted person-centred planning were supports for greater self-determination. Services vary in their quality but key features for positive outcomes include: use of assistive technology, organizational policies promoting person-centred planning, and staff characteristics.	Larger group homes generally rate higher in depersonalization.
Kaehne & Beyer, 2014	Stakeholder engagement and participation of key stakeholders was closely associated with the success of the development of alternative options, it needs to be backed by accessibility to options and resources. Person-centred planning must be perceived as a method to develop an individualized service and a vital part of service planning.	Adult support agencies were mostly absent from planning meetings, despite being an important part of transitions.
Lakhani et al., 2018	Key areas that facilitate service users' engagement with self-direction: personal responsibility for budgeting, personalized services, and a cultural shift in practice and delivery. Attributes that support informed decision making: comfortability with provider, provider competence, reliable information, utilization of professional advice, strengths-based approaches, and experiential knowledge. Individuals who can support the process of	Attributes that inhibited informed decision making: limited accurate information, remote areas with minimal access, and conflicts amongst family and providers. Inadequate information, limited resources, and high costs can be barriers to informed decision-making.

Author, year	Supports	Hindrances
	decision-making include trusted staff, a strong social support system, or family caregivers. Services must ensure the development of activities that align with the person's interests (tailoring to the person's needs) and providing diverse experiences, therefore a flexible approach is needed.	
Martin et al., 2016	Communication and collaborative teamwork are required to ensure consistency in planning. The right people, attitudes, and actions are key elements to success. The right people: those who know the person well, have the capacity to support, were chosen by the person, and included natural supports (not only paid staff). The right attitudes: focus on the person, their strengths, abilities, and aspirations, commitment to planning members being involved throughout the process, need to respect choices. The right actions: promote and facilitate choice making, be accountable to the person, foster connections, listening to the person, work collaboratively, and identify supports. Knowing the person, listening, accountability, and commitment were elements identified as being key to success. Documentation was identified as a key component to ensure that plans and the results were captured. Accountability, commitment, and empowerment were additional supports identified.	N/A
McCausland et al., 2022	Good communication between all parties was vital to success in setting and achieving community participation goals. Better community participation was achieved when family played a stronger supporting role for the individual's participation in social activities.	84.6% (143/169) identified potential barriers to achieving the goals set out in their PCP. Most common barrier, was 'myself' (46.7% 79/169) and staff support issues: familiar staff (30.8% n=52) and adequate staffing levels (29.2% n=50). Organization as a potential barrier (27.9% n=46). Notable barriers: unfamiliar staff, staffing resources, access to resources, and changing health status.
Niven et al., 2020	Adequate support is required to support individuals in achieving a satisfactory quality of life on a long-term basis. Community capability and resource availability are important factors to consider.	N/A
Ottmann & Mohebbi, 2014	Communication, capacity building, and encouragement were identified as key factors for older individuals utilizing community services.	Challenges to self-directing at a higher level: a lack of perceived knowledge, feeling overwhelmed, a lack of desire to handle money, a lack of perceived skills, inadequate communication, difficulties with English language, negative experience with changing care arrangements, a lack of self-confidence, fear of losing a case manager, and health concerns. Only 14 individuals (2.1% of the total eligible population)

Author, year	Supports	Hindrances
		were comfortable enough to choose Level 3 in terms of control over administrative and financial processes (may be due to personal preferences, health and medical status/issues, a decline in confidence levels, lack of willingness to take on administrative tasks).
Parsons & Theobald, 2004	A visual approach to planning may be useful given that the clients responded well to it, it also helped in breaking down the barrier between staff and clients (facilitating a better relationship). Providing staff with the proper resources and tools provides value for staff.	Main obstacle was time, including time for facilitators to get used to PCPs, time to practice the tools, time to prepare a client for using PCPs, time to complete the plan, and time to follow up. Staff also need time to adjust to an increase in expectations in terms of responsibilities that require extra time to facilitate (it may impede on other work). Some found it logistically difficult to involve families and friends in the planning process, resulting in some PCPs only being carried out with staff.
Ratti et al., 2016	Caregivers play an important role in the success of PCPs and shaping the lives of individuals with IDs. PCPs need to be embraced at all levels of the organization to be successful including service delivery and commitment to its implementation.	N/A
Ritchie, 2015	Support staff that are flexible and creative is important. Creativity is an important factor in making opportunities accessible to individuals with learning disabilities. The individual's skills, confidence and decision-making abilities are equally as important.	N/A
Vlaskamp & van der Putten, 2019	Commitment to a long-term process is a support.	Time is a significant barrier, specifically as building meaningful relationships can be a lengthy process.
Watchman et al., 2021	N/A	Sometimes participants were tired or did not want to partake in the intervention.
Yamamoto et al., 2014	Staff participants reported that observing positive outcomes helped shift their mindset and re-evaluate how they determined services for their clients.	N/A

*Intellectual disability (ID); person-centred plans (PCPs); complex support needs (CSNs)

Table 6

Extracted Details of Impacts and Effectiveness Related to Individualized Participatory Care Planning Approaches

Author, year	Impacts	Effectiveness
Claes et al., 2010	PCPs are associated with improvement in social networks (closer contact with family and friends, or greater involvement and engagement in group activities) and a positive impact on community involvement. Five studies evaluated the effect of positive behaviour support and PCP on challenging behaviour; a reduction in challenging behaviour and increased engagement was noted in all 5 studies. Improved communication, incorporation of the individual's desires in written goals, development of a larger vision, and a significant effect on parental participation in planning meetings. One study found increases in parent-child interactions. One study found increased or maintained high levels of general education participation. One study reported improved academic performance and increased involvement in group activities. PCPs had no impact on inclusive social networks, employment, physical activity, medication and change in a negative direction for risks, physical health, and emotional and behavioural needs. No effect on wage or length of employment. One study found a decrease in life satisfaction.	PCPs may be a paper exercise that is not fully related to the lives of the individuals. Scarce evidence on the evaluation of outcomes related to PCPs, this could be due to the lack of a clear definition of PCPs as the components of PCPs are complex and hard to define. The lack of literature could suggest that it is not adopted internationally.
Collings et al., 2019	National Disability Insurance Scheme (NDIS) planning opened an opportunity for personal growth and has the potential to increase social and economic participation of people with ID. The planning process did not always facilitate more social connections for those who listed that.	N/A
Collings et al., 2016	N/A	The proper supports and planning are needed to accurately and effectively execute support planning for individuals with IDs and CSNs.
Espiner & Hartnett, 2011	The facilitation opened up a space for the adults to participate in the process of planning and implementation of their personal plan. Seven of the adults communicated that they were happy with their plan (facilitation and outcome). It was too early for two adults to comment on the effectiveness of their plan and one adult was frustrated with the lack of action and support towards their goal. All supporters and staff agreed/strongly agreed that the facilitation had resulted in a useful planning document. Adults believed that the facilitation approach had increased their sense of ownership and self-direction, including a greater sense of control by being more involved in the process of the plan. Self-determination was illustrated through the adults' reflection that they did not need to agree with the supporters and staff on suggestions and	N/A

Author, year	Impacts	Effectiveness
	could change or alter their goals at any time. The new facilitation approach had been a positive experience for 9/10 participants. This approach enhanced a sense of ownership, increased involvement, and motivated adults to view their plans as a living document. Supporters and staff agreed that the approach allowed for a better understanding of the adults' goals and aspirations that could be translated into aligned supports and services.	
Fleming-Castaldy, 2013	Self-directed personal assistance services empower individuals to participate in society, attain and maintain a satisfying QoL. Personal control and an increased ability to self-manage helps increase satisfaction and QoL. Control and choice in personal assistance services are more important determinants of QoL than level of impairment.	N/A
Friedman, 2018	72/111 (64.86%) waivers offered participant direction of approximately 600 services. The majority of waivers offered participant direction, but these waivers only served approximately 12% of the potential applicable population. 85.9% of participant-directed services from 71 waivers allowed employer authority, participants became co-employers in 43 waivers (60.6% of cases), while in four waivers (5.6%) participants functioned as a common law employer.	N/A
Hagner et al., 1996	Five individuals enjoyed the process, were pleased with the outcome, and wanted to have another meeting.	Individual implementation issues need to be closely monitored and evaluated to ensure that wide-scale implementation of person-centred planning holds the same integrity.
Heller, 2002	Self-determination features associated with PCPs must be backed by resources (although these were found to not promote self-determination). High staff-resident ratios are associated with less self-determination but more connections with nondisabled persons. Higher resource availability (i.e., more staff) does not promote self-determination. Active support and assistive technological interventions are a better fit for individuals with more severe disabilities.	N/A
Kaehne & Beyer, 2014	Person-centred planning approaches by themselves does not guarantee an improvement in choices (needs to be backed by accessibility to options and resources). PCP approaches to meetings can increase the opportunity for parents and the individual to express their needs and preferences.	N/A
McCausland et al., 2022	Person-centred planning may provide a good basis for planning community participation for adults with ID and may provide opportunities for people with more complex needs to improve their level of community participation.	The majority of goals (approximately six) had been achieved (M ¼ 6.32, SD ¼ 3.86, n ¼ 168) with an average of two goals not achieved, or still in progress (M ¼ 2.09, SD ¼ 1.78, n ¼ 168)

Author, year	Impacts	Effectiveness
Ottmann & Mohebbi, 2014	Satisfaction with services and care was high at baseline, compared to those recorded in the UK. Participants at Level 2 were far greater familiar with self-direction and appreciated the efficiency of coordinating their own care. Level 3 participants had a positive attitude about self-direction and liked having greater control and financial benefits. There were few home and personal care needs that were unmet. Holistic support and mentoring have the potential to increase older people's sense of choice and control over their care services. This facilitates them to contribute to a better outlook on life. A stepped approach has the potential to build older persons capacity to self-direct their care in a range of domains. Substantial opportunity to improve the care outcomes of older people enrolled in self-directed community programs by adopting a stepped approach and focusing on capacity building.	Almost half of the participants felt lonely, 1/3 reported they did not have a good social life and were not fully occupied with activities of their choice.
Parsons & Theobald, 2004	Extremely positive feedback from staff and clients. Individuals were proud of their plans and wanted to display them. Feedback from staff and clients was positive regarding the PCP pilot study.	N/A
Ratti et al., 2016	Person-centred planning may provide a good basis for planning community participation for adults with ID and may provide opportunities for people with more complex needs to improve their level of community participation. Participants reported feeling better, looking at their lives differently, more confident, and happier as a result of PCPs. One study found that participants receiving PCPs had a six times greater improvement in scores in QoL compared to those in the control condition receiving the traditional Individual Service Planning framework. No significant positive effect was found on self-reported life satisfaction (three studies). Seven studies explored the impact of PCP on choice-making. 6/7 studies found the approach had a positive impact on daily choice-making. 3/6 studies suggest a positive impact of PCP on self-determination and empowerment, the other three studies suggest a limited impact on self-determination. Eight studies described the impact suggesting that the approach has a moderately positive impact on participation in activities. Four studies found that PCPs had a positive effect on community participation. Seven studies showed that the data is inconsistent on the impact of PCPs on improving relationships and expanding social networks for individuals with IDs. There is good quality evidence on a small scale that PCPs can have a successful impact on many different outcomes for individuals with IDs.	Implementation of PCPs on a wider scale is still unknown.
Robertson et al., 2006	Some participants had a plan developed after Round 1 of data collection, others after Round 2, etc. The study found an increase in the number and variety of activities and an increase in social activity (visits to and from friends). 34% decrease in the average score on the Strengths and Difficulties Questionnaire Peer Problems subscale and a 23% decrease in the number of individuals in their social network. Statistically significant changes in the positive direction -	28 participants (30%) had not developed a PCP by the final data-collection round, this includes 8 who dropped out of the study and 1 who died. 30% of participants had no plan by the final data-

Author, year	Impacts	Effectiveness
	changes in life experiences after the implementation of person-centred plan. Significant increases in the size of an individual's social network, the active contact and family in social network, the level of contact with friends, and in the active contact with friends. Significant increase in the number of activities involved with, the number of different activities, and the number of hours per week scheduled in a day activity. Significant increase in choice before six months. Statistically significant changes in the negative direction - changes in life experiences after the implementation of person-centred plan. Statistically significant increase in hyperactivity. The results support that person-centred planning is a positive step in the right direction and can enhance the quality of life of people with IDs.	collection round (or either dropped out/passed away).
Vlaskamp & van der Putten, 2019	Most staff said that since Individual Support Programs had been introduced, they had worked in a more pedagogical (65%), methodical and systematic (88%) way and aimed more towards the evaluation of the set goals (93%). Workload increased substantially due to the time needed for regular reporting or consultation. The program has resulted in the team working more efficiently as an interdisciplinary team. The positive impact of the program was mainly seen regarding communication and contact. Other effects on clients were generally positive for aspects of communication, mood, contact, interaction, and level of alertness.	N/A
Watchman et al., 2021	Confirmed intervention had positive effects: reduction in distress and agitation, improved mood, communication, and social interaction. The intervention led to the staff having increased confidence, allowing them to change their practices, implement, and initiate a wider organizational change. The opportunity for participants to select interventions provided them with respect and care that was personalized, shifting the control to the participant with ID. Staff claims that the interventions benefited participants were corroborated by the behaviour change tool and the number of goals met.	32% of goals were met in Cycle 1 and 43% exceeded expectations. In Cycle 2, 35% of goals were met and 37% exceeded expectations. 75% of participants in the study living in small group accommodation were more likely to have their goals met than those living alone. Those living in larger care homes with more than three residents were less likely to have their goals met.

*Person-centred plan (PCP); intellectual disabilities (IDs); complex support needs (CSNs); quality of life (QoL)

Chapter 3

3 Examining an Individualized Participatory Care Planning Approach for Individuals with Intellectual and Developmental Disabilities: A Qualitative Descriptive Study

This chapter presents the qualitative study examining PHSS's approach to individualized participatory care practices that utilized semi-structured interviews with community-care staff. The chapter begins with an introduction to the topic and then delves into the paradigm and methods chosen for this research, alongside the results and discussion of the study. The research aimed to answer the overall thesis question: How do individualized participatory approaches to care planning play a role in improved health and social care for individuals living with intellectual and developmental disabilities?

Terminology

One of the outstanding debates in disability literature lies within the language used to describe disability. While there is no consensus, this study uses identity-first language alongside person-first constructs (Crocker & Smith, 2019; Dunn & Andrews, 2015). This choice has been guided by Dunn and Andrews (2015) and Andrews et al.'s (2022) examinations of the evolution of disability language. Person-first language (e.g., person with a disability), developed from the social model of disability, recognizes disability as a neutral characteristic rather than a medical issue that requires a cure (Dunn & Andrews, 2015). The move towards person-first language was meant to emphasize the individuality of the person rather than their impairments, this was believed to be less objectifying (Dunn & Andrews, 2015), but there have been major evolvements over the past years. Identity-first language (e.g., disabled people), developed from the minority model, shifted disability from neutral to positive attributes, focusing on social, cultural, and political experiences, interpreting disability as a result of sociopolitical experiences (Dunn & Andrews, 2015). As such, the minority model has been linked to disability culture, highlighting community, and promoting diversity (Dunn & Andrews, 2015). There is no clear consensus within disability literature (Crocker & Smith, 2019). Preference for language varies from person to person and can change throughout an

individual's life as their identity develops and interacts with different cultural and personal factors (Botha et al., 2021; Crocker & Smith, 2019; Dunn & Andrews, 2015).

As I understand these variations in preference depend on the individual, I have opted to use the terms 'persons', 'people', or 'person-supported' over 'patient' where possible to support the language used in community-care and PHSS Medical and Complex Care in Community's (PHSS) philosophy. The literature is filled with widely recognized terms, including 'patient-centred' and 'patient engagement', especially within health care. By limiting my use of 'patient' I aim to highlight the perspective of directing the focus on the individual as a whole rather than any medical conditions they may experience (Crocker & Smith, 2019; Kumar & Chattu, 2018). The term 'client' is also utilized on a large scale within the disability and community-care literature to refer to individuals who use and receive the services within the community-care sector. As noted by Shevell (2009), the Latin root of the term 'client' is 'cliens', which also means follower or someone who requires protection. The Latin root contradicts our study's aim to empower individuals with IDDs, instead the chosen language in this report aligns with the topic of person-centred care as it recognizes the uniqueness of each individual, their goals, needs, desires, and preferences (Kumar & Chattu, 2018).

3.1 Introduction

Person-centred care (PCC) appears in the literature as a promising intervention to improve the quality of care, care experiences of providers and clients, and to reduce strains on health and social care systems (Hibbard & Gilburt, 2014; Jo Delaney, 2018; Stewart, 2000). It is an applicable approach for the care of individuals living with intellectual and developmental disabilities (IDDs) and/or complex care needs to decrease the health disparities and care system challenges this population faces (Sullivan et al., 2018; Sullivan & Heng, 2018). The American Psychiatric Association (2013) defines IDDs as lifelong conditions developed before the age of 18, distinguished by limitations in adaptive and intellectual (IQ $\leq$70; $\pm$ 5 points for error) functioning. Individuals living with IDDs are a heterogeneous population as healthcare challenges can vary depending on etiological factors, including genetics and the environment which may change throughout their lifespan (Lin et al., 2019; Sullivan et al., 2018). Moreover, individuals

with IDDs may display challenging behaviours, which can occur when their health and personal needs are not thoroughly understood, leading to a mismatch of needs and supports, and a lack of environmental accommodations (Sullivan et al., 2018). Compared to the general population, individuals with IDDs have poorer health outcomes (Ervin et al., 2014); of those Canadians ages 15 and older who report having a developmental disability, only 17% describe their mental health as "very good" or "excellent" compared to 70% of the general population (Health Canada and the Public Health Agency of Canada, 2021). Health inequities experienced by those living with IDDs have been associated with systemic barriers including poor accessibility to services, a lack of provider experience with this population, and communication challenges translating to low-quality care (Ervin et al., 2014; Todd et al., 2020). An approach to care that adapts to these complex care needs is required to ensure that individuals living with IDDs are properly supported (Lin et al., 2019; Sullivan et al., 2018).

PCC presents an opportunity for service delivery organizations to partner with person-supported to integrate the person-supported's beliefs and values (Jo Delaney, 2018; Lindblad et al. 2016). To implement this approach, professionals must respect the persons-supported and their wishes, integrating compassion into their practice to enable conversations on an individual's preferences (Jo Delaney, 2018; Santana et al., 2018). PCC can create care that is inclusive of the person-supported's voice, reflected in the communication, planning, decisions, and delivery of care (Lindblad et al., 2016; Sullivan et al., 2018). By executing a PCC approach, professionals can empower persons-supported resulting in a power gradient shift towards a shared power partnership, not only contributing to the health equity of individuals living with IDDs but also greater systemic equity (Lindblad et al., 2016).

IDD Supports in Ontario

A formal diagnosis of an IDD by a physician can translate into eligibility for supports including academic services, residential placement, vocational support, respite services, financial aid, and many more (Lin et al., 2019; Papazoglou et al., 2014). In Ontario, once an individual turns 18 their access to children's developmental services comes to an end (Developmental Services Ontario, 2022). Subsequently, they can apply through

Developmental Services Ontario (DSO) for adult services funded by the Ministry of Children, Community and Social Services (MCCSS). If eligible, the individual may receive specialized, housing, community participation, and caregiver respite support, and partake in the Passport funding program, delivered by various private and non-for-profit community-care organizations (Developmental Services Ontario, 2019; Ministry of Health, 2021). The Passport program is a funding reimbursement program specific for adults with developmental disabilities, meant to facilitate activities related to community participation as well as goals related to their PCPs (Government of Ontario, 2023b). A common social assistance support is from the Ontario Disability Support Program (ODSP), a type of income support that individuals must apply for to confirm eligibility (Government of Ontario, 2023a).

Many individuals living with IDDs rely on community-care support services that address both the adaptative and intellectual functioning needs of the population, including basic support services for daily living, complex medical care (i.e., palliative care and chemotherapy), and social support (i.e., access to education and engagement in meaningful activities) (Forrester-Jones et al., 2021; Purbhoo & Wojtak, 2018). This availability of services can differ based on the organization and funding source, often leading to uncoordinated, fragmented, and inconsistent care contributing to health disparities (Developmental Services Ontario, 2023; Purbhoo & Wojtak, 2018).

Person-Centred Planning

Person-centred planning, also known as person-directed planning, are one of the specialized services community-care organizations offer (Developmental Services Ontario, 2023). Person-centred planning is an individualized participatory approach that encompasses the elements of PCC to support individuals in achieving their goals and dreams (Dingwall et al., 2006). A person-centred plan (PCP) typically identifies an individual's gifts, talents, and dreams to set goals for the future (Developmental Services Ontario, 2023). Developmental service organizations are mandated by the 2008 Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (SIPDDA) to develop an individual support plan for each client with a developmental disability (Ministry of Children, Community and Social Services, 2021). The person-

centred planning process can vary between organizations and there is a dearth of evidence on implemented approaches. As such, this study aims to provide evidence on an implemented individualized participatory approach to care for individuals living with IDDs and/or complex care needs.

3.2 Methods

The study aimed to understand the key components and impacts of the individualized participatory individual service agreement/person-centred planning approach utilized by PHSS.

3.2.1 Research Design

A qualitative descriptive research design was chosen given the lack of understanding surrounding PCPs (Kim et al., 2017). Descriptive studies are used in health sciences research to develop a description of a phenomenon and further refine the understanding of interventions (Kim et al., 2017; Neergaard et al., 2009). Kim et al. (2017) found that many qualitative descriptive studies explore the factors related to interventions and participant experiences, aligned with this study's research question. The strength of using a qualitative descriptive design is the flexibility it offers; this research design provides flexibility in framework design and for researchers to thoroughly examine a phenomenon (Kim et al., 2017; Sandelowski, 2010).

3.2.2 Paradigm

Identifying a paradigmatic stance is important within qualitative inquiry (Guba & Lincoln, 1994). A pragmatic position was chosen as it allows for flexibility in the research process, relying on the researcher to analyze what fits the nature of the situation (Allemang et al., 2021; Kelly & Cordeiro, 2020). Pragmatists do not value "one type of knowledge or research method over another" but place emphasis on knowledge that stems from human experience (Allemang et al., 2021, p. 41). As such, understanding can develop from the connection between experience, knowledge, and action (Kelly & Cordeiro, 2020). Kelly and Cordeiro (2020) specify the effectiveness of utilizing a pragmatist stance when researching organizational processes; they identify the significance of exploring staff experiences and actions to achieve a level of understanding

that goes beyond formal organizational processes and documentation. This strictly aligns with our use of qualitative interviews with PHSS staff to gain knowledge and understanding of PHSS's organizational approach to individualized participatory care practices.

Moreover, we chose a pragmatic stance given the significant alignments between pragmatist concepts and patient-centred research. Allemang et al. (2021) lay out three intersecting concepts between pragmatism and patient-centred research: democratic values, collaborative approaches, and the pursuit of social justice. Democratic values lie at the core of pragmatic research, focusing on minimizing power imbalances by engaging the perspectives of marginalized communities (Allemang et al., 2021). Community members can highlight research priorities and determine research questions that align with both groups' interests through collaborative approaches (Allemang et al., 2021). Our collaborative research process exemplifies these democratic values, focusing on PCC to highlight the importance of amplifying the voices of persons-supported.

Lastly, pragmatism supports action-oriented research, encouraging the researcher to seek solutions that apply to relevant issues (Allemang et al., 2021; Giacomoni, 2010; Kelly & Cordeiro, 2020). Conclusively, pragmatists agree that the knowledge gained from the research should be shared and disseminated to the community along with any other key stakeholders (Allemang et al., 2021; Holtrop & Glasglow, 2020). As our research utilizes an integrated knowledge translation framework to guide the project, we co-conducted the project with PHSS to transform our research into actionable knowledge, aligning with pragmatist values (Allemang et al., 2021; Kelly & Cordeiro, 2020).

3.2.3 Model for Research

We chose an integrated knowledge translation (iKT) framework to guide this research given the partnership between the researchers and the knowledge users (PHSS) in developing this study and the larger project described in Chapter 1. An iKT approach involves a collaborative research approach that can generate knowledge to improve health system execution and therefore, associated health outcomes (Gagliardi et al., 2016). PHSS collaborated with Western University researchers to develop the research questions, create the interview guide, engage in recruitment, interpret the results, and

disseminate the end-of-project findings. A strength of the iKT framework is the uptake of the end-of-project findings to translate into changes in policy and practice (Gagliardi et al., 2016). This is extremely relevant to PHSS's request for data on the impact of their individual service agreements/person-centred planning approach to care and can be utilized to improve and expand their care delivery approaches.

3.2.4 Ethics

This study received approval from Western University's Health Sciences Research Ethics Board (Project ID 120382) before the start of the study (Appendix B). As part of the recruitment process, participants received information regarding the purpose of the study alongside the potential costs and benefits of the research project via the letter of information (Appendix C). Once individuals agreed, we obtained informed consent including consent to audio record the interviews.

3.2.5 Setting

This research examined PHSS's individualized participatory person-centred planning approach to care. PHSS, previously known as Participation House Support Services, is a non-profit organization based out of London, Ontario, Canada that provides support and services to individuals with complex medical, physical, and/or developmental disabilities to facilitate the lives each person desires to live. PHSS began supporting individuals in 1988 when the first location opened and has been part of the paradigm shift away from institutionalization, with now more than 60 locations across Ontario and supporting more than 250 individuals. The organization provides a range of developmental services and supports including recreational programs, 24-hour residential support, day and overnight respite, and in-home support for individuals living with their families. PHSS's philosophy focuses on persons-supported, recognizing their diverse needs and the uniqueness of each individual, with a mission to provide tailored support. This philosophy aligns with PHSS's goal to be a support that is determined by the persons-supported, ensuring that the individual partakes in a decision-making role.

3.2.6 Participant Recruitment

The PHSS senior team and the Western University team recruited one group of PHSS staff to participate in the semi-structured interviews. In July 2022, the PHSS leadership team sent a recruitment email (Appendix D) to all PHSS staff containing an invitation to participate. An email was sent prior to scheduling an interview that contained further details regarding the study alongside the letter of information and consent form (Appendix C). If the interested parties showed continued interest in participating, they were asked their gender and the number of years of experience they had in their current role at PHSS. These questions were asked to screen for a variety of participants in our study; variations in the participant pool came naturally and at this stage, we did not have to exclude any interested party. Following the screening, a time and place were scheduled for the interview at the convenience of the participant. It was noted during the research design that we would recruit until we reached saturation (assumed to be approximately 12-16 participants based on previous studies) (Thorne, 2020). In the interest of being inclusive, we also sought to interview any participant who expressed interest in participating.

3.2.7 Data Collection

The research team received emails from 19 interested parties. The study recruited and included participants with varying levels of experience and job titles (n=11). The team excluded eight other parties due to a lack of response after multiple attempts, data saturation, or issues with Microsoft Outlook, specifically email delivery errors. In the literature, data saturation has varying definitions and is sometimes used without explanation. As such, it is important to describe how the research team defines data saturation and the process by which we determined we had reached it. For this study, data saturation is defined as the point at which the data collected is sufficiently rich and any additional data would be repetitive and superfluous (Thorne, 2020). Saturation was determined by the interviewer [MD] and an additional researcher [MM] who read through the interview field notes. One additional interview was conducted after saturation was determined.

Qualitative interviews were completed from July to September 2022. The research team created the interview guide which was pre-tested with an external health professional for feedback on clarity. Interviews followed a semi-structured interview guide (Appendix E) to enable participants to converse freely about their experiences with PCPs at PHSS. MD obtained informed consent prior to the interviews; verbal consent was also collected prior to the start of the interview. Interviews took place both virtually and in person. Four participants chose to participate in-person, one over the phone, and six virtually (utilizing Zoom Video Communications software). The time and location of the in-person interviews varied and interviews were scheduled based on the convenience of the participant and at a location where they felt most comfortable. One interview was conducted in a Western University meeting room, one interview took place at the PHSS main office, and two interviews took place at the interviewees' place of work.

The interviews varied in length from 30 minutes to 1 hour, were audio-recorded and then securely sent to a professional transcriptionist for verbatim transcription.

3.2.8 Reflexivity

Pragmatism recognizes the significance of intersecting "physical, psychological, and social worlds, including culture, language, institutions and subjective thoughts" (Allemang et al., 2021, p. 41). As such, it was important to engage in reflexivity throughout the research process. Reflexivity is a critical element in qualitative research to ensure rigour, transparency, and sincerity in data collection and analysis (Baxter & Jack, 2008; Tracy, 2010). The researcher can articulate the interactions between themselves, members of the research team, the participants, and the research process to the audience to illustrate sincerity, rigour, and transparency (Tracy, 2010). Guided by this theory, I engaged in reflexivity throughout the research process by utilizing a reflexive journal and engaging in field notes. The field notes were used to record observations of the environment, interactions, potential bias, and impressions (Phillippi & Lauderdale, 2018). The reflective journal was used to document an ongoing conversation of connections, dynamics, and interpretations, as well as to keep track of the decisions and influences throughout the research process (Finlay, 2002).

3.2.9 Data Analysis

All interview transcriptions were uploaded to QSR International's NVivo version 12 qualitative data analysis software to manage the data. NVivo was useful in organizing the data, codes, and notes for discussions (Mattimoe et al., 2021). It is important that researchers consider how to organize their data when it comes to data analysis as it can help streamline procedures to provide for an effective structured process (Mattimoe et al., 2021). MD developed a coding plan to create a system of coding that ensured validity and consistency through intercoder reliability (Daniel, 2019). Three researchers partook in coding, MD coded all 11 interviews and SLS and JD coded four interviews (36.36%) each.

To begin, all coders inductively coded two transcripts each; one transcript from earlier in the data collection phase and one that occurred later were chosen. Once both transcripts were coded, two researchers [MD and JD] met to discuss initial thoughts and ideas that stood out, important themes that were starting to form, and the wording/phrasing of codes to begin creating an initial version of a coding framework. Another meeting occurred with all three researchers to discuss the initial two coded transcripts; more codes started to form alongside their preliminary descriptions. Moreover, the codes were categorized and version one of the coding framework was constructed. This initial version of the coding framework was sent to advisory committee members for feedback and informed the creation of a second version that was used to deductively code all 11 transcripts. All three researchers met to discuss the process of deductive coding and while there was a strong consensus on the richness of the data, there was also an agreement that version two of the coding framework did not fully capture the data. This meeting was further used to discuss the codes, including dividing some codes, the categorization of codes, the phrasing, and the descriptions. At a subsequent meeting with MD and JD version three (Appendix F) of the coding framework was discussed, which was then finalized by all three coders. Another round of deductive coding was carried out to reflect the changes in the coding framework and aid in the understanding of the results.

3.2.10 Supporting Data Analysis

Field notes were created by the interviewer [MD] immediately following each interview, guided by a framework that was revised throughout the data collection process to enhance the recorded reflections (Phillippi & Lauderdale, 2018). These field notes were used as supporting documents to complement data collection and were key in ongoing analysis (Phillippi & Lauderdale, 2018). The field notes provided a larger context in which the data were placed and facilitated preliminary coding as important ideas were highlighted consistently by participants and key themes started to form (Phillippi & Lauderdale, 2018).

3.2.11 Quality Criteria

We used Tracy's (2010) *Eight "Big-Tent" Criteria for Excellent Qualitative Research* to guide markings of high-quality research within our study, the criteria include: (1) a worthy topic, (2) rich rigour, (3) sincerity, (4) credibility, (5) resonance, (6) significant contribution, (7) ethics, and (8) meaningful coherence.

Tracy (2010) defines a worthy topic of research to be something that provides significance to the field. By addressing the gaps in research on implemented person-centred planning approaches for individuals living with IDDs and collaborating with PHSS on all aspects, our study has the potential to provide relevant evidence to PHSS and other care providers. Researchers can encourage rich rigour by ensuring that data collection and analysis methods are sufficient to produce significant data (Tracy, 2010). Throughout the research process, various measures were taken to enhance rigour including but not limited to data saturation check-ins, consistency through intercoder reliability, detailed reports of the step-by-step process, and the utilization and input from the integrated knowledge translation team (Daniel, 2019; Tracy, 2010). Sincerity is illustrated through transparency and vulnerability within the research process, displayed using approaches including self-reflexivity and data auditing (Tracy, 2010). I engaged in self-reflexivity through a reflexive journal used to ensure transparency of the challenges and authenticity with myself, the research, and the audience. Tracy (2010) emphasizes that researchers can promote credibility by engaging with crystallization, a term used to encourage the use of multiple sources of data, methods, or theoretical frameworks.

Crystallization can also be displayed using multiple researchers, effectively bringing different lenses to the research (Ellingson, 2008). This study used an iKT approach and therefore involved a research team (including researchers from Western University, health system leaders from PHSS, and a consultant affiliated with PHSS) of different experiences and backgrounds to create a more in-depth and complex understanding of the findings.

Resonance refers to the study's ability to produce findings that reverberate with the audience, achieved through generalizability, transferability, and evocative writing (Tracy, 2010). Transferability is when the audience feels as though they can transfer the research to their own context (Tracy, 2010). While I recognize that qualitative research should not be generalizable, specifically given the context of person-centred care, we hope that our findings encourage care professionals of vulnerable populations to implement similar approaches. Transferability can be further demonstrated through a detailed description of participant characteristics (Daniel, 2019), included in this report. To evoke feelings and emotions within the readers powerfully the report used quotes to better illustrate a story of the person-centred planning process and the resulting impacts.

Tracy (2010) describes research as a significant contribution if it produces findings that are unique and build on current understandings. This study provides practical significance in what Tracy (2007) calls 'phronetic research', described as research that "enables practical wisdom and a space for transformation" (p. 846). Our findings provide care professionals with practical evidence on implemented PCPs, encouraging the transformation of system-centred care to PCC. Ethical research is a vital criterion which can be viewed through procedural and relational ethics (Tracy, 2010). This study received ethics approval from the Western University Health Sciences Research Ethics Board. To promote relational ethics, researchers must be mindful of their actions, their impacts, and the potential consequences they may have on others (Tracy, 2010). During interviews, mutual respect was displayed, and the connection between the interviewer and participants was acknowledged within reflexive notes. Lastly, the study demonstrates meaningful coherence by reasonably aligning the research question(s), methods, and findings (Tracy, 2010). Our study used our pragmatic stance to interconnect the research design, data collection, and analysis. As we recognize that one group of

criteria is not a definite evaluation of high-quality qualitative research, we additionally utilized the Standards for Reporting Qualitative Research (SRQR) checklist to guide the reporting of our study (O'Brien et al., 2014).

3.3 Results

The results section begins by presenting the characteristics of the interview participants, followed by the creation and implementation of the PCPs, the supports and challenges, as well as the impacts of the PCPs. This order of results was chosen to paint a story for the readers and to facilitate a deeper understanding of how PCPs are created and facilitated from the beginning to the end, supported by verbatim quotes from the findings. The results are presented with the five bigger pictures as the subtitles (i.e., 3.3.2), this method of labelling was used to categorize the themes. Within these individual sections, themes are bolded as titles; readers will see that some themes spanned over multiple sections (i.e., accountability in 3.3.2 and 3.3.4).

3.3.1 Participant Demographics

With a total of 11 participants, their ages ranged from 23 to 65 years; two participants did not disclose their age (Table 7). Nine (81.82%) participants identified as women and two (18.18%) as men. We asked participants the number of years for which they had experience at PHSS, which was an average of 14.5 years (median of 11 years); participants also disclosed the years of experience in their current roles, which was an average of 6.77 years (median of 7 years).

Support workers responsibilities include but are not limited to carrying out health and personal care duties and supporting tasks related to daily living and recreation. Additionally, these individuals often partake in implementing the PCPs and supporting individuals within the activities included in the PCPs. Assistant coordinators, coordinators, and senior coordinators lean towards the managerial side of responsibilities, including coordinating staff and funding.

Table 7

Participant Characteristics

Characteristic	Category	Number of Participants
Gender	Women	9 (81.82%)
	Men	2 (18.18%)
Job Title	Support Worker	3 (27.27%)
	Assistant Coordinator	1 (9.09%)
	Coordinator	4 (36.36%)
	Senior Coordinator	3 (27.27%)

3.3.2 Creating the Person-Centred Plans

PHSS created PCPs on an annual basis at meetings that are referred to as 'celebrations'; "we really try to make it a celebration… decorations and food… music … they get quite lively. Others like a more sombre, quieter… discussion… very person-specific" (Participant 4). This participant provides a vivid description as to why the annual meetings are referred to as 'celebrations'; it is highlighted that the celebrations are person-specific and therefore look different for each individual. The person-supported partakes in planning the celebrations, inviting individuals who play meaningful roles in their lives, they "invite anybody that's important to them that… they want to assist them in making their goals come true… that can be family, staff… an employer… And then…we have facilitators that have been trained" (Participant 7). The person-centred approach to planning opens a space where persons-supported can share discussions about their dreams. One participant gave an example of a celebration that was tailored toward the individual:

> this young woman… she loves Shania Twain… her mom wanted her to have a grand entrance. She had a tiara on, she had Shania Twain blaring and into the room she came filled with 20 people, family, friends, staff, team members… present in-person and virtually. We then introduced everybody and… this person's gifts, talents, what her week looks like… very much celebrated this

> young woman… her mom and her had some goals that they wanted to work on. So, that's when we did that brainstorming… She wanted to go to a lady's group that she had found, she wanted to visit an aunt out east. Lots of laughs, lots of stories. We had a full-on dance party at the end… mom had put together individual charcuterie boards… We had a poster that everyone signed and just, you know like, 'reach for the stars'… words of encouragement…There were pictures everywhere… a true on celebration… to celebrate somebody… It was fun (laughs). (Participant 4)

This example provides an illustration of the celebration and discussion that developed within the meeting; further, it delivers insight as to how the topic of goal setting is discussed. When asked how the PCPs are tailored towards a person-supported, a handful of participants had an answer along these lines,

> All of mine are tailored… absolutely tailored to the person… what they want to do and what that looks like and how we can make it happen… Their condition and their ability to be able to communicate, we have to tailor. (Participant 2)

Meeting topics range from "interests and talents" (Participant 5) that flow into discussions about goals and aspirations, other times celebrations take on a more structured agenda with steps.

> There's one section that we call a view of the week in the person's lives… what do they do on… all the days of the week… Another section is their interests… And then there's… it's a diagram… the little circle in the middle is whoever the person we're meeting with, and then the next circle is for people that are friends or very, very close family members. And then outside that are acquaintances and then the outer section is paid employees… people they don't see on a regular basis… then we go to the goals, like what, what have we done in the past? (Participant 7)

The more structured approach follows the paperwork that is filled out to support the process of goal setting.

Accountability of PCPs

PHSS has mandated that when a person-supported is new to the organization a celebration must take place "within three months" (Participant 4) of a person moving into one of PHSS's residences. At the year mark, each person-supported is offered the opportunity to partake in another celebration by PHSS, this is mandated by the Ministry of Children, Community and Social Services (MCCSS); "people [persons-supported] that are agreeing and want to be a part of the person-centred plan… to be compliant with the Ministry… I have to offer you another meeting within the year" (Participant 8). Before the annual celebration, PHSS keeps their staff and the persons-supported accountable to the goals by mandating a six-month review. At the six-month mark, staff alongside the person-supported review the progress of their goals, documenting any progress and changes;

> the six months is just to review… they [PHSS] have forms and it just asks for dates, what progress has been done, what steps have been done to accomplish this [these] goals? And then, if it didn't get accomplished, why? Like, what were the barriers? And then we sign off on it… then we just go from there and try and work on it for the next six months. (Participant 7)

Offering person-centred services needs to be accompanied by flexibility and adaptability; PHSS offers this through the option for each individual to partake or withdraw from participating in any part of the PCPs. This can range from not having a PCP to not partaking in a celebration. In cases where individuals choose to not create a PCP, a document is drawn up that might say, "I've been offered to partake in [the] person-centred planning process; however, I have respectfully declined… [the person-supported] signs it; I [staff member] sign it; submit that. And 2023 comes around and we do the same thing" (Participant 8). There are other times when a person-supported chooses not to partake in a celebration but wants to create a PCP;

> there's different options… we're not in the business of forcing people to sit down… tell me all your goals and… accomplish them… the celebration part of it, I guess some people have said it feels a little bit remedial… we don't have to have

> a big meeting, but if you want to write them down… just the two of us… (Participant 8)

As per the quote, the process of a celebration might not be the best fit for each person-supported and PHSS adapts their services to fit each individual's preferences. "Compliance is very black and white, and we as an agency, are not… we value people's choices… we've worked out a solution that we think appeases both" (Participant 4).

Types of Goals and Activities

The goals set in the PCPs at PHSS are diverse and include physical activity, hobbies, entertainment (e.g., concerts and movies), communication, mental health, daily living activities (e.g., eating in the kitchen), vacation, paid jobs, volunteering, and much more. PHSS's approach to goal setting helps guide the activities in which each person-supported participates. For example, a participant recalled a person-supported whose "goal was, I want to teach…" (Participant 5). This person-supported's goal developed into her becoming "a Girl Guide leader. She volunteered there for almost 10 years…" (Participant 5). Over time the activities evolved, although her main goal of teaching remained the same,

> one day she… says, 'I want more' … we started talking about it… she wanted to teach more… wanted to start working with adults… she used to go and do the lecture at [name of college]… So, she would teach that to the kids… And she would tell her story, and her story was a clear example of having valued roles in society. And… one day… she goes, 'More.' So, then we ended up teaching at the university… (Participant 5)

Another participant described a daily living activity goal for a person-supported with higher support needs,

> one goal was…[for a] gentleman… he's in a secure unit, was to be able to come out of the unit and eat at a table – because he was eating out of his lap… we started… with one, one meal. The goal at the end of the year is for him to eat all meals [at a table]… (Participant 6)

Many of the goals aim to integrate the persons-supported in the community. PHSS values giving persons-supported the opportunity to participate in the community where they may not have had a chance to otherwise; "we… focus on inclusion and community involvement" (Participant 4). Engaging persons-supported in the community is part of the organization's culture and is a key part of the staff's responsibilities; "it's more the community, being out in the community, being part of the community" (Participant 11). One example given by a participant was of a person-supported who wanted to start fishing;

> we started… a fishing group and a fishing derby and one of the people… really enjoys sports and fishing… people from the other agency houses come and join us as well out in the community to fish every week… So, we had some people from Community Living [another community-care organization] join us. We had Angling Sports [a sports store] … help support us by donating stuff to our fishing tournaments as well as we have people come from the community with their boat and kind of teach us about fishing as well… (Participant 3)

In this example, the community within PHSS (including persons-supported and staff) as well as those outside of PHSS (local residents) participated in facilitating the activity (forming a fishing group and derby). In this instance, the person-supported was not just participating in the community, but formed his own community that supported and facilitated his goal. Community participation can also be exhibited by joining local clubs and groups (e.g., sports teams and choirs), "the gentleman that lives here… he has been an active member of the Lions Club in London for 30-some years. He goes to the business meetings; he goes to some of the events" (Participant 7).

Community participation is an important part of PHSS's supports and services. In some instances, a person-supported's goal may be to start their own business or raise funds towards a goal;

> we started a small business with her and her group of friends… making beeswax food wraps… One of the girls went and did the shopping… even though she has anxiety, she really, really enjoyed it and she was able to do a lot of it herself…

> they could authentically participate… stamping the bags, delivering the orders… they… produced… and sold the product… it was awesome. (Participant 9)

3.3.3 Implementation of the PCPs

The implementation of the PCPs requires many considerations, including but not limited to funding, transportation, staffing support, infrastructure, and safety. The process of implementing goals can be broken down into achievable steps to tackle the many considerations that are made when planning the facilitation of goals.

Accessible Transportation and Infrastructure

Transportation is a major factor when it comes to the facilitation of goals. As PHSS serves many individuals with physical limitations and severe medical conditions, accessible transportation is important. PHSS heavily relied on its own vehicles;

> We have our own van here… a lot of the houses in the agency also have vans and then you can go on there [the scheduling program] and check to see if there's other vans free… we can sign them out and then bring them in… (Participant 3)

Agency vehicles are just one method of transportation for PHSS staff and persons-supported, however, it does require that the staff are vehicle trained; "many people aren't able to drive an agency vehicle, and a lot of people that we work for use wheelchairs" (Participant 5). Other forms of accessible transportation are buses, para-transit services (a public transit service), and taxis. One participant brought up the challenge of using methods of transportation that are external to the organization such as para-transit;

> if we have to book para-transit… you have to book three days in advance. And… there's no guarantee you're going to get what time… you might call and they might say, 'You know what, all I've got is a 6:30'… and he's going to have to go early and sit there and wait… (Participant 7)

Finding and booking accessible transportation can be a challenge, this quote demonstrates the additional challenges that may arise such as additional time for booking, planning, or even waiting. Other issues can arise when working with external transportation methods, for example when a para-transit bus was early for pick-up;

> They're having a barbeque and the food just didn't get cooked very fast so para-transit was supposed to come… para-transit was 15 minutes early – and my staff said to the… driver, 'Can you just wait while I… put some food on a plate?' He [the driver] said, "No problem." So, my staff thought… that he had 15 minutes … But… when he went… the driver was gone… and they wouldn't come back, they had other people to pick up… no accessible cab were working at that time. So, what ended up happening… my staff had to push the guy [person-supported] to the bus stop… make a couple transfers, and they finally got home… it was a challenge, for sure… (Participant 7)

This quote demonstrates the issues that can arise with the timing of transportation when dealing with external modes of accessible transportation.

Staff Support

Considerations for staff support include the number of staff needed, the characteristics of the staff, and sometimes scheduling a volunteer rather than an additional staff member. At PHSS, the base number of staff scheduled for each residential location depends on the needs of the persons-supported. A few participants mentioned the words 'healthy and safe' to guide their staffing decisions;

> [staff support] is based on what the person needs. So…do they need an awake staff because they have epilepsy or they have medical [needs]… that have to happen at night that they need three staff, or… two staff… it really depends… you always have to say, is the person going to be healthy and safe if I make the decision to put in however many staff? (Participant 5)

If there are activities taking place outside of the residences such as community participation, additional staff members or volunteers may be scheduled, "the overlap [additional] shifts are very much community-based" (Participant 4).

The number of staff is not the only factor considered at PHSS when trying to fit team members into the schedule. Staff characteristics and interests are also given thought in regard to the activities being carried out. In an example given by a participant, a person-supported's goal was to attend an engine repair course at a local college,

> nobody specifically was in my teams that I really felt was a good fit, so I put it out to the organization as a whole and asked who was interested in… [the engine repair course]… trying to find a good match. And then a lady came back, very similar in age and she said, '…I'm really interested, and I know a lot about this… So again, kind of partnering and matching is a really big part of helping find support… for those goals… (Participant 8)

In this circumstance, the coordinator looked outside of their main staff team to find an individual who could best support the person to achieve his goal. Matching staff members to best fit the persons-supported's goals can not only benefit the persons-supported but the staff as well. PHSS's person-centred approach to support gives the opportunity for staff to engage in activities and work that is meaningful to them. This contributes to an environment where staff are excited and enthusiastic to attend work.

Time

Time is required to create and facilitate the PCPs and is tied into many of the other considerations mentioned previously, including but not limited to accessibility, staffing, and transportation. For example, PHSS's respite day programs are run during typical work hours (i.e., 9 am-5 pm), yet many activities such as sports games, carnivals, and theatre productions only run at night, after the day program's regular hours. In addition to that, some of these events are hosted a few hours away from the residential locations, and as such day program hours may need to be extended. "If… they want to go to the Toronto Blue Jays game… we'll figure it out… I'll have to move staffing around… I'll do my best to make those kinds of things happen" (Participant 2). In this example, staffing hours were adjusted to accommodate an outing to a baseball game.

One participant gave an example of the additional time that is required to plan for accessibility; "A lot of the time it comes down to accessibility… Say if we're going to a concert, calling the venue, setting up a time to come in early and get set-up, but things can still happen" (Participant 1). Sometimes, additional time needs to be scheduled to include arriving early in order to receive the proper accessibility accommodations.

Impacts of Gender and Age on PCPs

Gender

When asked about whether gender impacts the PCPs many participants said "It doesn't. How a person identifies does not affect it in any way" (Participant 4). However, a few participants provided examples of how a person-supported's goals and interests may be reflective of their gender based on gender normative roles. "Gender? I'm sure it does [impact the PCPs], because… if a guy wants to go to… a wrestling match" (Participant 11). The example provided falls in line with gender normative roles, stating that a man would potentially want to attend a stereotypical masculine-viewed sport. The participant goes on to say, "if they had a support staff that was a male, it might be easier to have more excitement and to be more involved in it than if you had a female that wasn't as involved" (Participant 11). This further emphasizes the life cycle of gender stereotypes and normative roles while also highlighting the impacts of PHSS's practices in matching staff to the activity.

Other participants provided examples where gender can impact the staff members who are scheduled to implement a goal. In these instances, staff were matched to the activity meaning that gender and age may be included as considerations when implementing PCPs, but "it depends on what that goal is" (Participant 8). Another participant echoed a similar idea but emphasized the idea of matching staff to the activity;

> gender isn't as specific as matching the staff… you need to match the staff to the activity. If… you're sending somebody fishing and they do not do well with worms… then obviously that's not a good match… Or if … the staff is shy and the person needs to make friends. Well, somebody who's shy is not going to do well with… helping make friends and connections. (Participant 11)

Matching staff to the activity can include various factors, including but not limited to gender, age, personality, and interests. For example, a participant gave an example of a person-supported whose goal was to spend time in a hot tub every week. To facilitate the person-supported's goal, the staff considered using the facilities at their local YMCA community centre;

> there is a hot tub in the elite section of the YMCA… in the men's change room… we looked at funding opportunities for this person to… upgrade their membership

> [to have access to the hot tub facilities]… But the barrier would be, he would have to have always a male staff with him… the person he would normally swim with was female… (Participant 5)

This example gives perspective into how the activity (i.e., using the hot tub facilities at a community centre) can impact staffing based on gender.

Age

The examples given by participants regarding the impacts of age on PCPs mirrored similar ideas that were highlighted with gender impacts. More specifically, goals and activities are "reflective of the person's age… those appropriate conversations are happening" (Participant 4). Age considerations also come along with health and capability factors,

> [it] comes down to their ability and what their mobility is… because as people age, their health status can go down. So, somebody in their 30s can handle the heat and… play baseball with us; whereas somebody who might be in… their later years, that might be too hot… (Participant 3)

Age-appropriate activities are viewed in relation to the person-supported's health and is particularly considered as it is "a little bit trickier because the population that we [PHSS] support tends to age faster and differently than the general population… Age plays a huge, huge part" (Participant 9).

One participant brought up the idea of matching the age of staff to the person-supported to create a "natural match" (Participant 5).

> He's… going to be 50 this year. So, you'd want him going with… similar ages of persons because it just looks like a natural match… you don't want it looking like this young person's out with their mom… it just doesn't look good. And you are approached that way in community. So, you're not approached as a staff worker, you're approached as the mom. (Participant 5)

Matching the age of the staff member to the person-supported is an important consideration, two participants emphasized the idea of creating 'natural situations' as well as 'natural relationships', meaning that they look natural to the general population.

> I think age is very much a number… I think that the best fit for the person is going to feel comfortable and natural… If we go somewhere and it's very obvious that I'm wearing a suit and tie… you can tell very clearly that this is a supported role… I prefer that people fit in and it looks comfortable, and it's much more comfortable for the person that we're supporting, then it looks like they're just two friends hanging out… we're trying to bring in a lot more natural relationships through that process. (Participant 8)

Another idea that came forward was matching the staff to the activity and as such, age may be a factor. For example,

> if a person is participating and is a senior participating in a senior's group, I couldn't necessarily send a young person to the senior's group because they don't fit… You got to try and get the match to happen and creatively figure out how to work with… the rights of the person versus the rights of the staff… (Participant 5)

This was a very similar idea to what was discussed with gender and the impacts it has on the PCPs.

3.3.4 Supports of the Creation and Implementation of PCPs

Many of the supports of the creation and implementation of PCPs identified from the interviews were also factors included within the creation and implementation sections.

Staff Characteristics

Staff characteristics include the individual's enthusiasm, ability to motivate the person-supported, and willingness to engage in activities and/or goals. Staff who are enthusiastic can be a strong support of the implementation process; "I truly believe that… the person supporting the individual can really make or break their goal or their experience" (Participant 8). Staff who have a positive outlook and are enthusiastic can motivate the person-supported which may aid the person in feeling comfortable with trying a new activity. The staff at PHSS are committed and dedicated to executing the PCPs but may not always be comfortable engaging in new activities due to a lack of experience. As PHSS practices typically include trying to match staff and volunteers with

persons-supported based on interests and experience with the activity, staff members who are willing to go outside of their comfort zone can be a signification support to the implementation of PCPs;

> especially if the staff is gung-ho and wants to help and assist… Not every staff is able to and willing to, some people just want to come in and do their job… some people are not extroverts and don't do well with making new friends and talking to strangers… that makes a big difference for sure… (Participant 11)

Further, staff who are enthusiastic and can aid in motivating the person-supported can make a difference in the activities; "having staff… who are enthusiastic and passionate about it and actually care and will put… time and effort and love… into creating these plans for people, is also a plus" (Participant 1). Having staff and volunteers with a set of diverse interests and experiences is a support to implementing PCPs, specifically given PHSS's approach to matching staff; "people request volunteers… it's… person-first… somebody might want a music volunteer to… play their instrument or to jam with them… so then we go searching for someone who would match… what the individual wants" (Participant 5).

Another key staff characteristic mentioned was a staff's proactive nature to take initiative; "Even if it's just something small like, okay, I'm going to paint your nails every time I'm in… often it's the same people doing it all… it's important that everybody understands that that's part of your job" (Participant 9). Staff who take the initiative in implementing the PCPs are a huge support to the process that drives the goals forward. Creativity was also a significant characteristic of staff to support the implementation process; "a coordinator that can, think outside the box to achieve the goals" (Participant 11).

Organizational Culture

PHSS's organizational culture provides a strong foundation to carry out the PCPs. The organizational culture at PHSS is illustrated through many factors, including accountability, personnel support, person-centred and flexible services, creativity, and PHSS's person-centred values. There are many components of PHSS's organizational culture that were identified within the data as facilitators of person-centred planning.

Person-Centred Values

A driver and support of PHSS's person-centred services are their values and focus on individual capabilities. When asked what supports PHSS to carry out their approach to PCPs, a participant said

> I think our vision and our mission and…the practices which they teach the staff… we've had extensive training in the past on social role valorization… They [PHSS] do person-centred plan training with the staff… it's kind of the whole vision of the agency that everybody is a unique individual. (Participant 5)

This quote highlights the vision of PHSS and how each individual is unique, creating a unified understanding and vision within the organization has been a significant support to delivering person-centred services. It is important that there is a common understanding of this so that the people who support the person-supported ranging from stakeholders to frontline staff can help support the activities and goals as best to their ability.

Person-Centred and Flexible Services

Providing person-centred care and support needs to be accompanied by services that are flexible and can adapt to each person's needs. One approach in which PHSS demonstrates flexibility is through the process of creating PCPs. As described in an earlier section (3.3.2 Creating the Person-centred Care Plans), the creation of PCPs is typically drawn out in celebration meetings. For example, if a person-supported has anxiety, a party-style meeting with a large number of people may not be the preferred method to create PCPs; "they could have some people come virtually instead … the person-supported is physically with less people in the room" (Participant 1). This quote demonstrates how PHSS can adapt their services and the typical process of creating a PCP to fit an individual's wants and needs. Persons-supported may prefer a different approach to the celebration;

> the celebration part of it… some people have said it feels a little bit remedial… one individual I supported in the past… that was his take on it… we can tailor it to you and what you want to get out of it. I'm sure you still have goals… we don't

> have to have a celebration… a big meeting, but if you want to write them down and you can kind of, just the two of us… (Participant 8)

Another approach through which PHSS illustrates flexibility is through their staffing hours at their day program. As events such as concerts and theatre productions can occur outside of normal program hours, PHSS adapts to the needs of the persons-supported to facilitate the PCPs and community participation.

> For instance… [the musical] runs for two and a half hours, so it's going to go… until about 3:30… so now what I'm going to have to do is extend my staffing hours and I'm going to have to drive them home… I'll do whatever we need to do to make that happen. I'll change the hours for the two staff that are going… it's all about being adaptable while being able to pivot, being creative with the barriers that you're given when you can be… (Participant 2)

When asked if the PCPs themselves have limitations, a participant said "no… it's a fluid document" (Participant 4), meaning that persons-supported can make changes to their PCPs at any point; "the best part of it, nothing's concrete" (Participant 8). For example, if a person-supported

> would like to work out as my goal… we start a process by which I [person-supported] go to the gym… to learn to workout and I don't like it… 'I'm not into this, like, I don't want to do this.' …in that situation, maybe… the goal of, working out and being healthy, maybe I instead join a bowling team… the person has the right to change their mind… (Participant 5)

Additionally, plans can change on a day-to-day basis and flexibility is shown through participating in spontaneous activities; "some days are very organized with what's going to happen and other days it could be spontaneous, you know… it's [a] beautiful day… we can just go to [Activity 1], go to [Activity 2]" (Participant 3). Spontaneity and flexibility within PHSS are driven by the person-centred nature of their services; "whatever they're in [the] mood [for]… depending upon their health and also their mental health, like what they want to do…we're … super flexible" (Participant 11). Even sometimes cancelling plans;

> sometimes you just make [a] plan and they're not in a mood on that day to do it, we'll just cancel it. It's like, okay, you plan something and then it's raining and… didn't get enough sleep last night, so you don't want to go… (Participant 10)

Creativity and Problem-Solving

Creativity and problem-solving go hand-in-hand with PHSS's flexibility and adaptability which are ingrained in their services and care; "we are out-of-the-box thinkers" (Participant 4). When asked to identify any barriers that hinder the process of creating and implementing PCPs, participants said "I'm sure there probably is, you just have to be creative… it's hard if you're not a creative person" (Participant 7). Creativity is seen as a support of the PCP process to facilitate the goals and activities. Creativity is demonstrated when funding is needed to support the facilitation of a goal; staff members "try and make the funding happen and finding creative ways… bake sales and fundraisers… extra money to do something a little bit special for somebody" (Participant 9). Utilizing PHSS's resources to raise funds can require creativity, specifically when holding fundraisers that foster community support;

> We just did a fundraiser and raffled off a BBQ… we got a few people and places to donate some stuff and the participants helped… sell tickets to make some money for different activities that happen that we want to do here… (Participant 3)

Creativity is demonstrated when an activity does not work out for an individual;

> For example, we had a fellow… he didn't want to walk anywhere…But he needed to keep physical. So, we thought maybe he'd like a bike… we're always… looking at what we can do differently to make them more successful or more engaged in the activities. (Participant 9)

Some participants called this 'pivoting' activities to problem-solve what they can modify within the activity to ensure success,

> let's say he didn't like swimming at the Y. Well, can I try the Aquatic Center? Can I try an outside pool? Can I try the splash pads, you know? So, I wouldn't

> [say]… well, that's it… But I would try to meet [the same goal]… whether it was food-related or task-related or learning-related… (Participant 6)

This typically includes an evaluation of the many different factors to assess what could have gone wrong and what could be changed.

Creativity was an important factor in facilitating goals and activities during the COVID-19 pandemic when the community-care sector was restricted to participating in activities virtually. "We still made plans… whatever was possible… PHSS did… so many activities… a bingo night… movie night, there's a trivia night… a men's club…music classes… art and craft and then baking classes… even though it was on Zoom" (Participant 10). PHSS held a variety of virtual activities to ensure each person was engaged in activities that were meaningful to them.

Accountability and Documentation

Accountability of the PCPs at PHSS starts with documentation of the plans and goals. PHSS draws up paperwork for the annual celebrations as well as the six-month review discussed in the above section *3.3.2 Creating the Person-centred Care Plans.* The accountability pieces (the annual celebrations and six-month reviews) have created a goal-setting process that is tightly wound into PHSS's organizational culture. From the interviews, it was clearly depicted that the staff team is dedicated to facilitating the goals. "I don't let too much stop me when I want something… I'm going to make it happen" [Participant 2]. This dedication to the goals is shown through problem-solving, an ability that was mentioned numerous times. When one participant was asked about funding barriers, they answered "we've always figured it out… it's good problem solving" [Participant 4]

Documentation of the plans in accessible formats can act as a motivator or reminder for persons-supported;

> A lot of people-supported, because they like visual things instead of print… I'm noticing vision boards being put up around the houses… what they're working on is visual on a wall in their home or in their bedroom… you know that… vision trigger to go, 'Oh, yeah, this is what they're working on' (Participant 4)

Personnel Support

Staff Teams. The staff team at PHSS is at the forefront of providing person-centred services and therefore are strong supports of PCPs. Staff work effectively as a team, with members collaborating to create a common understanding of the person-supported's wants and goals while also creating a chain of accountability. When asked what things help PHSS carry out their approach to PCPs, one participant highlighted that "everyone working as a team… [it does] make a huge difference" (Participant 10). Another participant described the process of intake when a person-supported first comes to PHSS as information needs to be collected to inform the transition:

> each location has a care coordinator… They would collect it [information] –, we are involved in that process too. Sometimes it takes a few people just to work together and gather all of that information. (Participant 4)

Staff members each take on responsibilities within their roles to contribute to the intake process as well as the overall process of PCPs, typically

> it's on the coordinator to be… looking for a way for it to be done… making sure that things are being completed, but then also individual staff hold a lot of responsibility too… it's not all on one person… (Participant 1)

Being able to rely on other team members is an important part of a functioning team, "now let's say… we just… cannot come up with any ideas. Then… we always have… other coordinators and assistants at other houses" (Participant 7). Additionally, the staff team supports the implementation of PCPs by utilizing their resources. For example, when a person-supported's goal was to volunteer at a farm, the staff reached out to their connections to help facilitate this process. "We try to… utilize – like, a friend of mine has a horse farm. So, we go just drive out and go see the horses" (Participant 6).

Community Support. Community support at PHSS includes natural supports such as the persons-supported's family and friends, alongside the larger community that supports PHSS by participating in activities hosted by PHSS or contributing to fundraisers and donating resources to support the implementation of PCPs. The person-supported's community are sometimes heavily relied on "with non-verbal persons-

supported, we usually rely a lot on the family and the friends to help them come up with ideas for what they're interested in" (Participant 1). As individuals within their community typically understand the person-supported's interests, likes, and dislikes, they play a large role in the creation of PCPs and celebrations.

One example given of the community of support created within PHSS is about the family of a person-supported;

> They're so gracious and they want their child to go… they know [other persons-supported] who don't have money here and they'll pay for a certain person… I'm so lucky to have such wonderful great parents who not only think of their child, but they think of everyone else too. (Participant 2)

This quote illustrates how community members within PHSS can come together to support each other in the facilitation of PCPs.

Additionally, there are members outside of the inner PHSS community who form a larger community of support. This is demonstrated when PHSS hosts fundraisers in the community;

> We've also done ones out in the community… concert style fundraisers and… we had [Singer 1]… we've also had [Singer 2]… come and do different stuff with raffles. And other families and participants and the agencies are also involved in this as well… (Participant 3)

In this example, members of the community and other community-care organizations came together to create a larger community of support that helped drive the PCPs forward.

Leadership Support. Many participants highlighted the continuous support they receive and feel from the leadership team.

> PHSS, they're very supportive of their staff… I honestly feel that I could confidently, right now, phone in any of those head guys and say, '…I really need help with… this person-centred plan', and they would be right here… I think they're awesome… I don't feel like… I'm lost in here by myself trying to figure it all out. (Participant 6)

The participant goes on to say, “I’ve never felt not supported; if I say I need this to make [Name]’s trip safer to… make everybody safe and happy…whatever to make something happen” (Participant 6). This quote illustrates the drive of the leadership team in facilitating goals. Participants echoed similar ideas when it came to the leadership team supporting adequate staffing numbers to facilitate PCPs; “we’ve never, ever had any issues with me calling my supervisor and saying, ‘Okay… I need a staff in here three extra hours every Wednesday to go with [Name] to [a local choir],’…” (Participant 7). Another participant gave an example of when a tangible resource and additional funding were needed,

> I’ve never had a problem. So, a gentleman – he’s an executive… I can text him right now and say… ‘I need skipping ropes… and I guarantee you, they’ll be here in an hour… they’re amazing… I’ve never had a problem, they’re just always there. If it’s to make the guys have fun or make the guys’ lives better… they’re like, 120% on it… (Participant 6)

3.3.5 Challenges with the Creation and Implementation of PCPs

Similar to the supports of PCPs, the challenges are significant factors that need to be considered during the implementation of the PCPs.

Infrastructure and Transportation Accessibility Challenges

Accessibility can be a challenge in the form of transportation and infrastructure. Infrastructure was identified as a barrier for some staff; “Especially if someone uses a wheelchair… if I’m going on an outing or something, really aren’t built for people in wheelchairs, which is super unfair and it sucks, but we do face barriers related to that” (Participant 1). The challenge of accessible infrastructure was turned into a goal for a person-supported, putting the challenge in a more positive light;

> for instance, [Name] wanted… to be able to have her hairdresser in her community… we found a hairdresser and you couldn’t get in the door. So, we ended up finding a company that would make a ramp for them to put on the front of their building… it does happen, but we try and work around it… (Participant 11)

Transportation is an important factor in the facilitation of goals and the unavailability of accessible transportation can therefore pose a significant barrier. One participant expressed transportation as a major challenge; “Oh god, transportation is a nightmare (laughs)… it’s definitely a challenge… we always try to plan ahead if you can. Unfortunately, then, you know, being last minute is not always possible” (Participant 11).

Managing Expectations

Managing expectations can become challenging for staff when the person-supported or their community has a lofty goal; “when I’m putting all that into a plan, is it doable? Is it achievable? … I’m not setting somebody up for failure” (Participant 6). As dreams and aspirations are a part of the person-centred planning process, it is a delicate balance between encouraging big dreams and managing expectations.

> …sometimes parents get upset… sometimes I have to explain to parents that that’s just not going to happen… it’s an uncomfortable conversation… but it has to happen because sometimes parents… they get excited… sometimes, they want to jump way too far ahead… And that’s such a parent thing… every parent’s dream is for their kid to do all the things that they wish they could… (Participant 6)

Managing expectations can also work the opposite way, such as when a person-supported who had previous experience in an institutionalized residence where their natural supports such as family were not involved in the care process: “I’ve got great parents… but they had some experiences from past that they didn’t like, but we’ve worked through it… that’s part of it” (Participant 6). Sometimes it may be difficult for parents to dream big for the person-supported “it’s great to see and I think the parents don't ever think of their child beyond whatever their limitations… it’s hard for them to look past all of that” (Participant 2). This is where staff can sometimes contribute to the brainstorming process to aid in the goal-setting process.

Funding

Funding is a critical support of the implementation of the PCPs, however, it can be challenging “finding funding… for somebody to be able to obtain their goals”

(Participant 8). Participants identified funding as a significant challenge to facilitating activities and goals; “Challenges are always money… That’s one of the major ones” (Participant 11). There are four main methods by which persons-supported can receive funding within the community-care sector in Ontario. The first method of funding is through the Ontario Disability Support Program (ODSP), which individuals need to be eligible to receive. However, participants emphasized that ODSP funding is often not enough to fund meaningful activities for the individual: “they may have to rely only on their ODSP. And to be honest, there’s not much left by the time they get their basic living expenses paid for” (Participant 9). The second source of funding is through the Passport program funded by the MCCSS; “people have… passport funding, which kind of helps” (Participant 3). The third source is through family support or a paid position (i.e., occupation). These funding methods are also not consistent from person to person; “some people would get to do fun things because… their family could…have the money to support that, others wouldn’t” (Participant 3). The fourth method is through raising funds by starting a business, hosting fundraisers, or even applying for external grants.

> for instance, [Name of person-supported]… is playing bocce ball… her goal is to get onto the Canadian bocce team. So, we’ve had to… to apply for different grants for her… it helps in paying for gym rentals, equipment, coaching… (Participant 11)

This fourth type of funding requires additional time to either apply for funding, start a business, or plan fundraisers.

> So, sometimes people have… done… a fundraiser… selling something. Or sometimes… they’re trying to get a ramp, so they have a GoFundMe page… It might take longer… if anything, like a goal is just extended for a while, until the funds are raised… (Participant 5)

This participant put funding in a more positive light, stating that it is just another step toward achieving a goal;

> the goal takes on another piece. So, if I have a goal to go on a trip, one of the things might be I have to figure out how to get the money for the trip… that’s part of the goal though… (Participant 5)

Although finding the money to be able to fund an activity or goal can require additional time, it is part of the natural process of implementing goals.

Misalignment of Persons-Supported Wants and the PCP Process

As PCPs at PHSS follow person-centred values, each individual chooses whether they would like to partake in creating a PCP on an annual basis. “One of the gentlemen always refuse [a PCP]… it's just hard to come up with ideas… [I] don't know a lot about… his interests and stuff” (Participant 10). Persons-supported who choose to not create a PCP may also not disclose their interests to staff. This poses a challenge for staff on how to best support the individual in living a meaningful life if they are unsure how the person-supported defines it.

Capacity and Health Status of the Person-Supported

A person-supported’s capacities and health status can present challenges to creating and implementing PCPs. A common challenge identified was an individual’s capacity to communicate whether it be very limited or non-verbal communication; “not everybody communicates the same way and not everybody is able to communicate everything they want and need in life, so that is a barrier” (Participant 1). One participant identified that building a trusting relationship between the person-supported and staff can be a significant supporting factor; “because there are communication barriers, you have to build trust… so that they trust when… I’m in public with [Name], he needs to know that I’m going to keep him safe, and I know what he needs” (Participant 6). Building rapport can ease anxiety and create a trusting and comfortable space for the person-supported. Time is a significant factor required to build rapport and create a safe space for persons-supported. Additionally, focusing on cultivating a relationship can aid staff in getting to know the person-supported better, their interests, and methods of communication to ultimately better support the individual.

Changes in an individual’s health status can also result in changes to goals and PCPs; “so, the lady with anxiety, maybe the goal is to [join a local choir]… and maybe after a while… all those people, it’s just too much” (Participant 7). In this example, a person-supported chose to change her goal based on her anxiety levels. Another instance where health status can impact PCPs is if a person-supported’s health status is on a

decline for a long period; “especially if [the goal is] wanting to get out in the community and… if they’re in and out of hospital… That’s pretty difficult to be able to achieve a goal when they’re sick all the time” (Participant 11). Health status changes such as hospitalization can result in additional time needed to complete a person-supported’s goals and might mean prolonging their goal. Health status changes can also occur day-to-day, for example for individuals who deal with anxiety; “we have one lady here that has anxiety issues… big time. That plays a big deal… a day-to-day kind of thing sometimes whether, you know, we can work on the goal that day or not” (Participant 7). In this instance, the goal might be postponed for only a short period of time.

Lack of Community/Social Circle Involvement

The person-supported’s community (i.e., their family, friends, loved ones, etc.) can be described as individuals who are important to them and know them well. These individuals take on an important role during celebrations as they can contribute to the creation of the PCPs; “some parents have been very busy, so I’m not always able to tap into what they want” (Participant 2). In some cases, persons-supported come to PHSS after residing in institutional settings where members of their community are not typically involved in care planning;

> some families don’t want to be involved. And I find that with the older people that we serve… [who] used to live… [in] institutions… [they were] very segregated. And their families may have not had any interaction with them for 50 years. So, to have them be expected to be this much involved may not be wanted. (Participant 4)

Staff face additional challenges in figuring out what persons-supported want if they neither have the capacity to communicate nor a large community:

> anyone who presents communication and comprehension [challenges] – sometimes we’re just shooting in the dark… they don’t have a big circle and a lot of people… it’s just a guessing game… you’re… watching how they react to a certain situation or opportunity that they’re involved in… (Participant 8)

Another participant expressed the same idea; “usually if we have family involvement it makes it a lot easier … if their mom or dad or siblings are there, they can kind of help [with communication and expressing wants and needs]” (Participant 1). These situations also highlight the importance of staff building rapport with persons-supported and getting to know them over time to support the creation of PCPs.

COVID-19 Barriers

COVID-19 was identified by participants as a significant barrier, a participant described it as “one of the biggest challenges” (Participant 10). The COVID-19 pandemic and resulting limitations put in place for the general population and even stricter regulations for the community-care sector in Ontario presented many challenges and barriers to PHSS’s person-centred services and PCPs:

> Obviously, with COVID, there was a lot of lock-down in [facilities], especially with long-term care and community living settings… for those like, 2+ years, they [persons-supported] have really seen no one… there were different restrictions put on long-term care and community supports… much more severe… (Participant 8)

When asked how the COVID-19 pandemic impacted the PCPs a participant responded “Oh, tremendously. The people on my teams were so active in the community and different groups… that stopped abruptly” (Participant 4). Moreover, many community events were shut down during the COVID-19 pandemic; “we’ve gone on day trips to Toronto with the pop-up things that used to happen before COVID” (Participant 2). To help curb the impact of restricted socialization PHSS “purchased iPads for every location very quickly. So, we have been able to maintain connections with families, friends, activities that went virtual… that was amazing” (Participant 4). One of the major challenges for PHSS was facilitating PCPs in the community with persons-supported who face vulnerable health needs. The complex health needs that the persons-supported at PHSS face alongside the government restrictions set barriers to community participation and integration, and therefore many of the goals and activities. With many of the goals and activities taking place in the community, PCPs were almost put on hold, “for something like two and a half years, we didn’t have person-centred plans, because you

couldn't get people together, you couldn't really go out a lot and their goals are community-based" (Participant 8).

The COVID-19 pandemic set different barriers for the respite day program at PHSS, "the program was closed due to the state of emergency directed by the government in March 2020. So, there was no goal set… for two years we didn't have [PCPs]" (Participant 2). With the community-care day program being closed for approximately two years, staff observed a health decline in some individuals. This was also observed with communication; "two full years we didn't have them [person-supported in the program]. So, I've really seen changes in people in their communication and their physicality and their medical status" (Participant 2).

3.3.6 Impacts of the PCPs

Impacts of the Person-Centred Planning Process

Direction

PCPs and the goal setting process can provide direction for staff on how to best support the person-supported in living a meaningful life, however they may define it.

> It gives us, as caregivers and support staff, goals so, that we're not sitting here looking at it, well, what are we going to do this week… We have goals as a unit and we can work together to make those [happen]… we're just a part of helping them be able to accomplish these things. (Participant 7)

This quote is also an example of how PCPs facilitate a unified aim for teams to work together to best support the individual. As the organizational culture at PHSS aims to support individuals in living a meaningful life, the person-centred planning process provides reassurance for staff. By engaging in the person-centred planning process, staff are able to better understand what the person-supported wants; "But just with having them, it… keeps us knowing that… this is what they want to do" (Participant 3). Further, it provides reassurance that staff are providing support for activities that are meaningful to the person-supported; "I'm providing support to and… know that they're having meaningful days or meaningful… experiences" (Participant 3).

Motivation

The person-centred planning process creates a space where persons-supported can dream and discuss their aspirations and what they define as a meaningful life; "[persons-supported are] excited because they're going to be talking about the future and goals" (Participant 7). Celebrations and goal planning occur on an annual basis and can motivate persons-supported to continue dreaming and motivating them to let their goals evolve. When participants were asked what they perceived as the benefits of the PCPs, one participant answered, "[Persons-supported] … have a target to look forward to" (Participant 10). PCPs facilitate a goal-planning process where persons-supported "can kind of zero in on… [a] direction… sparking the interest in them [person-supported]" (Participant 8). Dreaming and goal planning can also be an exciting and motivating experience for family, as well as anyone else in the person-supported's community; "typically the parents are really, really excited to see them [person-supported] doing all these things" (Participant 8).

Impacts on the Community and Support Personnel

Staff Engage in Meaningful Activities

PHSS's methods of matching staff based on the activity creates opportunities for staff to engage in meaningful activities as part of their support roles;

> typically if you find somebody who's like-minded and it's something that you enjoy as well, you're getting to do stuff you enjoy doing yourself… and I'm getting paid for it… what a benefit… this is… such a great opportunity and I would love to be doing this [meaningful activity] anyways, so it's nice to have somebody to do that with… (Participant 8)

Moreover, PHSS's services and approach to PCPs have created a work environment that staff look forward to; "it is our job to foster and help the supported people meet those goals. That's the fun part of our job (laughs)" (Participant 4). This approach to care and services has fostered an environment where staff often are emotionally invested and therefore put love and care into their work.

> For staff… I think it makes things more meaningful and it makes you… engaged in your job yourself… the nice thing about… the person-centred plan-based program… for staff, you can make your job what you want it to be… (Participant 9)

Participants perceived this as a benefit for volunteers as well; "…bringing people [volunteers] to our organization to enrich their lives" (Participant 5).

Facilitating Goals

The person-supported's community (i.e., family and friends) and the staff who support them play a large role in the accomplishment of goals. With these accomplishments can come personal and emotional fulfillment as a result of their role in supporting the person-supported in living a meaningful life. Experiencing success with the PCPs and goals "encourages [the staff] too… 'let's just do [goals] more often'" (Participant 10). Staff described this role as rewarding; "when the pieces are all put together, it's very, very, it's very rewarding to see" (Participant 7). Another participant expressed similar emotions they have felt while in a support role;

> I like planning goals… seeing things happen, I like seeing staff get inspired… we had one of the [persons-supported] make his own mug cake yesterday. Oh my god, his face when he was eating his own cake… I live for those moments… it's a really fun job. (Participant 6)

The person-supported's community (i.e., family and friends) also gets to observe their loved ones accomplish their goals; "they see their loved one grow and blossom and become adults that are capable and able" (Participant 5). Further, family and friends have an opportunity to "give their input on what they think the person should… or could be doing… helps them be more involved as well for sure" (Participant 11). PHSS's process for creating and implementing PCPs integrates the person-supported's community, giving them the opportunity to play a role in the implementation of PCPs and therefore the facilitation of goals. "I think families probably enjoy it as much, [now they're] watching their loved ones accomplish their goals…" (Participant 8). The emotional fulfillment that comes alongside that is demonstrated in this example:

> a gentleman got out of his wheelchair and put… a life jacket on and went swimming in the lake for the first time… his caregiver was… crying in tears to be… part of his goal… to see her brother and his dad see the son, they were… brought to tears… the family seeing them [person-supported] achieving their goals… (Participant 8)

Impacts on the Persons-Supported

Person-Directed Opportunities to Foster Goals

PCPs give persons-supported increased autonomy over their care and support:

> it's really focused on the person… it gives them as much control and autonomy as possible, and a lot of the time people with disabilities might not have experienced that their whole life… that's something PHSS is really big on… giving people as much control as is safe… that's part of dignity is… choosing your own path in life. (Participant 1)

PCPs give persons-supported the opportunity to discuss their goals and aspirations; "that's probably one of the biggest benefits is working together to help… achieve a goal versus you having a goal… and never telling anyone. That's a lot harder to achieve" (Participant 8). By opening a space where persons can discuss their goals, PHSS and the accompanying support staff are able to support them in facilitating their goals. Another participant described it as "a safe space for them [person-supported]… that they're able to try activities"(Participant 3). This quote illustrates how PHSS provides a space where persons-supported are encouraged to try new activities. Further, the goals can develop and evolve over time; "But… the best for them and they learn and grow and change" (Participant 6). This also applies to daily living skills, for example, if a persons-supported's goal is to improve their communication capabilities: "So, the communication skills is getting better and we're learning more of what he likes and he can express more what he likes" (Participant 6). The participant goes on to explain how PHSS provides the space to grow and evolve to support persons in reaching their potential: "the person-centred plans, I like it… Not only… these guys move forward so they can… reach their potential… we're always evaluating… Can we grow on that?" (Participant 6).

Community Integration

PHSS's approach to PCPs and values focused on community integration and participation provides persons-supported with the opportunity to be integrated into the community. This can include social participation and building social connections with other community members, opening opportunities to be part of a community they might otherwise be excluded from. One participant highlighted the value of community integration, "We're trying to impact their lives and getting them into the communities" (Participant 7). Another participant expressed how they try to participate in the community, "We are tapped into the community as much as we possibly can…" (Participant 2). An example of community integration and participation is of one person-supported who loved biking;

> he did a community bike rally this summer… and he loved it. It was like a parade and… a bunch of people came over and helped him decorate his bike… It was awesome… was a good community engagement too… He meets a lot of people… a lot of people come over and want to talk about this bike… he really loves it… (Participant 9)

This example illustrates a time when a person-supported participated in a community event but was also integrated into the community where he made social connections with other members of the community. Persons-supported also have the opportunity to contribute to the community, which can be through charitable activities; "we've had… a toy drive… having that person be involved in dropping off boxes and picking up toys and dropping the toys off…" (Participant 11).

3.4 Discussion

This section discusses the findings in relation to the objective, which was to understand the key components and impacts of PHSS's individualized participatory approach to PCPs.

Organizational Culture

The organizational culture at PHSS is reinforced by the PCPs and resultingly has created more support for PHSS's approach to PCPs. The person-centred values, as well as

the organization's mission to support individuals in living meaningful lives, can be distinguished throughout all organizational levels, a factor Ratti et al. (2016) identifies as an important support to person-centred planning. The personnel at PHSS ranging from the leadership team to the frontline staff demonstrate a dedication to the implementation of the PCPs. This level of commitment is noted in the literature, where staff and services should provide the necessary support for individualized care planning (Collings et al., 2016; National Quality Forum, 2020; Ratti et al., 2016; Vlaskamp & van der Putten, 2009). A large part of the organizational culture at PHSS is due to their personnel. The personnel at PHSS work as a team to support the PCPs and achieve persons-supported's goals. Claes et al. (2010) and Martin et al. (2016) note teamwork as a support of a participatory approach to care planning.

Further, PHSS integrates the person-supported's community into the creation and implementation process of PCPs. The interview participants note similar benefits to the literature of having these individuals involved in the process, most notably their role in goal-setting meetings (Espiner and Hartnett, 2012; Collings et al., 2016; Collings et al., 2019; Dowling et al., 2007; Hagner et al., 1996; Lakhani et al., 2018).

Flexibility

A large part of PHSS's ability to implement individualized PCPs is their commitment to providing person-centred services. Ritchie (2015) also notes that a flexible approach to care is ideal for providing individualized services. While the literature notes that flexible supports and services are difficult to provide in large systems (Claes et al., 2010; Heller, 2002), PHSS has demonstrated how to implement PCPs while providing care for a large number of individuals (over 250 individuals in over 60 locations). Moreover, Purbhoo and Wojtak (2018) highlight that a balance between standardization and individualization is needed. PHSS's ability to maintain this balance is demonstrated in the verbatim quotes.

Accountability

Approaches to accountability are engrained in PHSS's culture, ensuring the services are person-centred. Accountability provides momentum to the goals, driving the PCPs forward. The literature emphasizes that evaluation should be used by the

organization to confirm that a person-centred approach is being utilized (Hagner et al., 1996; Kaehne & Beyer, 2014; National Quality Forum, 2020). PHSS demonstrates this through their annual celebrations to reset/reaffirm goals as well as through their six-month reviews to ensure that the PCPs are moving forward and to check that the activities are still meaningful for the person-supported.

Utilizing Staff Characteristics to their Maximum Potential

PHSS utilizes a unique approach to matching staff characteristics to the activity, utilizing staff characteristics to their maximum potential. Specifically, PHSS utilizes staff's knowledge, experiences, and interests to guide their schedules to ensure that persons are being supported to the best of the organization's ability. While the literature does not highlight such an approach, it does emphasize that staff's characteristics such as their personality (i.e., warmth and biases), their range of skills (i.e., communication, facilitation, and planning), as well as their working methods (i.e., ability to empower an individual) are significant supports to providing individualized participatory approaches to care (Collings et al., 2016; Collings et al., 2019; Engen et al., 2019; Espiner & Hartnett, 2012; National Quality Forum, 2020). As an organization, PHSS recognizes the significance of their staff's characteristics and has found an approach that not only benefits the persons-supported but the staff as well. PHSS's approach to PCPs may increase retention amongst community-care professionals. There are broader health workforce issues within community-care, including the recruitment and retention of personal and developmental support workers (Saari et al., 2017). Further studies should explore how organizational culture has helped to overcome common workforce issues in the community-care or broader healthcare sector.

Impacts

While the literature provides scarce evidence on the impacts of similar individualized participatory approaches to care planning, the findings from the interviews demonstrate that the impacts of PHSS's approach to PCPs extend beyond the persons-supported but also impact the lives of their community and the staff who support them. Notably, the findings illustrate how PHSS's approach to care has created an environment where staff look forward to attending work, giving staff the opportunity to engage in

activities that are also meaningful to them. This impact on staff provides great insight into the organizational culture at PHSS.

The verbatim quotes illustrate aspects of PHSS's organizational culture. Moreover, they highlight PHSS's approach to matching staff to activities that have created a motivating workplace and cultivated a supportive working culture. While our study did not directly look at the impacts of the COVID-19 pandemic on the PCPs, it is evident that the staff perceived that there were major impacts on the community-care sector. Our findings have implications for future research to examine the impacts of the COVID-19 pandemic on PCPs.

3.5 Reflexivity

Throughout the research process, I kept a reflexive journal which was used as an opportunity to record my thoughts, interactions with members of the research team and participants, impressions, and biases (Baxter & Jack, 2008; Tracy, 2010). Pragmatism highlights the importance of recognizing one's thoughts in relation to external forces such as "physical, psychological, and social worlds" (Allemang et al., 2021, p. 41). With little to no experience and knowledge of the community-care sector and individuals living with IDDs, I jumped at the chance to partake in this project as part of my thesis work. Working with external stakeholders, specifically members of the PHSS leadership team and consultants was an exciting opportunity and proved to continue to be throughout the project. One of the hardest learning curves I experienced during this project was changing my perspective to one that mirrored what PHSS values, very much a person-first culture. It was invigorating to get first-hand recounts of the love and care that goes into the PCPs, the passion rang true through the examples given by participants. Hearing these stories and the impacts of PHSS's services and PCPs taught me a lot about the evaluation of person-centred services and the importance of support to achieve a unified culture.

My reflexive journal also delved into the process of data analysis. Going through data analysis independently first and then having the chance to discuss the analysis and codes with other researchers demonstrated the importance of collaborative research. There were many points during the data analysis process when JD and SLS provided

insights that were “wow” moments for me. It became apparent to me the importance of a research team that brings forth various perspectives and experiences.

3.6 Limitations

As with all interviews, there is a possibility for social desirability bias. Social desirability bias is when the interview participants provide answers that they feel will make them look good as per the social context, impacting the data (Bergen and Labonté, 2020). The interviewer [MD] provided assurances throughout the interviews to limit social desirability responses (Bergen and Labonté, 2020). Specifically, this may have occurred when the participants were asked about the drawbacks of PHSS’s approach to PCPs and if gender and age impact the PCPs. With many of the participants answering that gender and age do not impact the PCPs, it is inconclusive how gender and age directly impact the PCPs. Participants also did not disclose many perspectives related to the drawbacks of PCPs, resulting in a lack of conclusive evidence.

Recruitment was facilitated by the PHSS team which made for a smooth recruitment process. However, the involvement of the organization’s leadership team in recruitment had the potential to impact the answers given by staff. Specifically, it could have led to participants reluctance to disclose issues, challenges, or changes they would make to the PCP process. While the research team took steps to ensure anonymity, some participants indicated their interest in participating by emailing the PHSS team rather than Western University researchers.

Two out of eleven of our participants identified as men. These demographics do not fully represent the perspectives of male-identifying individuals; however, it is acknowledged that the community-care sector is on a majority made up of women staff. Our study also focused on the perspectives of staff within the community-care sector at one organization and therefore does not capture the full picture of the components and impacts of PCPs. Future research would benefit from studies focusing on the perspectives of persons-supported as well as PCPs at other community-care organizations.

3.7 Conclusion

Our study highlights the extent to which PHSS facilitates person-centred services through PCPs. The findings demonstrate the positive impacts an individualized participatory approach to care in the form of person-centred planning has on persons-supported, their community, and the staff who support them. Moreover, our study illustrates how PCPs can be implemented and integrated into ongoing care and routine organizational processes. Organizations and care professionals can use this study to better understand how PCPs are operationalized and support a change in practice or culture towards one that encourages staff to engage in activities that are also meaningful to them. Over time, this has implications for improving staff retention and satisfaction.

By engraining the person-centred planning process within the organization, the services are inherently person-centred. PHSS has been able to take a government-mandated planning process to balance the needs of the organization as well as the persons they serve.

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3.9 Appendix B: Research Ethics Approval

Western University's Health Sciences Research Ethics Board Approval

Western Research

Date: 28 April 2022

To: Dr Maria Mathews

Project ID: 120382

Study Title: Achieving the quadruple aim: An assessment of a participatory approach to developing individual patient-centred care plans for community-care services

Application Type: HSREB Initial Application

Review Type: Delegated

Meeting Date / Full Board Reporting Date: 10/May/2022

Date Approval Issued: 28/Apr/2022

REB Approval Expiry Date: 28/Apr/2023

Dear Dr Maria Mathews

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study**.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
PHSS Organization interview guide 01APR2022	Interview Guide	01/Apr/2022	01APR2022
PHSS Staff interview guide 01APR2022	Interview Guide	01/Apr/2022	01APR2022
PHSS Provider Recruitment_Email sent from PHSS Staff 251APR2022	Email Script	25/Apr/2022	25APR2022
PHSS Organization Recruitment_Email 25APR2022	Email Script	25/Apr/2022	25APR2022
PHSS Provider Letter of Information and Consent Staff 25APR2022	Written Consent/Assent	25/Apr/2022	25APR2022
PHSS Organization Letter of Information and Consent 25APR2022	Written Consent/Assent	25/Apr/2022	25APR2022
Mathews.RESEARCH PLAN.Achieving the quadruple aim.25APR2022	Protocol	25/Apr/2022	25APR2022

Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
Mathews.REFERENCES.Q2.6.10Jan2022	References	10/Jan/2022	10JAN2022
PHSS CIHR decision and reviews Feb 28-2022	Scientific Review Documents	28/Feb/2022	28FEB2022
Budget PHSS study	Study budget	01/Apr/2022	1APR2022

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB , except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the

3.10 Appendix C: Letter of Information and Consent Form

Letter Of Information and Consent

Project Title:	Achieving the quadruple aim: An assessment of a participatory approach to developing individual patient-centred care plans for community-care services
Principal Investigator:	Maria Mathews, PhD Centre for Studies in Family Medicine, Department of Family Medicine Western Centre for Public Health and Family Medicine 1151 Richmond St, London, ON Canada N6A 3K7
Contact Information	[redacted]; [redacted]
Name of Funder	Canadian Institutes of Health Research (CIHR)
Conflict of Interest	No conflicts of interest identified

Introduction

You are invited to participate in an interview about the development of person care plans in the community care sector. We are hoping you will tell us about PHSS Medical & Complex Care in Community's (PHSS) approach to developing these plans.

This letter has been designed to provide you with the information necessary to make an informed decision about whether to participate in the interview. If you have any questions, please do not hesitate to contact our research team.

Background/Purpose

This study examines the organization and delivery of community-care to individuals with physical and developmental disabilities and complex medical conditions. By 'community-care' we mean the array of community-based health and social care services, including in-home professional and personal support services, community support services, and supportive housing that enable individuals to remain at home or in home-like settings, as well as supports for education, employment, and personal well-

being. Specifically, we are interested in understanding how community care organizations develop and update individual service agreements or person-centred care plans, and the supports and barriers in the community-care sector that facilitate or hinder the provision of care.

The project includes a scoping review of the literature, qualitative interviews with staff at PHSS, and qualitative interviews with community care organizations. You are being asked to participate in an interview of PHSS staff.

Study Design/Procedures

This is a qualitative study in which PHSS staff will be interviewed. In the interview we will ask about PHSS's approach to developing person-centred care plans and your thoughts of the benefits and drawbacks of these plans. Interviews will be audio-recorded. This is mandatory and necessary for analysis. A member of the research team will transcribe the interviews and NVivo (a qualitative analysis software) will be used for analysis.

If you agree to participate, you will be asked to take part in an up to one hour one-on-one interview. The interview will take place either by telephone, videoconference (using Western's corporate Zoom platform), or in person, whichever is most convenient for you. There will be a total of 12-16 participants in the staff interviews. The study also includes 12-16 Interviews with community organizations for a total of 24-32 interviews.

Voluntary Participation/ Withdrawal from Study

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any point up until your data are combined with other participants for analysis. You do not waive any legal rights by signing the consent form.

Risks

While all personal information will be handled with the utmost privacy and care as outlined below under 'Confidentiality', one cannot guarantee that there will never be a privacy breach.

Benefits

There are no known direct benefits to your participation in this study.

Confidentiality

All data collected will remain confidential and accessible only to the study research team and will be stored on Western University servers. Your full name, email address, and phone number will be used to schedule the interview and your gender, age, years in practice and location will be used to ensure variation in interview participants. All other identifying information that you may mention will be redacted during the transcription process. If the results are published, your name will not be used. Study data will be retained for 7 years then will be destroyed. Representatives of Western University's Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of this study.

PHSS will not see your transcript without your permission. Even with your permission, the transcript will be anonymized and will not include your name or other identifying information.

Compensation

You will be provided a $50 gift certificate, from your choice of a grocery store or café, for your participation in this study.

Questions about the Study

If you require any further information regarding this research project or your participation in the study, please contact Dr. Maria Mathews, [redacted], extension [redacted] or Leslie Meredith (Research Coordinator) [redacted] ext [redacted]

[redacted] at the Centre for Studies in Family Medicine, Western University.

If you have any questions about your rights as a participant or the conduct of this study, you may contact The Office of Research Ethics (519) 661-3036, email: ethics@uwo.ca.

This is your copy of the Letter of Information to keep for your records.

CONSENT FORM

Project Title: Achieving the quadruple aim: An assessment of a participatory approach to developing individual patient-centred care plans for community-care services

I have read the letter of information and the nature of the study has been clearly explained to me. All of my questions have been answered to my satisfaction.

Please date, print and sign your name below and return this form to the interviewer.

- ☐ I consent to having de-identified direct quotes from my interview used in any publication of results.

- ☐ I consent to PHSS seeing my anonymized transcript.

Participant's name _____

Participant's signature _____

Date: _____

My signature means that I have explained the study to the participant named above. I have answered all questions.

Person Obtaining
Informed Consent: _____ (please print)

Signature: _____

Date: _____

3.11 Appendix D: Recruitment Email

Participant Recruitment Email Scripts

Initial recruitment email from PHSS leadership team

Subject Line: Invitation to take part in research study on PHSS care plans

Hello,

PHSS is working with Researchers at Western University (Dr. Maria Mathews, Principal Investigator) to carry out a study examining PHSS's approach to developing person-centred care plans in community care.

The researchers would like to learn from how we develop these plans and your thoughts of their benefits and drawbacks. They invite you to take part in an interview that will last up to one hour.

You may be compensated for your time.

If you are interested in participating or learning more about this project, please contact Megann Dong ([redacted]).

Thank you,

[insert signature of the PHSS contact]

Please note that email communication is not a secure form of communication.

Follow-up email from researcher [MD]

Subject Line: Invitation to take part in research study on PHSS care plans

Thank you for reaching out regarding the research being undertaken through the PHSS program on the patient-centred individualized care plans for community care services.

I am the research coordinator on this project. Dr. Maria Mathews is the principal investigator along with other Western University researchers. In the study, we are interested in learning more about PHSS's approach to developing person-centred care plans and your thoughts of the benefits and drawbacks of these plans.

If you agree to participate, we will arrange an interview of approximately one hour. The interview could be by telephone, by Zoom videoconference or in person at a time that is convenient for you. You may be compensated for your time.

We have attached the Letter of Information and Consent form for your review. Please reply to this email to let us know if you would like to participate, or, if you would like more information, please feel free to contact me or Maria Mathews ([redacted]).

We look forward to hearing about your experiences.

Thank you,

[insert Megann's Signature]

Please note that email communication is not a secure form of communication.

3.12 Appendix E: Interview Guide

Semi-Structured Interview Guide

Script

Thank you for taking the time to speak with me today. We are conducting this study to understand how person-centred care plans are determined in the community care sector. We are hoping you will tell us about your organization, and its approach to developing these plans.

This interview should take us approximately one hour to complete. The interview will be recorded and transcribed. You will not be identified in any report or presentation; your name will be replaced by a participant code and any identifying information will be removed.

Participation is voluntary. You may end the interview at any time or choose not to answer any specific question. Do you have any questions before we begin? [Answer any questions and then begin audio-recording]

Interview Guide

First, I would like to ask some general background questions.

1. What is your job title? Please describe what you do at PHSS.
2. How long have you been working in your current position at PHSS?
3. How long have you been working at PHSS?
4. In terms of gender, how would you describe yourself?
5. May we ask your age?

In the next set of questions, I'd like to focus on the process that is used at PHSS to develop and update person centred care plans (PCPs).

6. Please describe the process used to create the PCP.
    a. Probe: Could you walk me through the process that is used to determine the support and service a person-supported by PHSS receives?
    b. Probe: What is considered when developing the plan?
    c. Probe: Who do you consult when you develop the plan

    d. Probe: Who approves the plan?
    e. Probe: How do costs or funding affect the plan?
7. Once a PCP is created, how does PHSS provide support and services?
    a. Probe: How do you know the plan is being followed?
    b. Probe: What are the challenges identified in implementing the plan?
8. Please give me an example of a PCP that has been tailored to an individual.
    a. Probe: How does the gender of the person-supported affect the plan? Can you give me an example?
    b. Probe: How does the age of the person-supported affect the plan? Can you give me an example?
9. How often is the PCP updated? Please describe the process for updating the PCP.
    a. Probe: Please give me an example of the types of changes that might be made to a PCP.
10. What do you think are the benefits of the PCP for persons-supported? Can you give me an example?
11. What, if any, are the drawbacks of the PCP for persons-supported? Can you give me an example?
12. What, if any, are the benefits of the PCP for families of the person-supported? Any drawbacks?
13. What, if any, are the benefits of the PCP for staff?
14. What, if any, are the drawbacks of the PCP for staff?
15. What things help PHSS carry out their approach to PCP?
16. And what are the barriers that hinder the process?
17. If you could change the process, what would you change?
18. Those are all the questions I have. Is there anything you would like to add?

3.13 Appendix F: Coding Framework

Finalized Coding Framework

Code Name	Description	Exemplar Quote
Domain 1: Organizational culture		
Goal-oriented culture	The organization is committed to fostering a meaningful life (to how the person-supported defines that) through the execution of person-centred goals. This is the motivation behind the supports and services PHSS provides and offers the organization direction. This further drives problem-solving in order to deliver goals and continuous quality improvement.	"If… they want to go to the Toronto Blue Jays game… we'll figure it out… I'll have to move staffing around… I'll do my best to make those kinds of things happen" (Participant 2).
Leadership support	Staff feel highly supported by the organization's leadership team (including coordination and clerical staff). The organization's leaders provide support to uphold the staff team aspect in order to facilitate person-centred plans and deliver goals.	"PHSS, they're very supportive of their staff… I honestly feel that I could confidently, right now, phone in any of those head guys and say, '…I really need help with… this person-centred plan", and they would be right here… I think they're awesome… I don't feel like… I'm lost in here by myself trying to figure it all out." (Participant 6) "we've never, ever had any issues with me calling my supervisor and saying, 'Okay… I need a staff in here three extra hours every Wednesday to go with [Name] to [a local choir],'…" (Participant 7).

Code Name	Description	Exemplar Quote
Person-centred	The organization's services and supports are person-driven. The person-supported is engaged in shared decision-making but ultimately has control over the direction and approval of the PCPs (i.e., who attends the annual meetings). Where communication barriers exist, the final approval comes from the family or another suitable advocate who has the person-supported's best interests in mind.	"All of mine are tailored… absolutely tailored to the person… what they want to do and what that looks like and how we can make it happen… Their condition and their ability to be able to communicate, we have to tailor." (Participant 2)
Flexibility	Since the organization is committed to person-centred services, it is important that there is flexibility in the process and there are no limitations to changes in the PCP. The PCP process, specifically the yearly planning meeting looks different for everyone and the process is adjusted to the person. Given the fact that person's with and without IDDs can have mutable goals and desires for their lives, goals can change at any point in time.	"this young woman… she loves Shania Twain… her mom wanted her to have a grand entrance. She had a tiara on, she had Shania Twain blaring and into the room she came filled with 20 people, family, friends, staff, team members… present in-person and virtually. We then introduced everybody and… this person's gifts, talents, what her week looks like… very much celebrated this young woman… her mom and her had some goals that they wanted to work on. So, that's when we did that brainstorming… She wanted to go to a lady's group that she had found, she wanted to visit an aunt out east. Lots of laughs, lots of stories. We had a full-on dance party at the end… mom had put together individual charcuterie boards… We had a poster that everyone signed and

Code Name	Description	Exemplar Quote
		just, you know like, 'reach for the stars'… words of encouragement…There were pictures everywhere… a true on celebration… to celebrate somebody… It was fun (laughs)." (Participant 4)
Creativity	Staff's creativity are important factors to the goal-oriented culture. Creativity was utilized to pivot activities/goals during COVID lockdown restrictions and is used when a person-supported does not want to continue with their current goal. Staff, leadership, and persons' supported creativity along with their community (family, friends, partners, etc.) is also key to circumventing funding challenges and barriers to accessing activities or spaces within the community.	"we are out-of-the-box thinkers" (Participant 4) "try and make the funding happen and finding creative ways… bake sales and fundraisers… extra money to do something a little bit special for somebody" (Participant 9).
Asset-based focus	The staff focus their discussion on the positive capabilities and achievements of the person-supported, including their talents, gifts, abilities, and opportunities. The focus remains on what resources can be accessed as opposed to what cannot.	"typically if you find somebody who's like-minded and it's something that you enjoy as well, you're getting to do stuff you enjoy doing yourself… and I'm getting paid for it… what a benefit… this is… such a great opportunity and I would love to be doing this [meaningful activity] anyways, so it's nice to have somebody to do that with…" (Participant 8) "There's one section that we call a view of the week in the person's lives… what do they do

Code Name	Description	Exemplar Quote
		on… all the days of the week… Another section is their interests… And then there's… it's a diagram… the little circle in the middle is whoever the person we're meeting with, and then the next circle is for people that are friends or very, very close family members. And then outside that are acquaintances and then the outer section is paid employees… people they don't see on a regular basis… then we go to the goals, like what, what have we done in the past?" (Participant 7)
Staff team	The staff team, including everyone employed at PHSS not just front-line staff who work directly with person-supported, work together to create and follow-up on PCPs and execute goals. This includes the resources that staff have (i.e., connections with people who can aid in facilitating goals).	"everyone working as a team… [it does] make a huge difference…" (Participant 10) "each location has a care coordinator… They would collect it [information] – as well as myself, as a senior coordinator, we are involved in that process too. Sometimes it takes a few people just to work together and gather all of that information." (Participant 4)
Community	The PHSS community (family, friends, and the connections/resources they have) come together to create a PCP and help execute it. The PCP process is inclusive of the person-supported's community there is an emphasis on family input where possible and where	"with non-verbal persons-supported, we usually rely a lot on the family and the friends to help them come up with ideas for what they're interested in…" (Participant 1)

Code Name	Description	Exemplar Quote
	family members are willing to provide input and support and liaise with PHSS.	"They're so gracious and they want their child to go… they know the people [other persons-supported] who don't have money here and they'll pay for a certain person… I'm so lucky to have such wonderful great parents who not only think of their child, but they think of everyone else too." (Participant 2)
Domain 2: Challenges/Barriers		
Staffing challenges	There are staffing shortages in the community care sector. There is a lack of staff formal education (prior to PHSS employment) in the type of meaningful supports and services PHSS provides. This includes time challenges in finding the staff to support the execution of goals (i.e., if an extra staff is needed at a location).	**"**I mean, the biggest barrier right now is having enough staff." (Participant 5)
Funding challenges	Funding can be a barrier to fulfilling the PCPs. Often times, it can be viewed as a challenge as the organization/staff bridge funding gaps (i.e., applying for grants, fundraising) but this also requires extra time.	"finding funding… for somebody to be able to obtain their goals" (Participant 8). "Challenges are always money… That's one of the major ones" (Participant 11).
COVID challenges	The community-care population was on lockdown for longer than the general public, this created challenges to executing community participation/involvement as part of PCPs. This was also a challenge for persons-supported as some are used to	"Obviously with COVID, there was a lot of lock-down in [facilities], especially with long-term care and community living settings… for those like, 2+ years, they [persons-supported] have really seen no one… there

Code Name	Description	Exemplar Quote
	their daily routines. The lockdown had additional physical health impacts on some persons-supported, potentially introducing more complex medical care needs as barriers to achieving goals.	were different restrictions put on long-term care and community supports… much more severe…" (Participant 8) "Oh, tremendously. The people on my teams were so active in the community and different groups… that stopped abruptly…" (Participant 4)
Challenges to managing expectations	Staff must balance between fostering goals and managing expectations of goals for persons-supported and families. Goals that seem lofty/out-of-reach pose some challenges.	"…sometimes parents get upset… sometimes I have to explain to parents that that's just not going to happen… it's an uncomfortable conversation… but it has to happen because sometimes parents… they get excited… sometimes, they want to jump way too far ahead… And that's such a parent thing… every parent's dream is for their kid to do all the things that they wish they could…" (Participant 6) "it's great to see and I think the parents don't ever think of their child beyond whatever their limitations… it's hard for them to look past all of that" (Participant 2).
Changes in health status	Changes in health status can impact the plans for executing PCPs, sometimes these changes can be sudden. This includes the health impact COVID-19 had on the persons-supported physical	"especially if it's [PCPs] wanting to get out in the community and… if they're in and out of hospital… That's pretty difficult to be able to

Code Name	Description	Exemplar Quote
	health which may have resulted in additional health challenges.	achieve a goal when they're sick all the time" (Participant 11).
Lack of accessibility	There are accessibility barriers in society including structural barriers such as transportation barriers and entrances to places in the community. Other barriers include high sensory environments and crowded areas as well.	"if we have to book para-transit… you have to book three days in advance. And… there's no guarantee you're going to get what time… you might call and they might say, 'You know what, all I've got is a 6:30'… and he's going to have to go early and sit there and wait…" (Participant 7) "Many people aren't able to drive an agency vehicle, and a lot of people that we work for use wheelchairs" (Participant 5).
Lack of community involvement	A lack of community involvement (including family, friends, partners, etc.) can create a challenge to the PCP process. Often the person-supported's community contribute information on the person's likes and past activity experiences that are helpful in the process. A lack of community involvement may make the process slower, based on assumptions, and often a trial-and-error process.	"some families don't want to be involved. And I find that with the older people that we serve… [who] used to live… [in] institutions… [they were] very segregated. And their families may have not had any interaction with them for 50 years. So, to have them be expected to be this much involved may not be wanted." (Participant 4) "anyone who presents communication and comprehension – sometimes we're just shooting in the dark… they don't have a big circle and a lot of people… its just a guessing game… you're…

Code Name	Description	Exemplar Quote
		watching how they react to a certain situation or opportunity that they're involved in…" (Participant 8)
Challenges of misalignment	Misalignment of what the PCP process typically looks like at PHSS and what a person desires (in terms of how their PCP process looks like).	"one of the gentlemen always refuse [a PCP]… it's just hard to come up with ideas… [I] don't know a lot about… his interests and stuff" (Participant 10).
Capacity challenges	A person-supported's capacity is often a challenge for this population, this includes communication and anxiety. This may create time barriers and result in PCPs that are based on assumptions. This may also result in a trial-and-error process.	"not everybody communicates the same way and not everybody is able to communicate everything they want and need in life, so that is a barrier…" (Participant 1) "so, the lady with anxiety, maybe the goal is to [join a local choir]… and maybe after a while… all those people, it's just too much…" (Participant 7)
Staff comfort	Staffs' willingness to engage is an important facilitator/barrier of PCPs. The staff at PHSS are committed and dedicated to executing the PCPs but may not always be comfortable due to lack of experience. Practices at PHSS include trying to match staff with persons-supported based on interests. This can be challenging if staff within a location do not have matching interests and/or are not comfortable with trying new things. This can create challenges in terms of the time it takes to find staff from different locations and schedule them.	"gender isn't as specific as matching the staff… you need to match the staff to the activity. If… you're sending somebody fishing and they do not do well with worms… then obviously that's not a good match… Or if … the staff is shy and the person needs to make friends. Well, somebody who's shy is not going to do well with… helping make friends and connections." (Participant 11)

Code Name	Description	Exemplar Quote
Domain 3: Impacts		
Direction	PCPs also provide direction for staff and persons-supported (i.e., what are we going to do).	"It gives us, as caregivers and support staff, goals so, that we're not sitting here looking at it, well, what are we going to do this week… We have goals as a unit and we can work together to make those [happen]… we're just a part of helping them be able to accomplish these things." (Participant 7) "But just with having them, it… keeps us knowing that… this is what they want to do" (Participant 3).
Motivation	PCPs provide motivation for persons-supported and families.	"they're [persons-supported] excited because they're going to be talking about the future and goals…" (Participant 7) "typically the parents are really, really excited to see them [person-supported] doing all these things…" (Participant 8)
Fostering goals	Persons-supported have the opportunity to lead meaningful lives (based on how they define it). This can give them a sense of accomplishment.	"one day she… says, 'I want more' … we started talking about it… she wanted to teach more… wanted to start working with adults… she used to go and do the lecture at [name of college]… So, she would teach that to the kids… And she would tell her story, and her story was a clear example of having valued

Code Name	Description	Exemplar Quote
		roles in society. And… one day… she goes, 'More.' So, then we ended up teaching at the university…" (Participant 5) "one goal was…[for a] gentleman… he's in a secure unit, was to be able to come out of the unit and eat at a table – because he was eating out of his lap… we started… with one, one meal. The goal at the end of the year is for him to eat all meals [at a table]…" (Participant 6)
Facilitating goals	Staff play a hand in the accomplishment of goals, there is personal and emotional fulfillment as a result of their role in supporting the persons-supported live meaningful lives.	"typically if you find somebody who's like-minded and it's something that you enjoy as well, you're getting to do stuff you enjoy doing yourself… and I'm getting paid for it… what a benefit… this is… such a great opportunity and I would love to be doing this [meaningful activity] anyways, so it's nice to have somebody to do that with…" (Participant 8) "I like planning goals… seeing things happen, I like seeing staff get inspired… we had one of the guys make his own mug cake yesterday. Oh my god, his face when he was eating his own cake… I live for those moments… it's a really fun job." (Participant 6)

Code Name	Description	Exemplar Quote
Community involvement	The person-supported's community (family, partners, friends, etc.) have the opportunity to participate in the PCP process. They also get to watch their loved ones accomplish their goals.	"a gentleman got out of his wheelchair and put… a life jacket on and went swimming in the lake for the first time… his caregiver was… crying in tears to be… part of his goal… to see her brother and his dad see the son, they were… brought to tears… the family seeing them [person-supported] achieving their goals…" (Participant 8) "give their input on what they think the person should… or could be doing… helps them be more involved as well for sure…" (Participant 11)
Person-directed	The person-supported's have autonomy, they are able to choose when to participate in the formation and execution of goals as is amenable to them/possible given communication challenges.	"it's really focused on the person… it gives them as much control and autonomy as possible, and a lot of the time people with disabilities might not have experienced that their whole life… that's something PHSS is really big on… giving people as much control as is safe… that's part of dignity is… choosing your own path in life." (Participant 1)
Community integration	Persons-supported have the opportunity to be integrated into the community. This includes social participation and building social connections with other community members. They are given the opportunity to be part of a	"we started… a fishing group and a fishing derby and one of the people… really enjoys sports and fishing… people from the other agency houses come and join us as well out in the community to fish every week…

Code Name	Description	Exemplar Quote
	community they might otherwise be excluded from.	So, we had some people from Community Living [another community-care organization] join us. We had Angling Sports [a sports store] … help support us by donating stuff to our fishing tournaments as well as we have people come from the community with their boat and kind of teach us about fishing as well…" (Participant 3) "it's more the community, being out in the community, being part of the community" (Participant 11).
Domain 4: Accountability		
Client to Provider and Organization	Clients are accountable to express their wishes for the upcoming year (if any) to PHSS and staff with as much participation/input as is amenable to them/possible given communication challenges.	"I send them into [Name], like I send them into whoever is the person setting planning, which is [Name] right now. So, I make sure mom and dad see the plan, they sign the plan, they like the plan. I go through it with the person-supported, 'Is this what we want to do, is this for sure what you want to do?'" (Participant 2).
Provider to Client	Even though PHSS has compliance regulations they must follow given by the Ministry, to maintain the person-centred vision and services providers must provide flexibility and be able modify the process of PCPs to fit the individual. The provider is accountable	"there's different options… we're not in the business of forcing people to sit down… tell me all your goals and… accomplish them… the celebration part of it, I guess some people have said it feels a

Code Name	Description	Exemplar Quote
	to provide person-centred services and supports to the client. There is also a sense of rigidity to the rules, this is to the benefit of the client.	little bit remedial… we don't have to have a big meeting, but if you want to write them down… just the two of us…" (Participant 8) "Compliance is very black and white, and we as an agency, are not… we value people's choices… we've worked out a solution that we think appeases both" (Participant 4).
Provider to Organization	There are rules within PHSS for the organization to keep staff accountable. For example, every 6 months there is a PCP review and within 3 months of receiving PHSS supports a person-supported must have a PCP meeting.	"the six months is just to review… they [PHSS] have forms and it just asks for dates, what progress has been done, what steps have been done to accomplish this [these] goals? And then, if it didn't get accomplished, why? Like, what were the barriers? And then we sign off on it… then we just go from there and try and work on it for the next six months." (Participant 7)
Organization to Ministry	There are mandates the Ministry asks of community-care organizations. For example, an annual review of PCPs must be facilitated for each person-supported every year. This form of accountability is commonly referred to as Ministry "compliance" among PHSS staff and leaders.	"people [persons-supported] that are agreeing and want to be a part of the person-centred plan… to be compliant with the Ministry… I have to offer you another meeting within the year" (Participant 8)
Organization to Community	The organization is accountable to the person-supported's community (family,	"some parents have been very busy, so I'm not always able to

Code Name	Description	Exemplar Quote
	friends, etc.) through staff reporting and liaising.	tap into what they want, but I certainly let them know, even if they don't want to attend, I let them know, hey, here's some goals we're going to be doing in the future. So I still keep them involved…" (Participant 2)
Domain 5: Gender and Age		
Gender (as a Person-supported and Staff Member)	Gender of the person-supported can affect their interests and goals within their PCP, and their annual planning meetings. Gender of the staff member can impact the implementation of the PCPs. Some activities call for natural situations in which female staff are matched with female person-supported. For example, if the person-supported wishes to visit a sauna in which the facility is female only.	"It doesn't. How a person identifies does not affect it in any way…" (Participant 4) "there is a hot tub in the elite section of the YMCA… in the men's change room… we looked at funding opportunities for this person to… upgrade their membership [to have access to the hot tub facilities]… But the barrier would be, he would have to have always a male staff with him… the person he would normally swim with was female…" (Participant 5)
Age	Age of the staff member and person-supported can impact the implementation of the PCPs. Some activities call for natural situations in which the age of the staff is matched with the age of the person-supported.	"comes down to their ability and what their mobility is… because as people age, their health status can go down. So, somebody in their 30s can handle the heat and… play baseball with us; whereas somebody who might be in… their later years, that might be too hot…" (Participant 3)

Code Name	Description	Exemplar Quote
		"a little bit trickier because the population that we [PHSS] support tends to age faster and differently than the general population… Age plays a huge, huge part…" (Participant 9)

Chapter 4

4 Integrated Discussion

This chapter aims to connect the findings from the scoping review (Chapter 2) and the qualitative descriptive study (Chapter 3) to present a unified discussion. Lewis et al. (2021) highlight the integrated discussion as an important part of an integrated thesis as it can serve to illustrate a deeper understanding of the results. This chapter provides a bridge between the scoping review and the descriptive study to further emphasize the contributions of the findings to answer the research question: How do individualized participatory approaches to care planning play a role in improved health and social care for individuals living with intellectual and developmental disabilities?

4.1 Thesis Goal

Individuals living with intellectual and developmental disabilities (IDDs) and complex medical conditions face challenges in receiving appropriate and high-quality care that meets their health and social care needs (Rowland et al., 2014; Sullivan et al., 2011; Todd et al., 2020). The community-care sector in Canada aims to bridge this gap as it provides both health and social care services to support individuals in living a meaningful life (Humphries, 2015; Kuluski et al., 2017; Lin et al., 2019; Purbhoo & Wojtak, 2018). Person-centred plans (PCPs) have been identified as a favourable upstream intervention for community-care populations to improve person-supported outcomes and experiences, improve provider experiences, and reduce costly and preventable health service utilization (Lin et al., 2019; Purbhoo & Wojtak, 2018). In alignment with this aim in Ontario, PCPs are mandated by the Ministry of Children, Community, and Social Services (MCCSS) for community-care organizations to facilitate care for each individual they support on an annual basis (Ministry of Children, Community and Social Services, 2021). This mandate provides a structure for organizations to support individuals in living meaningful lives, however, the individual may define it.

In April 2021, PHSS, a community-care organization, approached Western University researchers with the proposal of evaluating their services as they believed their

approach to person-centred planning was unique. An interdisciplinary team was formed to carry out this research and included community-care providers, academic researchers, and family members of individuals with IDDs. In late 2021, a preliminary search of the literature found scarce evidence on the evaluation of individualized participatory approaches to care planning for individuals living with IDDs and complex medical conditions, signifying a gap in the literature. To contribute to the growing evidence on individualized participatory approaches to care planning specific to the community-care sector, our research team undertook two studies as part of a larger project. We conducted the studies using a convergent parallel design (Creswell, 2014). We conducted a scoping review that aimed to identify the types and features, supports or hinders, and impacts and effectiveness of participatory approaches used to develop care plans for individuals with IDDs in the community-care sector. Additionally, we conducted a qualitative descriptive study consisting of semi-structured interviews with PHSS staff (n=11) that aimed to understand the key components and impacts of the individualized participatory individual service agreement/person-centred planning approach used in the PHSS model of care.

4.2 Summary of Studies

This section provides a short summary of the two studies detailed in Chapter 2 and Chapter 3, focusing on the goals and methods used. The results and key findings are discussed in the following section, 4.3 Synthesis of Key Findings.

4.2.1 Individualized Participatory Care Plans for Individuals with Intellectual and Developmental Disabilities: A Scoping Review

The aim of the scoping review was to examine the state of the evidence for and identify any gaps within individualized participatory approaches to health and social care for individuals living with IDDs and complex medical conditions. To accomplish this goal, the scoping review objectives were to identify the types and features, supports and hinders, as well as the effectiveness and impact of participatory approaches to developing individual care plans in the community-care sector. The primary researcher [MD] and a research librarian collaborator performed a search of the literature on six databases to identify articles that fit our inclusion and exclusion criteria, yielding 505 unique results. After title and abstract and then full-text screening as well as hand searching tables of

contents and reference lists of relevant journals and articles, our study included 26 studies and six additional grey literature sources. MD and GY utilized an extraction template to extract data that were relevant to our three objectives.

4.2.2 Examining an Individualized Participatory Care Planning Approach for Individuals with Intellectual and Developmental Disabilities: A Qualitative Descriptive Study

This descriptive study aimed to understand the key components and impacts of the individualized participatory individual service agreement/person-centred planning approach utilized by PHSS. MD conducted 11 semi-structured interviews with PHSS staff aged 23-65 years old. The findings revealed details of the PCPs from the creation to the implementation and impacts, as well as the supports and challenges to PHSS's process.

4.3 Synthesis of Key Findings

This section connects the findings from the scoping review (Chapter 2) and the descriptive study (Chapter 3) to illustrate their contributions to answer the overall research question: How do individualized participatory approaches to care planning play a role in improved health and social care for individuals living with intellectual and developmental disabilities?

The scoping review found limited literature (26 articles and six grey literature sources) on individualized participatory approaches to care planning for individuals with IDDs and complex medical conditions. There is high variability in the types and features of participatory approaches, including the participants, purpose, and process; the overall lack of consensus on the terminology used to describe the approaches could be a contributing factor to the lack of literature on implemented practices. For organizations that wish to implement individualized participatory approaches to care planning, variability in the literature can discourage uptake of new practices (Johnson & Austin, 2008; Pitsillidou et al., 2021). The 26 articles identified common supports and hindrances of the planning process. The most common supports were: the staff-person-supported relationship, communication and teamwork, staff characteristics, informal social supports, and the organizational culture. The most common hindrances were: a lack of time, support staff, and the challenge of balancing the person-supported, organizational,

and staffing needs and policies. Moreover, we highlight that there is a gap in research on the effectiveness and impact of individualized participatory approaches. Limited evaluation may be due to the lack of uptake of such practices, a domino effect of the lack of consensus on the types, features, supports, and hindrances. Limited evaluation of implemented approaches and empirical evidence demonstrating the impact/ of person-centred planning points towards a need for more research to understand how these approaches to care planning are operationalized in practice. Moreover, the lack of empirical evidence on the implications of these approaches is another potential factor that can deter organizations from implementing such approaches (Pitsillidou et al., 2021). The scoping review highlights an overall lack of understanding of the potential positive impacts is therefore highlighted. These findings provide a strong foundation for the need for interviews with staff, persons-supported, and community-care organizations to provide insight into how PCPs or similar individualized participatory approaches have been incorporated into care in Southwestern Ontario. Descriptive studies evaluating these approaches are needed to understand the effectiveness and impacts of these plans. The scoping illustrates the gap in research on individualized participatory approaches to care planning for individuals with IDDs, more specifically the lack of research on already implemented practices.

The qualitative descriptive study provides evidence to address the limited literature on operationalized participatory approaches to care planning for individuals with IDDs. While the scoping review provides a good base of understanding of individualized participatory approaches, we aimed to provide a more comprehensive picture of how person-centred planning is operationalized when combined with the descriptive study. The interviews with PHSS staff provide an understanding of the process utilized by PHSS to create and implement PCPs from beginning to end. The results provide insights into the features of PHSS's approach, alongside the supports and challenges to the person-centred planning process, that mirrored findings from the scoping review.

The interviews confirmed the scoping review findings. Triangulation of data occurs when more than one source of data supports the same conclusions (Flick, 2018; Tracy, 2010). Triangulation can provide a more "comprehensive understanding" of the

researched topic (Flick, 2018, p. 529), and create more credible findings (Tracy, 2010). The convergence of our findings, specifically the supports and hindrances, as well as some similar features, provides complementary evidence to encourage organizations to implement similar approaches. Key findings that overlapped are the importance of the organizational culture, staff characteristics, and the person-supported's community (i.e., family, friends, etc.) in facilitating a person-centred planning process.

4.4 Unique Contributions to the Literature

Individualized participatory approaches to care planning are widely supported in the literature and are mandated in Ontario by the Ministry of Children, Community, and Social Services (Ministry of Children, Community and Social Services, 2021; Purbhoo & Wojtak, 2018; Sullivan et al., 2018). Despite this, there is a lack of consensus on how to operationalize the approaches in practice, raising questions as to whether the policy is being operationalized as intended, or if it remains a paper-based checklist in organizations. This thesis provides unique contributions as it provides evidence of a person-centred planning approach used in the community-care sector for individuals with complex medical needs, demonstrating how key aspects identified in the literature (as included in the scoping review) can be implemented in practice. As PCPs are mandated in Ontario, it is important that organizations are supported to implement and facilitate the practice effectively, in alignment with the policy's intended aim. This thesis provides evidence to support organizations in implementing person-centred plans to align with government mandates.

Our descriptive study outlines the iterative and dynamic goal-setting process that calls for constant check-ins and accountability measures. It also highlights the dynamic services and policies that need to be put in place to create a uniform person-centred care experience for each person-supported. I use the word 'uniform' gently; it is not used in this sense to provide each person-supported the same experience but to offer an appropriate amount of support to each individual to facilitate and achieve their goals. The study findings provide a logic model with which to evaluate the impacts of personalized care plans. The study outlines how the process of creating a personalized care plan can lead to individual, staff, and community impacts. With that said, evaluation of outcomes

in terms of goal attainment is a challenging task. As we have seen from the descriptive study, goals can change, which can ultimately disrupt evaluation cycles. Rather it may be more important to focus on the process of goal attainment and the person-supported's satisfaction with the support and services they are receiving throughout the process. Moreover, it is important that evaluation focuses on the spectrum of end-users, including but not limited to persons-supported and their community (partners, family, friends, etc.), care professionals, organizational leadership, and stakeholders. By focusing on user experience, it is also important to question whether evaluative measures of efficiency remain important.

4.5 Integrated Strengths

There are several strengths across our studies. The use of a mixed-methods approach has allowed for the findings to be triangulated, enhancing the trustworthiness and credibility of the results (Tracy, 2010). We utilized a convergent parallel design to conduct both studies simultaneously and the findings from each study complement each other (Creswell, 2014). The scoping review identified a gap in the literature on operationalized practices and therefore the impacts and effectiveness of such approaches; our study fills this gap in the literature. A strength of our studies lies in the unique conclusions; our studies illustrate the features, effectiveness, and resulting impacts of a practiced approach, showcasing how key insights from the literature and scoping review can be put into practice.

Utilizing an integrated knowledge translation approach provided value in the research process throughout both studies. The opportunity to be part of an integrated research team that includes experts (community-care providers) in the field furthered our understanding and interpretation of the findings. This was highly relevant in the scoping review as the research team had the opportunity to conduct a consultation exercise to create a better understanding of key insights from the literature. This exercise also provided insights as to how PHSS has implemented such features into practice which aided the writing stage of the interview results. The ability to discuss the interview results helped create a story-like presentation of PHSS's approach to PCPs from creation to facilitation.

4.6 Integrated Limitations

Limitations must always be considered, and where possible minimized, within research findings. There were challenges to conducting a literature review on populations living with IDDs due to the variations in terminology across the literature. This was also true for person-centred planning, as many variations and types of approaches are similar in nature. To minimize these challenges, a preliminary search was conducted to identify keywords that are consistently used across the world and not just in North America; these keywords were then included in the search strategy. These variations posed challenges when screening the scoping review results as the varying approaches required a more thorough understanding of how it compared to person-centred planning than the papers typically included. To minimize errors in screening, reviewers talked to healthcare leaders on the research team and conducted further background research to better understand the approach before deciding if the source was relevant to our scoping review criteria.

While we conducted the study after the height of the COVID-19 pandemic, we did not specifically focus on the impacts of the pandemic on PCPs. The COVID-19 pandemic and its perceived impacts on PHSS, their approach, and the facilitation of PCPs were often brought up by interview participants. Participants repeatedly mentioned how day programs were shut down due to government restrictions on community-care services and how severe the restrictions were compared to the general population. Given how the researched population, individuals living with IDDs, have complex and vulnerable health needs, the context of the COVID-19 pandemic likely had an impact on our findings.

There are also limitations in our qualitative descriptive study as we aimed to understand the person-centred planning approach at one organization. These limitations lie in the participant group, solely made of care professionals at PHSS. The key features and impacts of PHSS's approach to PCPs may not be generalizable to all organizations that facilitate similar planning approaches. Further, as members of the PHSS leadership team were part of recruitment, there is a possibility of a conflict of interest as parties may have been interested in participating due to the perceived involvement of their boss/management.

4.7 Implications for Practice, Policy, and Future Research

Utilizing an individualized participatory approach to care planning such as person-centred planning is an ethically correct approach to take as it involves the individuals themselves. Moreover, approaches like person-centred planning take the person-supported's capabilities into account, but do not use these capabilities to limit the person-supported. Rather it takes an equitable approach to care to enable persons-supported to live a meaningful life as the person themselves define it.

Our study has implications for a wider uptake of person-centred planning approaches amongst community-care services for individuals with IDDs. Our findings enumerate the positive impacts of PCPs on persons-supported and the people who support them (i.e., family, friends, care professionals, etc.). These results have the potential to inform and encourage organizations to implement similar approaches to facilitate meaningful lives as defined by the persons-supported.

While policies like the one mandated by the MCCSS already support person-centred planning in community-care services, governments should implement more extensive guidelines to support organizations in implementing and facilitating PCPs to ensure the practices are implemented in alignment with the intended purpose. This can include more accountability measures or can consist of suggestions for how organizations can keep accountable to the persons they support to ensure goals are met. Essentially, this can include a framework with minimum specifications to allow for creativity and authenticity to align with person-centred values. Additionally, organizations can benefit from resources such as a toolkit of evidence to support them in effectively implementing such practices.

We also outline the importance of evaluating individualized participatory approaches to care planning. Governments can and should support organizations with funding to support the evaluation of their services. Alternatively, governments can support collaboration hubs where researchers and community organizations can collaborate and create partnerships to evaluate their services. One challenge within evaluation is deciding what to measure when it comes to PCPs. The success of goals must be defined by the persons themselves to ensure that success is being defined while

staying true to person-centred values. This can also be a challenge for organizations as evaluations of programs/services are often tied to a timeline, however, I bring up the issue of the flexible nature of goals. Persons should be free to change their minds on their goals, which may change the timeline of their goal, and therefore may not be considered successful at the end of the organization's evaluation timeline. These challenges may be mitigated by measuring the persons-supported's satisfaction with care supports, the person-centred planning process, and whether or not they are engaging in activities that are meaningful to them.

Future research should explore the perceived impacts and effectiveness from the perspective of the persons-supported and their families. As well, future research should focus on examining similar approaches implemented in other community-care organizations. Moreover, the applicability of person-centred planning approaches for other vulnerable populations should be explored.

4.8 Conclusion

There is extensive support within the literature for a shift towards individualized participatory approaches to care planning for community-care populations (Purbhoo & Wojtak, 2018; Sullivan et al., 2018). A preliminary search revealed that a large portion of this literature are opinion pieces meant to encourage the use of approaches such as person-centred plans, expressing the impacts of theoretical approaches to care planning. Given the nature of the literature, it was unclear what aspects of the evidence inform practice (and mandates) in Ontario within community-care organizations. This research aimed to answer the research question: How do individualized participatory approaches to care planning play a role in improved health and social care for individuals living with intellectual and developmental disabilities?

This research question was answered through two studies, a scoping review and a qualitative descriptive study. The scoping review identified a lack of consensus on the types and features of individualized participatory approaches to care planning, and scarce evidence supporting the positive impacts and effectiveness of such approaches. The review identified the need for a better understanding of how PCPs are operationalized in practice. The qualitative descriptive study filled this gap in evidence by examining

PHSS's approach to PCPs. The findings from this study identified PHSS's unified organizational culture as a foundation for the success of their approach, an element they believe to be unique.

Together, the studies suggest that PCPs have the potential to have immense impacts on improving health and social care by identifying appropriate supports as desired by the persons-supported themselves. PCPs can better support the well-being of individuals and may increase their satisfaction with care supports. Moreover, by focusing on goal-oriented care, organizations can work towards creating an organizational culture that utilizes care professionals' assets to develop an enjoyable and long-lasting working environment that supports individualized approaches. The findings illustrate a need for more evidence to fully support organizations in implementing similar approaches and to guide legislation within Canada and across the world. Governments should support their mandates with funding for evaluations to ensure that practices, such as PCPs, are implemented and facilitated in alignment with the intended aims, and to confirm that involving persons in their care enables persons-supported to engage in meaningful activities.

Individualized participatory approaches to care can identify appropriate supports, as determined by persons-supported, to enable individuals to live a meaningful life. Involving individuals in their care planning is important to identify these supports and can lead to positive impacts on quality of life and increased satisfaction with care for persons-supported. It is important that these care planning approaches be utilized for vulnerable populations where care needs may not be fully understood at an individual level.

4.9 References

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Curriculum Vitae

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EDUCATION

Master of Science in Health and Rehabilitation Sciences, Health Promotion (MSc.)
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- Thesis: Examining Individualized Participatory Approaches to Care for Individuals with Intellectual and Developmental Disabilities
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Bachelor of Health Sciences, Honours Specialization in Health Promotion (BHSc.)
Western University, London, ON
2017 –2021

PROFESSIONAL DEVELOPMENT CERTIFICATIONS

- Patient-Oriented Research Training & Learning – Primary Health Care (PORTL-PHC) Online Training Program (June 2022)
- National Collaborating Centre for Methods and Tools: Evaluating Knowledge Translation Strategies in Public Health (September 2021)
- National Collaborating Centre for Methods and Tools: Introduction to Evidence-Informed Decision Making (September 2021)
- Professional Management for Development Professionals: PMD Pro (July 2020)
- Tri-Council Policy Statement: Ethical Conduct for Research Involvement on Research Ethics - TCPS 2: CORE 2022 (April 2019)

WORKSHOPS ATTENDED

2023

- *Engaging Youth in STEM*, Let's Talk Science, Canadian Institutes of Health Research
- *The ABCs of Health Misinformation*, Canadian Institutes of Health Research
- *Instagram and TikTok for #SciComm*, Canadian Institutes of Health Research

2022

- *Blocks of Impact: Expanding the ways to showcase your research and scholarship*, Western Research's Level Up Research Excellence Series, Western University
- *Finding and Evaluating Open Educational Resources Workshop*, Western Libraries, Western University
- *Writing Executive Summaries*, Writing Support Centre, Western University
- *Writing Your Thesis or Dissertation*, Writing Support Centre, Western University

- *Writing Your Literature Review*, Writing Support Centre, Western University
- *Writing Effective Research Proposals*, Writing Support Centre, Western University
- *Punctuation*, Writing Support Centre, Western University
- *Summarizing Your Research into an* Abstract, Writing Support Centre, Western University
- *Refining Your Grammar Skills*, Writing Support Centre, Western University
- *Editing and Proofreading*, Writing Support Centre, Western University
- *Organizing and Structuring Your Work*, Writing Support Centre, Western University
- *Ins and Outs of Publishing Fees*, Western Libraries, Western University
- *Introduction to Qualitative Analysis with NVivo*, Western Libraries, Western University
- *Organizing Research with Reference Management Tools*, Western Libraries, Western University
- *Data Sources at Western Libraries,* Western Libraries, Western University
- *Getting Publish*, Western Support Centre, Western University
- *Intersections in Rehabilitation*, Faculty of Rehabilitation Medicine, University of Alberta

RESEARCH EXPERIENCE

Graduate Research Assistant September 2021 – Present
Western University, Sibbald Lab Team and Knowledge Translation Lab, London, ON

Graduate Research Assistant
Western University, Dr. Sheila Moodie Lab, London, ON March – August 2022

Graduate Research Assistant
National Institute on Ageing, Toronto, ON April – May 2022

WORK EXPERIENCE

Lead Grant Writer June 2023
Thames Valley Family Health Team, London, ON

Graduate Teaching Assistant May – August 2023
APPLHSCI9004: Determinants of Mental Health and Trauma-Informed Mental Health
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APPLHSCI9002B: Equity and Health Systems
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Graduate Teaching Assistant January – August 2022
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Western University, Faculty of Health Sciences, London, ON

Health Promotion Programs Officer June – September 2021
Routes Connecting Communities, Georgina, ON

HONOURS & AWARDS

- IKTRN Trainee Award, Integrated Knowledge Translation Research Network, May 2023
- Top Evaluate MSc Presenter, Health and Rehabilitation Sciences Graduate Research Conference, February 2023
- C Kingsley Allison Research Grant Competition, December 2022
- Western University Undergraduate Dean's Honor List, April 2021

CONFERENCES AND PRESENTATIONS

I) International Conferences *(N=1)*

Dong, M., Young, G., Dunne, B., Antony, D., Armstrong, R., Ryan, B., Mathews, M., Sibbald, S. *Examining Individualized Participatory Approaches to Care for Individuals with Intellectual and Developmental Disabilities.* International Conference on Integrated Care 2023 (ICIC23), International Foundation for Integrated Care, Antwerp, Flanders, May **2023**. Oral Presentation.

II) Local Conferences *(N=4)*

Dong, M., Young, G., Dunne, B., Antony, D., Armstrong, R., Ryan, B., Mathews, M., Sibbald, S. *Examining Individualized Participatory Approaches to Care for Individuals with Intellectual and Developmental Disabilities.* London Health Research Day, Western University, London ON, June **2023**. Poster Presentation.

Dong, M., Young, G., Dunne, B., Antony, D., Armstrong, R., Ryan, B., Mathews, M., Sibbald, S. *Examining Individualized Participatory Approaches to Care for Individuals with Intellectual and Developmental Disabilities.* Parkwood Institute Research Day, London ON, April **2023**. Oral Poster Presentation.

Dong, M. *Examining Individualized Participatory Approaches to Care for Individuals with Intellectual and Developmental Disabilities.* Western Research Forum, Western University, London ON, March **2023**. Oral Presentation.

Dong, M. *Examining Individualized Participatory Approaches to Care for Individuals with Intellectual and Developmental Disabilities.* Health and Rehabilitation Sciences

Graduate Research Conference, Western University, London ON, February **2023**. Oral Presentation.

III)* Presentations *(N=5)

Dong, M., Doughtery, M. *Land Acknowledgements.* Sibbald Lab Team, Western University, London ON, February **2023**. Oral Presentation.

Dong, M. *Imposter Syndrome.* Sibbald Lab Team, Western University, London ON, April **2022**. Oral Presentation.

Dong, M., *3 Minute Thesis: Participatory Care of Individuals with Intellectual and Developmental Disabilities.* Health Promotion Seminar, Western University, London ON, March **2022.** Oral Presentation.

Crichlow, G., DaSilva, M., **Dong, M.**, Joshi, A., Martin, J., and Thirunavukkarasu, A., *Research Paradigms.* Sibbald Lab Team, Western University, London ON, February **2022**. Oral Presentation.

Dong, M., *Healthy Menu Choices Act.* HS9721: Current Topics in Health Promotion, Western University, London ON, November **2021**. Oral Presentation.