EVOLVING SUPPORT NEEDS IN SMALL OPTION HOMES IN NOVA SCOTIA: POLICY IMPLICATIONS ON PERSONS WITH INTELLECTUAL DISABILITIES

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Dedication

To the Heathers and the Johnnys in my life. You are a piece of my heart.

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To the people with disabilities with whom I have shared various relationships over my life. Thank you for your friendships, for your wisdom, for sharing your strength and vulnerability. Thank you for sharing the heaviness and beauty of life with me.

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I would also like to thank my family and friends for their trust, understanding and gentle support. Thank you for providing the emotional space to vent and the physical space in your homes for me to hide away with my computer.

Finally, I am grateful for my cat, Minnie; the many long hours at my desk were so much more bearable with her curled up on my lap.

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Prologue

I show up to this work as a Settler, as a woman, a Nova Scotian, and as a person who once danced with the identity of disability. I show up as someone who has been forever impacted by the relationships of diverse friends, family members, colleagues, and schoolmates with disabilities throughout my life. Through this work and my daily actions, I hope to honour and illuminate the knowledge, passion, and lessons imparted onto me through those relationships.

I understand that most forms of emancipatory research are often motivated by experiences of the researchers. I do not claim to possess the experiences detailed in the fictional stories in the present study, but instead have drawn from various influences of those around me. It is inevitable that a subject matter that sits personally with me influences how I show up in this work; however, in the same way that this work challenges underlying beliefs and assumptions within government policy, I continue to challenge those same things within myself. I understand that learning is an ongoing journey and will continue to seek out my own knowledge gaps and the lessons that accompany them.

A brief note about language choices within this work. The present study contains both person-first and identity-first language with respect to the identity of 'disability'. I understand that both forms of identification are commonly used within the present disability landscape. I do not presently identify as a person with a disability and therefore do not believe it is my place to assume one approach over the other; thus, *person with a disability* and *disabled person* is intermixed throughout this piece.

Abstract

Recent legal events in Nova Scotia (NS) prompted the examination and reform of the provincial Disability Support Program (DSP). This initiative, coupled with the impacts of the COVID-19 pandemic, revealed devastating impacts of policy structures on persons labelled with intellectual disabilities (PWID). The present study examines how Nova Scotia Disability Support Program policies impact persons with intellectual disabilities experiencing increasing support needs while living in small option homes. Existing research focuses on group home settings, with nothing specific to NS, nor DSP policies. Guided by the theoretical frameworks of critical disability theory and intersectionality, and the analytical frameworks of critical policy analysis and Intersectionality-Based Policy Analysis (Hankivsky et al., 2014), a text-based policy analysis was conducted on DSP policies. The potential lived impacts of identified themes from the analysis were illuminated through two composite stories. The analysis revealed themes of medicalization, dis/empowerment, and colonial structures. These themes were situated within larger contexts of institutional ideologies, static beliefs about PWID, and intersectional complexities of accessing DSP supports. This study demonstrated the importance of connecting policy with lived impact during policy reform. Future research should further investigate how varied identities impact how PWID access DSP supports. Future policy reform must center lived experience throughout the entire process, and center the question "who am I impacting, and how?" throughout each point of change.

Keywords: Intellectual Disability, Disability Support Program, Small Option Home (SOH), Human Rights Remedy, Support Needs, Ageing in Place, Intersectional

Introduction

Home is meant to be a place of comfort and stability. Unfortunately, not all Canadians are afforded the right to this form of refuge. Such may be the case for persons labelled with intellectual disabilities (PWID) living in provincially funded homes, which were created with the intention to honour the rights of persons with disabilities (PWD) to live in the community. Canada has deep historical roots in the institutionalization of PWD dating to the 1700s. Formerly institutionalized people, allies, and activists across Canada are demanding provincial efforts to amend the generations of mistreatment. Compared to other provinces that have abolished total institutions (Carpenter, 2007), Nova Scotia (NS) is further behind in deinstitutionalizing, with almost 900 people still living in institutional care facilities, funded by the Disability Support Program (DSP; Bartnik & Stainton, 2023; Disability Support Program, 2021). After a recent legal human rights ruling and subsequent release of a legally binding Human Rights (HR) Remedy, the DSP is undergoing significant reform, including the elimination of institutions and group homes in the province, leaving small option homes (SOHs), which accommodate up to 4 persons per household, as the remaining congregate-style environment for PWD, including persons labelled with intellectual disabilities (PWID) transitioning out of institutional facilities. Given the drastic difference in environmental living conditions between an institutional facility and one which mirrors a typical family home, this provincial shift introduces a unique set of policy development considerations.

One important point of consideration in provincial policy development pertains to preserving the rights and dignity of PWID in SOHs who have increasing support needs.

Among other factors, an increase in support needs may look like age-related or health changes. The resources and approach to care differ between institutional settings and SOHs. Recent events generated a renewed focus toward policy reform that supports the health needs and well-being of PWID in community homes. These events include the devastating impact of COVID-19 in congregate care, and an ongoing human rights legal battle in Nova Scotia acknowledging systemic discrimination against disabled persons (*Disability Rights Coalition v. Nova Scotia (Attorney General)*, 2021), which subsequently led to the release of the Human Rights (HR) Remedy. Although research exists on the experiences of PWID with increasing support needs in larger congregate care settings (Bowers et al., 2014; Hussain et al., 2019; Northway et al., 2017; Webber, Bowers, & Bigby, 2010), none currently exists involving smaller settings such as SOHs, nor specifically related to the impact of public policy, including in NS. The present study examines how Nova Scotia Disability Support Program policies impact PWID experiencing increasing support needs while living in SOHs.

Historical Origins

Western society has a sordid history with housing for PWID; most significantly is the use of institutions through the past several hundred years, from which ideologies extend into housing frameworks today. An encompassing characterization of institutions originates from Goffman (1961). Goffman identified "total institutions" as establishments whose "*total character is symbolized by the barrier to social intercourse with the outside and to departure that is often built right into the physical plant...*" (Goffman, 1961, p. 4). Although the term originally extended to several forms of

institutions such as jails, concentration camps, mental hospitals, etc., "total institution" encapsulates the characteristics of the historical institutions for PWID. Total institutions are characterized by Goffman as *"…a breakdown of the barriers ordinarily separating these three spheres of life,"*— sleep, play, and work (Goffman, 1961, p. 6). This description aligns with various accounts outlining the orientation of institution grounds where all aspects of life would take place on the property: sleeping, eating, hygiene, medical care, education, work, recreation, and more (Barken, 2011; Brown & Radford, 2015; Reaume, 1997).

With a history dating back to the 1700s, earliest forms of institutions housed people known at the time as socially deviant, including PWID and others such as criminals, lunatics, and sexual deviants. Beginning in the early to mid-1800s, westernized institutions evolved to separate PWID from those deemed mad to promote greater rehabilitative environments for both groups. Institutions peaked in use through the 1800s to mid-1900s (Barken, 2011; Brown & Radford, 2015). Nova Scotia's institutions developed in the same pattern: their earliest forms of institutions were poorhouses and workhouses introduced in 1759, and by 1886, institutions were established specifically for PWID. Throughout the development of a market-driven economy in the 18th and 19th century, societal priorities shifted to individual efficiency and productivity as indicators of success. Persons with disabilities did not fit this construct; rather, they became indicators for the differentiation between productive and non-productive members of society, with non-productive members posing a threat to the success of the growing economy (Burghardt, 2017). Institutions were a product of how PWID were societally

regarded; they were seen as a social problem (i.e., drain of economic resources and threat to repopulation) to which society needed a solution (i.e., a removal from society; Barken, 2011; Burghardt, 2017).

Institutions were initially promoted as therapeutic, rehabilitative facilities to remove PWID from dire circumstances; however, they were truly custodial facilities run by the state within a cost-effective model. The state's goal to become self-sufficient was primarily directed through the forced and under/unpaid labour of residents and minimization of unnecessary costs such as education and recreation programs (Brown & Radford, 2015; Burghardt, 2017; Philo, 1989; Radford, 1991). As decades passed and institutions faced a greater influx of admissions over discharges, coupled with the financial strain of operations, overcrowding and neglect became a common reality. Victims of total institutions often experienced overcrowding, isolation, and abuse in many forms. Reaume (1997) details conditions in a branch of the Toronto Hospital for the Insane as being so overcrowded that some patients had to sleep on sofas in corridors. Far from embodying what "home" typically constitutes, institutional life was one of surveillance, neglect, and segregation from the rest of society.

Institutions were a mechanism of eugenocide on PWID. The act of removing men and women with intellectual disabilities from mainstream society (the central role of institutions) was in itself a eugenic strategy. Within institutional walls, overt eugenic practices included the separation of men and women and the extreme practice of documented and undocumented sterilization procedures (Brown & Radford, 2015; Hubert, 2000; Malacrida, 2015; Radford, 1991). Colonization introduced the concept of

eugenics (Meekosha, 2011); uptake of eugenic practices on PWID in British and North American policy was rooted in Sir Francis Galton's interpretation of Darwin's theory of natural selection, which he coined as 'Eugenics'. Specifically, *eugenics* referred to the notion that nature (not nurture) determines one's intellectual ability and that human reproduction must be managed to preserve our species' fitness. From the 1800s until late 1900s, segregation and sterilization remained the primary – and most highly debated within eugenic discussions in Western civilization – forms of reproductive control on PWID (Brown & Radford, 2015; Radford, 1991).

Victims of total institutions were not only segregated from the rest of society, but also separated by sex to prevent reproduction (Philo, 1989; Radford, 1991). Forms of forced labour were also separated by gender; males were assigned to traditionally "male" roles such as agricultural labour, whereas women were assigned traditional homemaker roles, such as cleaning or sewing (Radford, 1991; Reaume, 1997). Sexual sterilization, which was the most radical and invasive approach to preventing PWID from reproducing, was a reality in many institutions throughout North America. In Canada, Alberta and British Columbia legislated sterilization from the 1920s until 1972 (Alberta in 1928; British Columbia in 1932); although it was not legal in other provinces, there is strong evidence that it was still practiced (Koester, 2021; Ontario Human Rights Commission, 2016; Radford, 1991). Although these laws applied to multiple populations, PWID were disproportionately targeted. In Alberta alone, over 2800 PWD were sterilized between 1929-1972 (Ontario Human Rights Commission, 2016). Many of these procedures took place without the knowledge or consent of the victim. Specifically within institutions,

sterilization was at times a precondition of discharge from the facility; it served as a means to ensure that women in particular would not reproduce and 'pollute' society once released back into it (Radford, 1991). This provision demonstrates the entrenchment of eugenic ideals underpinning the function of institutions for PWID.

Fueled by the 1970s disability movement and the work of parents and allies of the disability community, deinstitutionalization began in the latter half of the 20th century and is still ongoing in Canada today. Public awareness evolved to acknowledge that the treatment and isolation of persons with disabilities, including PWID in institutions, was a human rights issue; subsequently, there was a push for PWID to be able to live in the community. Provinces began redirecting their efforts to developing community-based accommodations, and eventually, closing their institutions. Unfortunately, many formerly institutionalized PWID did not find themselves in enhanced living conditions; many communities were unprepared for the rapid influx of individuals, leading to other precarious living situations or re-institutionalization in the form of hospitals or incarceration. Today, many Canadian provinces have closed all of their total institutions, including British Columbia in 1995 and Ontario in 2009 (Brown & Radford, 2015; Friedlander, 2006). Presently, NS is still in the process of transitioning almost 900 PWID from institutions into community-based living (Barken, 2011; Bartnik & Stainton, 2023; Disability Support Program, 2021). Despite widespread deinstitutionalization efforts over the past several decades, institutional ideology has seeped into present community living initiatives (Ben-Moshe, 2011). Nova Scotia's deinstitutionalization efforts create

the opportunity to learn from past mistakes to prevent the reproduction of harms created in previous deinstitutionalization efforts.

Nova Scotia Community Living Today

In NS, the Disability Support Program (DSP), run under the Department of Community Services (DCS) provides services to PWD through various programs, including placements in community living homes (i.e., a 'support option'), which are funded by DSP and either publicly or privately owned. Some PWID qualify for placement in a support option once they reach adulthood or the family home is no longer suitable. Support options employ staff to support residents in their daily living. There are three primary residential services: small option homes (SOHs) consist of up to four PWD living who are usually supported by at least 1-2 staff at all times; group homes (GHs) consist of four to twelve residents who are supported by multiple staff at all times; finally, residential facilities, which are capable of housing hundreds of PWD and employ dozens of staff, and are most akin to the historical institutions that warehoused disabled persons (Barken, 2011; Bartnik & Stainton, 2023; Disability Support Program, 2021).

As of 2022, Nova Scotia has 2161 (*2021*:2,155) residential placements, 756 (*2021:*723) in small option homes, 535 (*2021:*545) in group homes, 424 persons between 18-65 in long-term care (LTC) homes, and 870 (*2021*:887) still residing in an institution (Bartnik & Stainton, 2023; Disability Support Program, 2021). These numbers do not include persons with disabilities who are living in other inappropriate forms of institutional care, such as hospitals or nursing homes, due to a lack of capacity to accommodate them elsewhere. In 2022, there were a total of 424 persons under the age

of 65 living in long-term care (LTC) facilities. 134 of those people also had "high cognitive ability, high personal care needs, and no dementia diagnosis." Further, although not specific to residential services, in 2022 there were 72 persons on the DSP service request list occupying psychiatric, forensic, or medical hospitals (Bartnik & Stainton, 2023). The demand for placement in SOHs is disproportionately high, with over 806 requests made in 2021 alone for a SOH placement (DSP Service Request List, 2021). In addition to the high demand for SOHs in NS due to their more intimate environment, there is a need for policy development to allow SOHs to adapt to the changing support needs of their residents.

Current Events

Over the past decade, Nova Scotia has made attempts to resolve problematic relationships with supported housing for PWID. The province released an initial report in 2008 detailing recommendations to improve their residential services for PWD (Department of Community Services, 2008). In 2013, the province's proposal *"Choice, Equality and Good Lives in Inclusive Communities* committed to phasing out institutions and ensuring equal access to housing by the year 2023. This proposal intended to transform the DSP to align with tenets of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and recommended an overhaul in the way NS approached community living for PWID. By 2021 – just years shy of the 2023 goal – their most concerted efforts were displayed through the construction of small option homes. As of 2023, there were 243 existing SOHs, with an additional 18 underway (Bartnik & Stainton, 2023). Although the construction of new SOHs is a positive and

necessary project, given the numbers above, it was clear NS was behind and needed to take a more aggressive approach.

What is more concerning are the beliefs underlying access to meaningful housing for persons with disabilities in the province. In October 2021, disability groups across the province celebrated a ruling by the NS Court of Appeal between NS and the Disability Rights Coalition and three individual human rights complainants. This ruling found systemic discrimination by the province of PWD on four grounds: unnecessary institutionalization, denial of assistance to eligible PWD in need who have the right to assistance, lack of choice over supports, and frequent and extended delays to deliver support (Bartnik & Stainton, 2023; *Disability Rights Coalition v. Nova Scotia (Attorney General)*, 2021). The victory was short lived, however: in December 2021, NS moved to appeal this decision to the Supreme Court of Canada, arguing that human rights legislation would hold too much power if the decision is allowed (Tutton, 2022). This appeal reveals the historically generated belief that housing for PWID does not 'count' as a human right, which is a direct contradiction to the founding of the deinstitutionalization movement in the first place.

By August 2022, Disability Rights Coalition (DRC) and the Province of Nova Scotia, specifically DCS, came to an agreement whereby they initiated an independent human rights review of the finding of systemic discrimination in DSP's services. The findings of this review were released in April 2023 as the Human Rights Remedy (HR Remedy; Bartnik & Stainton, 2023). The report identified six key directions for NS to take over the next five years which should lead to foundational change in the approach

and access to supports for PWD, including housing. Several recommendations are relevant to the present study. First, all homes with more than four occupants are considered under the deinstitutionalization plan, with institutions to be closed by May 2027 and group homes to be closed by March 2028. Second, any "young persons" (i.e., PWD aged 18-65) living in long-term care may return to the community. Third, to move away from SOHs as the primary solution for deinstitutionalization; instead, the province should move toward individual funding, choice, and control.

Nova Scotia's commitment to implementing the HR Remedy recommendations by 2028 generates a new-found sense of hope that PWD in NS will finally have access to more equitable and person-centered living services. Although the HR Remedy serves as a comprehensive blueprint for deinstitutionalizing Nova Scotia's community living services, we must proceed with caution. The ambitious timeline set out by the HR Remedy to close all institutions and group homes, coupled with the evidenced failure of the province on previous commitments creates a risk for history repeating itself; specifically, for individuals to be displaced from institutions without a proper new accommodation, thereby re-institutionalizing them in other inappropriate forms of accommodation such as hospitals or long-term care (Ben-Moshe, 2011). Policies governing the placement and daily living of individuals living in SOHs need to be examined to ensure persons with increasing support needs do not get re-institutionalized into LTC or hospitals.

COVID-19 Pandemic

When the COVID-19 pandemic hit Canada in March 2020, most COVID-related deaths occurred in congregate care facilities, both for ageing adults and PWID (Autistics for Autistics Ontario, 2020; Norris, 2020). Issues arose throughout the country relating to improper conditions and operations within homes, inconsistent policies and procedures for sending COVID-positive congregate care residents to hospital, and communication barriers impacting access to health care for PWD (Levy, 2020; Mialkowski, 2020; Payne, 2020; Sheldon & Malhotra, 2020). An outbreak at Northwood Long-Term Care in NS, which houses hundreds of adults, led to 246 residents contracting COVID-19, 53 of whom died (Lata & Stevenson, 2020). COVID-19 brought poor health care and residential management to public consciousness, and highlighted the shortcomings of the institutional-like framework upon which community living was built (Ben-Moshe, 2011; Kleinaltenkamp, 2018).

Events from COVID-19 also highlighted the under-preparedness of institutional environments to honour the rights of PWD living with higher support needs, leading to decreased mental or physical health, and at times, death. In April 2020, a B.C. woman with cerebral palsy died after spending days alone in the hospital without her family or support workers being allowed to visit. Ariis Knight, who was non-verbal and communicated through eye movements, relied on others to assist her with communicating. Although Ariis did not have COVID, hospital restrictions at that time prevented anyone accompanying her, thus keeping her from exercising a basic and fundamental right to communicate her needs during a time of sickness (Levy, 2020). Tragedies such as Ariis' death demonstrates that, in a time of crisis, care environments

prioritize adhering to broad, sweeping policies over individualized care (Sheldon & Malhotra, 2020).

Given the province's recent commitment to the HR Remedy recommendations, including to close all institutions and group homes, and the health and operational challenges that COVID-19 highlighted, there is need for a renewed focus on the impact of provincial policies on PWID living in SOHs who have increasing support needs. Existing literature has focused mainly on health responses in large institutional facilities and residential group homes; however, there is no literature on this topic that focuses on SOHs or specifically DSP policies and their potential lived impacts. The present study will contribute to the existing research by identifying the shortcomings existing within DSP policies and demonstrating the potential impacts on PWID with increasing support needs in SOHs. It will highlight the importance of connecting policy with the impact on individual lives and emphasize the need for this connection in future development of DSP policy in NS as the HR Remedy initiatives continue. This study will be the first contribution to literature focusing specifically on DSP and on SOHs in NS.

Current Study

The present study examines how Nova Scotia Disability Support Program policies impact PWID experiencing increasing support needs while living in SOHs. Current literature reflects health and age as the two prominent factors influencing changes in support needs; the present research also reflects this, with the flexibility to consider other factors as they arise.

Literature Review

There are many policy-based barriers in residential living that impact residents with increasing support needs, both outside and inside a home. Currently, no peer-reviewed data exists on the impact that DSP policy has on PWID with increasing support needs living in SOHs in NS. There are, however, provincial reports representing service users that highlight their needs and concerns around access to services. These concerns involve lengthy waitlisting, siloing of services, and inappropriate residential assignments.

In 2022, there were a reported 1834 Nova Scotians with disabilities on a waitlist to either receive a housing accommodation or who were requesting a different living arrangement through the DSP Service Request List, a number that has been steadily increasing for years despite provincial efforts to achieve the opposite (Bartnik & Stainton, 2023; Standing Committee on Community Services, 2021). Service users have reported being turned away until they reach a state of crisis with their housing needs, leading to adverse impacts on their health and well-being. Frustration has also been reported with segregation of services, such as those offered through the DCS and Dept. of Health and Wellness (DHW). Both have programs that support disabled persons, yet differential eligibility criteria leave some users without the full scope of their needs met (Dept of Community Services & Dept of Health and Wellness, 2013). Finally, many service users are forced to live in inappropriate living arrangements, such as hospitals or nursing homes, simply because it is the only option available to them (Dept of Community Services & Dept of Health and Wellness, 2013; Dotsika, 2012; Northway et al., 2017; Rankin, 2021). This reactive and service-focused approach to accommodation

does not center the rights or health of PWID attempting to access those services, thus putting them at risk for poorer outcomes before they even enter a home.

While there is no research in NS examining the intersection between DSP policy and lived impact on PWID with increasing needs in SOHs, there is a small body of literature based in Australia that discusses this issue relating to PWID who live in group homes. This is a relevant point of examination in North America, as Australia's approach to policy reform and subsequent implications of deinstitutionalization have mirrored those in the North (Barken, 2011). Although group homes accommodate a larger number of PWID under one roof, they have similar approaches to care and daily living; as such, they would resemble the closest body of literature. Many front-line barriers discussed in this research relate to staff training, communication barriers, lack of funding, and differing administrative approaches to meeting increasing care needs.

Difficulties have been documented relating to delays in the diagnosis of medical conditions in PWID residing in group homes. Staff may write off medical issues such as decreased mobility and change in behaviour as ageing in some residents. This is partly due to communication barriers; it may take a significant amount of time for staff and residents to build a trusting relationship to the point that staff can detect how a resident expresses something is wrong, which is complicated by the high turnover rate in the care field (Bowers et al., 2014; Northway et al., 2017). Further, once symptoms have been detected, a lack of knowledge around protocols and resources within group homes may hinder a diagnosis (Bowers et al., 2014). Research suggests that group home staff promote informed decision making from their residents about support need concerns,

whereas in hospital settings, resident concerns may end up dismissed due to medical practitioner assumptions that individuals do not have the capacity to understand nor communicate about their medical needs (Webber, Bowers, & Bigby, 2010; Webber, Bowers, & Mckenzie-Green, 2010). Delayed recognition and action towards health changes impacts both physical and emotional well-being. Whereas these issues are documented in group home and hospital settings, it remains a question whether the same medical issues would be detected in the personal, intimate setting of a small option home.

Many community homes are not structured to adapt to changing health needs. Staff may not be trained to manage the chronic physical and medical needs of residents who develop long-term illnesses (Bowers et al., 2014; Northway et al., 2017; Webber, Bowers, & Bigby, 2010; Webber et al., 2010). Further, homes may be physically inaccessible and lack funding for mobility equipment or structural modifications. Although some organizations attempt to keep a resident in their home for as long as possible, many of those with long-term complex health needs are re-institutionalized in larger facilities, or worse, into a hospital due to a lack of capacity elsewhere (Northway et al., 2017; Webber et al., 2010). Residents in SOHs face the unique issue of having fewer staff, but in a much more personal and home-like setting. Thus, it is imperative to examine the policies impacting decisions around increasing support needs in SOHs to differentiate them from those in larger facilities.

From unacceptably long wait times and improper placements, to securing knowledgeable and reliable staff or adequate funding models that support residents' desires, current literature details numerous barriers arising from policy impacting PWID

in community living. To date, only two researchers have examined residential services in NS (Barken, 2011; Dotsika, 2012). Dotsika (2012) examined the implications of regulating long-term care homes in the province on ageing adults, which is not specifically pertaining to PWID, but related. Barken (2011) examined the de-institutionalization movement in NS more broadly. Neither of these works specifically focused on SOHs, nor the intersection of policy and PWID with increasing support needs. With substantial changes taking place to the structure of the DSP, it is essential to understand how policy implications uniquely intersect with those living in the more personal and intimate environment that a SOH provides.

Theoretical Framework

The current research will be guided by two theoretical frames, including critical disability theory (CDT) and intersectionality theory. Critical disability theory engages with the histories, systems of power, reflexivity, and groups implicated in the production of disability in society, while centering disability in each of those factors. Driven by activism and an emancipatory approach, CDT challenges these systems and questions the conditions that allowed them to be accepted and normalized as the 'natural' order of things in the first place (Meekosha & Shuttleworth, 2009; Procknow et al., 2017).

In the context of the present study, CDT is valuable because it pushes analyses beyond identifying isolated issues in policy associated with PWID in SOHs. Instead, broader social factors implicated in the issue will be considered to challenge this topic, such as power dynamics (e.g., state versus individual control), historical underpinnings (e.g., institutionalization of PWID), attitudes and acceptance of the issue (e.g., current

community living arrangements accepted as the main form of housing), extra-cultural approaches to living (e.g., how do other cultures approach this issue?), and societal movements (e.g., the human right to housing for PWD). For example, one may question power dynamics within the state-economic-individual system of community living: how does the state exert and maintain control over PWID through community living? One could go further and question why community homes – and communal living, for that matter – are accepted as the ideal housing option for PWID, and consider the histories, attitudes, and processes leading to that school of thought. Probing these points of analyses push boundaries from a simple 'policy-SOH' context and into a realm of emancipatory thought that demands future change.

Intersectionality is another critical theory which seeks to dig beneath the surface of what is accepted as the 'norm.' Born from critical race theory, intersectionality pushes beyond accepting oppression as a unilateral construct by acknowledging that degrees of privilege or oppression associated with memberships of various identity groups (e.g., gender, age, ability, race, sexuality, socioeconomic status, citizenship status) uniquely interact to create one's experience of broader forms of systemic discrimination (Bowleg, 2012; Crenshaw, 1991; Hankivsky et al., 2014; Hankivsky & Christoffersen, 2008). In the context of the present study, factors such as age, ability, socioeconomic status, ethnicity, culture, and geographic location intersect in various experiences of PWID with increasing support needs in SOHs and are key factors contributing to the analysis of DSP policy impacting PWID in SOHs.

Methodology

The current study is a text-based policy analysis that investigates how Nova Scotia DSP policies impact PWID experiencing increasing support needs while living in SOHs. Health and age-related changes were primarily considered as factors contributing to increasing support needs. Policy analysis was conducted with the aid of two analytical frames: critical policy analysis (CPA) and Intersectionality-Based Policy Analysis (IBPA), which are explained in more detail below. Analyses were situated in the creation of two fictional composite scenarios that provided examples of the potential impact that these policies may have on individual lives.[i]

Methods

Text-Based Data Collection

Documents analyzed or used to support analyses in the present study were obtained from online resources available to the public. Documents included provincial policies, reports, ministerial documents, and legislation[ii]. All documents obtained for analysis in the present study were dated within the past 10 years unless they are of historical or contextual relevance to current events.

Data Analysis

To examine how NS policy governing the placement and daily living of PWID in SOHs impacts PWID with increasing support needs, a text-based critical policy analysis (CPA) was conducted, guided by the Intersectionality-Based Policy Analysis framework (IBPA; Hankivsky et al., 2014). Often, a policy may have implications that differ from its intent. Rather than focusing on the stated intentions of policies, CPA seeks to determine the true implications of policies and associated procedures on broader systems

and persons involved. While situating an issue within systemic contexts, CPA directs analyses to question why and how an identified issue materialized, and what can be done about it (Diem et al., 2014; Taylor, 1997; Walt et al., 2008). The approach is impacted by guiding theoretical perspectives, specific CPA frameworks, and other methodological approaches in research (Diem et al., 2014; Duncan et al., 2006; Walt et al., 2008). In the present study, CPA was an effective tool to examine documents through a lens of social change and realize the living consequences that policy has on PWID experiencing increasing support needs living in SOHs.

Analyses in the present study were also guided by the IBPA framework. Created for health policy application, IBPA employs a critical and intersectional approach to understanding "…multi-level interacting social locations, forces, factors and power structures that shape and influence human life and health" (Hankivsky et al., 2014). Its application is centered around eight guiding principles that emphasize employing flexible, intersectional analyses to promote equity and social justice. It also provides twelve questions which guide the user through descriptive (e.g., "What is the policy "problem" under consideration?") and transformative (e.g., "What are feasible short, medium and long-term solutions?") characteristics of the analysis (Hankivsky et al., 2014). Employing IBPA within the current context provided a grounded intersectional approach to identifying themes, assumptions, and problems that arise from NS policy associated with the placement and daily living of PWID in SOHs. Further, IBPA contributed to identifying solutions that are reflective of the unique and complicated interconnectedness of dynamics in SOHs and the PWID living within them.

An important factor in this study is to realize the potential implications of policy with lived consequences. Therefore, I expanded and situated my analyses within two fictional composite scenarios that illustrate the impact these policies may have on individual lives. I drew from current literature, events, and past interactions with PWID to create these scenarios to convey the potential individual human consequences of disability policy in NS.

Procedure

Policy analysis process took place by identifying relevant provincial documents, reviewing for important themes and issues, analyzing themes, and contrasting them with current literature. This process is broken down into three phases, outlined below.

Phase 1: Data Collection & Organization

Nova Scotia Disability Support Program policies and supporting documents, such as provincial reports, policies, strategies, and frameworks were identified. Overviews of these documents were recorded in a Microsoft Excel spreadsheet.

Phase 2: Analysis

In a separate Microsoft Excel sheet, all recorded documents were reviewed for salient themes, issues, and pervasive ideologies. Points for further examination were noted. Important information was captured under one of three questions from a series provided in the IBPA framework: *How have representations of the 'problem' come about?; How are groups differentially impacted by this representation of the 'problem'?; What are the current responses to the 'problem'?* (Hankivsky et al., 2014). Major themes were probed with principles of CDT and intersectionality, including identifying

systems of power, situating issues within histories relevant historical and current events, identifying perceived versus accepted attitudes, and how people from varying identity groups may experience issues differently. The analysis was then contrasted with current literature discussing issues at a policy level and broader theoretical systems.

Phase 3: Situate Results

The major themes and sub-themes were mapped out with relevant literature. To bridge theoretical analysis with real-world issues, the analyses were contrasted with literature discussing person-centered impacts resulting from various policy barriers. Combined with influences from personal interactions between myself and PWID and current events in NS, potential implications of the identified issues were situated within two fictional composite stories. The composite stories were written with the consideration of varying intersectional factors identified in the literature.

Composite Stories: Introducing Heather and Johnny

The following composite stories detail the lives of two fictional characters who are inspired by aspects of relevant literature, current events in NS, and various aspects of the lives of individuals I have had the honour of sharing friendships, mentorships, and working relationships with over the years. Character profiles are delivered in the present section, and a follow-up to their stories is included after the Analysis and Discussion.

Heather

Heather lived in a SOH in Halifax, Nova Scotia. She was an exuberant and headstrong individual in her 40s who lives with Down syndrome. Heather lived in SOHs for about twenty years since the passing of her mother, who was her primary caretaker.

Heather was raised on reserve in Bear River First Nation, a small Mi'kmaw community about two hours away from her current home. About five years ago, Heather experienced medical issues that prompted the move to Halifax to regularly access healthcare services. Since her medical issues arose, Heather became very anxious about attending appointments, and sometimes ran away from them to make herself feel better. Most practitioners did not seem to have time or patience to help her when she felt anxious at her appointments, which made her feel even worse.

The move to Halifax was very difficult for Heather; at her last SOH, she lived closer to her sister, Jean, and her aunties with whom she would regularly visit. Unfortunately, due to the distance, she seldom sees her family. She also missed the comforting feelings of home that her loved ones brought with them; no one else here seemed to share her interests or hobbies she grew up with. Nonetheless, she built a lovely life with the support of the motivated staff at her home. She maintained a job at a local bakery and shared strong relationships with her coworkers, house mates, and several of her support staff. A couple of the staff in her home regularly helped her with her hair and makeup before work; she really enjoyed feeling put together and loved when they offer to assist her with this.

Recently, Heather was diagnosed with early onset dementia. Her employer first noticed her occasionally forgetting how to do certain tasks that were an everyday part of her job, followed by bouts of confusion as weeks passed. Her employer reported it to the support staff at her home, and after several months of tracking and observation, Heather's support staff observed increasing memory lapses, confusion, and unpredictable

irritability. Staff would occasionally find her pacing in her room at night, which was uncharacteristic of her. Her support staff and the home's supervisor watched her closely and supported her as her illness progresses.

Johnny

Johnny was a man in his 60s who lived in a SOH in Bridgewater NS, about 100 kilometers from Halifax. He lives with intellectual disabilities and hydrocephalus (excess cerebrospinal fluid, or CSF, around the brain), which is controlled through a shunt installed when he was a child. Johnny lived with his two female housemates for over 30 years; he was like a big brother to them and took pride in looking out for them. Although he loved to go for drives and visit new places, Johnny didn't get out much; neither he nor his housemates worked or travelled independently so they relied heavily on the support staff to get out of the house. He was close with a handful of the support staff at his house; a few of them had been there for over 10 years, and his favourite staff, Sherry, worked with him for over 25 years. They were like family to him. His favourite activities with his closest support staff were to go for coffee, a walk, or play bingo. He also loved to crack jokes with people, but only if they weren't strangers to him. Johnny had a tough time with the rotation of staff through his home. Every time their shifts changed, there were new rules, attitudes, and routines to get used to. For that reason, it took a long time to build trust with them.

Johnny's favourite person is his mom, who lived nearby and visited regularly. His dad passed about five years ago, and though his mom was getting older and was hard for her to get out of the house, she still came by about once a week. Johnny also got to

go home occasionally, and all holidays were spent with his mom and extended family. Even when he was not visiting his family home, it sometimes still felt like he was at home; over the years he acquired all his favourite things from his family to keep in his bedroom: his recliner chair where he played bingo, the model ship above his own TV and radio, his sock collection, and his closet full of clothes. He always had lots of clothes and never had to go shopping for them at the thrift store like his roommates did. Whenever his family brought something to Johnny, they always made sure to bring something for his housemates, too.

Although Johnny was always slightly unsteady on his feet, recently his support staff noticed he was dragging his foot more than normal while walking. This symptom progressed to loss of mobility on one side of his body, resulting in him using a wheelchair. His support staff brought him to repeated medical appointments and the emergency room on two occasions, but results were inconclusive.

Johnny had a difficult time expressing whether he was in physical pain, but it was apparent to his support staff that he was unhappy with using a wheelchair. Johnny communicated his feelings clearly through his actions, but it took someone with a long-standing relationship with him to be able to extrapolate what his actions meant. He would often try to live and navigate as he used to, which created ongoing safety risks. His home was also not wheelchair accessible, which prevented him from accessing certain areas of the house. Eventually, Johnny needed to be monitored by a support staff around the clock for his own safety, which did not align with the staff schedules set in his home. With advocacy from the support staff and Johnny's mom, the home supervisor

and Johnny's Care Coordinator all began working together to determine what the next steps would be.

Analysis

The present study sought to examine how Nova Scotia Disability Support Program policies impact PWID experiencing increasing support needs while living in SOHs. A review and analysis were performed on DSP policies, the HR Remedy, and other government reports and supporting frameworks through a CDT and intersectional lens. Three major themes were identified: Medicalization, Dis/Empowerment, and Colonial Systems.

Medicalization

Despite the concept of community living arising in the 1970s as a response to the civil rights movements and during the introduction of the social model of disability (Brown & Radford, 2015; Chowdhury & Benson, 2011), Nova Scotia has largely adopted a model of community living that maintains the medicalization of PWID. This assertion is evidenced through the language used throughout the policies, and the rigidity of the supports offered, and the reactive approach to supporting PWID accessing the DSP.

Language use

Despite the DSP's stated purpose of *"…[promoting] a participant's independence, self-reliance, security, and social inclusion"* (Department of Community Services, 2016, p.10), the use of medicalized language in DSP policies to frame PWID and the services provided communicate the opposite. The DSP policies use language that promotes the medicalization of PWID at all stages of accessing the program.

Medicalizing language is first evident in the definitions provided in DSP policies. Definitions provide the starting point from which every matter engaged with is framed. In the DSP policies, definitions of different types of disabilities are populated with medicalizing words such as “deficit,” “limitation,” and “difficulties in functioning” (Department of Community Services, 2016, p.10-11). This outdated language contrasts the definitions of disability from rights-based legislation such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; 2006) the Accessible Canada Act (2019), and the Nova Scotia Accessibility Act (Accessibility Act; 2017), where disability is defined through a social model lens; specifically, that an individual’s impairment(s) interacting with social barriers prevents full participation in society. This legislation sets the precedent at an international, national, and provincial level for how disability should be understood and engaged with at a systems level, and the DSP has failed to follow suit with one of the most foundational elements of engaging with rights-based practices.

The entrenchment of medical model ideologies in the Nova Scotia DSP policies aligns with Smith-Carrier et al.’s (2017) findings of medicalization within Ontario Disability Support Program (ODSP) policies. Specifically, they argued that the ODSP remained embedded within a medical model in both policy and practice despite over 20 years of evolving approaches to framing disability in other legislation, such as the social model approach evident in the Accessibility for Ontarians with Disabilities Act (AODA) or the international rights-based framework in the UNCRPD. This finding is parallel to that of Nova Scotia’s DSP; despite ample opportunity to align DSP policies with a social

model or rights-based approach with the Accessibility Act or the UNCRPD, it remains medicalized. The HR Remedy implicitly attempts to amend DSP's approach to defining disability through a widespread system transformation toward a social model approach to their services but does not explicitly outline definitional language changes and whether they should align with related legislation.

Although a social model lens has been officially adopted through provincial and international legislation, it is limited in scope through historical rootedness in white Disability Studies (Bailey, 2019; Bell, 2006). Policy makers should push beyond a social model lens to acknowledge and empower non-white understandings of disability. Stienstra (2018) demonstrates this argument to move beyond the social model in their analysis of policies and legislation. In their discussion of "Indigenous Inclusion," Stienstra (2018, p.7) highlights how language associated with bodily difference was not an existing concept in Indigenous culture and arose from colonial practices (Barnes, 2012). They assert that the UNCRPD is embedded with definitions of bodily differences through the use of the social model lens to defining disability, which excludes Indigenous people who have become impaired or disabled through colonial practices. They argue for the reflection of Indigenous ways of knowing and being in frameworks such as the UNCRPD. Although some of the recommendations in the HR Remedy incorporate intersectional approaches to transforming the DSP, it falls short in primarily being rooted within a social model, colonial, and rights-based framework which leads to a reasonable assumption that the transformed DSP will inevitably follow suit.

Beyond the definitions of disability, DSP policies are populated with medicalized approaches to their services. A striking example of this approach is demonstrated through DSP's system for prioritizing service requests, which are requests made for a placement in a 'support option' (e.g., a home). This hierarchical 7-level ranking system is used to determine the priority level a request is given, with emergency-related requests categorized as higher priority levels, and non-emergent requests categorized as lower priority (Department of Community Services, 2016, p.21). Participants living in a DSP option who experience an increase in support needs fall directly in the middle of this list (priority 3). This approach to prioritizing requests is initially problematic because it addresses emergencies under the same system as non-emergent requests. It reduces the significance of non-emergent requests and, in a system that is drastically under-capacity to meet the existing demand, risks only being able to address emergent needs while non-emergent needs go chronically unmet until they become an emergency. Further, this model puts the requester in a position of having to take whatever is next available to them, rather than having choice and control in where they live. At 1834 requests in 2022, the HR Remedy noted a 29.8% growth in the service request list between 2017-2022, which did not include an additional 569 participants living in institutions who would soon be added to this list as institutions close throughout the province (Bartnik & Stainton, 2023, p. 34; p. 50). Those individuals' requests deserve to be treated before reaching a critical point.

The prioritization system for the service request list, on a deeper level, is problematic because it reduces the individual to their service request rather than the

complex interworking of someone's life that is submitting the life-altering request. It separates the state (Care Coordinator) from the individual and reinforces the transactional nature with which requests are granted. Parallels of separation and capacity issues can be drawn between the present community living system in NS and the system of historical institutions. Whereas institutions historically reached capacity well beyond the number of beds they could offer and resulted in residents sleeping in precarious spaces throughout the grounds (Reaume, 1997), the same scenario can now be observed with the present service request list. Specifically, that NS is beyond capacity with the number of beds they offer through DSP; rather than being under one roof, service users are spread throughout the province in various living arrangements that range in precarity while awaiting their placement. Parallels of separation can also be observed: while historically institutions served to keep PWID separate from society (Brown & Radford, 2015; Goffman, 1961), the stripped-down characteristics of the prioritization of the service request list separates the state (Care Coordinator) from the individual consequences of the system being well beyond capacity.

Structural Rigidity

Medicalized definitions within DSP policies materialize into rigid and inflexible criteria for, and provision of, supports at all stages of participating in the program. Many aspects of these policies assume that PWD are static and unchanging, and when people inevitably do change, they are forced to adapt to the system rather than the system possessing the flexibility to adapt to changes. The service request list is an example of this style of rigidity; however, it is most prominent in sections of the DSP policies meant

to address changes to participant support needs once they are in a support option, including up until end of life. Although on the surface the measures in place seem to promote system adaptation to participant changes, they ultimately serve to preserve the transactional nature and financial well-being of the DSP.

The DSP's procedural responses to changes in participant support needs are restrictively operationalized. There are numerous circumstances where a change in a DSP participant's support needs could subject them to precarious living circumstances involving support level reassessments and deadlines. Section 11.2 "Changes in Level of Support" of the DSP Policies indicate that a participant shall be transferred to another support option when "… *[their] support needs can no longer be safely met within the scope of services and staffing complement of their current program support option, and with the assistance of standard community resources*[iii]*"* (Department of Community Services, 2016, p. 27). This statement extends the DSP's responsibility to meet participant needs only within existing resources and supports and puts a participant at risk of being re-institutionalized at what is likely already a time of profound change in their life. Further, it puts the service providers in a position where they are forced to "pick up the slack" to try to implement solutions within the confines of available funding and resources.

There are subsections of DSP policies associated with section 11.2 "Changes in Level of Support" that could impact a participant prior to a support option transfer. Any major change in a participant's support needs prompts a reassessment of their 'Level of Support,' which requires a full review and update of the participant's Individual

Assessment and Support Plan (IASP), and all necessary medical documentation from relevant medical practitioners. The reassessment is conducted by the Care Coordinator, in collaboration with the participant and relevant support persons. Section 12.0 'Temporary and Extended Absences" details DSP's responsibility for provision of funding should a participant become hospitalized, where DSP will continue to fund the participant for a maximum of 30 days. Should their stay extend beyond 30 days or if the participant's support needs change to a degree where they cannot be accommodated within the home, the participant's residential support option "shall be cancelled" unless otherwise approved by the "Casework Specialist" (Department of Community Services, 2016, p. 28). This provision ultimately removes housing supports from the participant, which is a violation of universally-accepted human rights (UNCRPD, 2006, Article 19; Article 28-1) and risks unnecessary hospitalization due to a lack of available supported housing. A similar scenario took place with complainants in *Disability Rights Coalition v. Province of Nova Scotia*, which led to the findings of systemic discrimination for failure to provide persons with disabilities the resources needed to live in the community, ultimately leading to the Human Rights Review and Remedy (Bartnik & Stainton, 2023).

The sections of DSP policy discussed above demonstrate a structural rigidity with respect to the provision of services and require a participant to adapt to the system at a time of significant personal change. Many studies raise bureaucratic barriers at the state level with respect to inflexibility of adapting to support level changes, including Corrado (2013)'s finding that "physical, financial, and bureaucratic barriers" play the most significant role in restricting service providers from making adaptations necessary to

support age-related support changes of PWID. After interviewing management and support staff of service providers in the United States, Spassiani et al. (2019) found that limited funding and a lack of dedicated state policy enforcing specific allocations of funds create barriers to providing health-promoting initiatives for ageing PWID. Bigby (2008) discussed similar funding structures and outcomes for PWID with support need changes in Australian disability policy, where individuals are ultimately displaced from their home, should their support needs exceed the available services.

Support decisions at the provincial level can profoundly impact front-line responses to PWID with increasing support needs. The restrictive responses to changes in support needs as outlined in the DSP policies put individual responsibility onto service providers to work within existing provisions to determine responses to support need changes. This system creates a risk of varied responses to support need changes, impacted by individual service provider values and attitudes toward residents remaining in their homes (i.e., 'age in place) through illness or ageing-related health changes. It also puts service providers who favour residents remaining in their home in a difficult position of either drawing on existing resources, or advocating to the DSP (their funders) for exceptions to the limiting funding and support provisions outlined in their policies; neither of which are sustainable long-term solutions and ultimately put PWID at ongoing risk of being institutionalized (Bigby, 2008; Webber, Bowers, & Mckenzie-Green, 2010).

Recommendations within the HR Remedy set out to resolve the issue of rigid and inflexible supports. Relevant proposed recommendations include an individualized funding system attached to DSP participants rather than the administration, the

breakdown of the Care Coordinator role into three separate roles, and the decentralization of disability supports into multidisciplinary regional ‘hubs’ (Bartnik & Stainton, 2023, p. 40, 54, 58). These recommendations, if implemented properly, will create a significant positive impact on the way PWID living in SOHs have control over their living and support options and are able to access local resources. However, there is a marked absence of attention toward responses to increases in support needs due to ageing or illness in the present DSP policies and in the HR Remedy – perpetuating the ongoing threat of reactive and insufficient responses to supporting PWID with increasing support needs in SOHs.

Reactivity of supports

Medicalized approaches to disability materialize in the application of rehabilitative responses in order to fix a ‘problem’. This approach is also reactive (rather than proactive), as it is typically only employed once there is a problem to fix. The DSP policies outlining provision of supports to PWID living in support options assume a person is static and unchanging and heavily relies on reactive responses to support participants once issues arise. There is also a marked absence of any provisions supporting proactive measures to promote a healthy quality of life for program participants throughout their life stages.

Disability Support Program policies center on the administration as it relates to individual participants, and any forms of support are provided reactively rather than applying proactive measures to preventing further needs from arising. For example, various sections of the policies addressing health or support level-related matters treat

them as individual circumstances that are to be addressed after the onset of an event. If a participant develops an illness that requires a long-term change in support needs, present DSP policy stipulates that the Care Coordinator will conduct an assessment of the participant to determine if their support level has changed and what resources are available to support the individual. If there are no resources accessible through the current supports provided in the home or through Standard Community Resources or the Basic and Special Needs policy (temporarily), the participant would be required to move into another home with greater supports. There is nothing in the policies that supports the promotion of healthy ageing or cultivating support options that can reflexively address support-related changes as they arise. Processes such as this only take place after a need is identified. The absence of this type of proactive support throughout DSP policies puts the responsibility onto the service providers, leading to variability and inconsistency in what is offered to participants living in a support option, and thus varied experiences in the lives of individuals themselves.

Literature discussing the promotion of health and well-being for ageing PWID discusses policy-based challenges associated with these initiatives. Through the use of photovoice with American-based group home residents, staff, and management, Spassiani et al. (2019) identified a lack of formal policy on healthy ageing as a key barrier to maintaining community-based health participation initiatives. At the federal level, there were no identified policies mandating agencies to allocate funds to maintain these initiatives, which resulted in inconsistent values around healthy ageing across agencies and in-house issues with ad hoc approaches to healthy ageing, lack of staffing to support

such initiatives, and staff inquiries about additional compensation to support the extra work. These findings align with the present argument that a lack of proactive policy provision to healthy ageing leaves decisions in the hands of individual providers, resulting in inconsistencies and varied participant treatment.

The absence of state or provincial age-related disability policy is also noted by Bigby (2008) and Leahy (2021). They noted that social services treat disability and ageing separately, resulting in inconsistent and ad hoc options for PWID who are ageing that may not honour the unique circumstances of a person who both has an intellectual disability and age-related needs. PWID living in support options may face a complex "either-or" situation of remaining in/transferring into a support option that can meet their disability-related needs, or moving into a long-term care facility that can meet their age-related needs. Sections of the DSP policies related to age-related changes in support needs are consistent with the findings of Bigby (2008) and Leahy (2021). There are no formal policy provisions for agencies to allocate funds to support proactive healthy ageing. Aligning with the binary approach to understanding disability and ageing, the DSP Level of Support Policy dictates that PWID experiencing age-related conditions can apply for, and receive, supports through the Dept. of Seniors and Long-Term Care (SLTC) in their current support option only until a support option run by SLTC becomes available, at such time the participant will move to that option (Department of Community Services, 2016, p. 52). The dichotomous treatment of 'disability' and 'ageing' in DSP policies and subsequent isolation of PWID based either on their

disability, age, or illness demonstrates the importance of intersectional considerations that should be reflected in policy provisions to meaningfully ensure the rights of PWD.

Restrictive medicalized understanding of disability and the rigidity and reactivity of supports outlined in DSP policies all contribute to forms of intersectional oppression of PWID in Nova Scotia. Such approaches to disability policy reduce individuals to a narrow and unchanging version of their disability and do not account for how the beliefs and experiences of other shared identities beyond disability may impact their needs and experiences in the DSP. Oppression is further perpetuated through DSP provisions that reinforce the disempowerment of PWID in SOHs.

Dis/Empowerment

An excerpt of the DSP's policy statement reads, "*The DSP promotes a participant's independence, self-reliance, security, and social inclusion*." Despite these stated intentions, many aspects of the DSP policies implicitly serve the opposite purpose; specifically, to maintain financial and social power of PWID in NS, including those living in support options. DSP participants are at risk of experiencing two forms of disempowerment: structural disempowerment (e.g., policy that systematically removes power and control from PWID, either implicitly or explicitly); coupled with existing practical factors, there is a risk of participants experiencing a secondary form of disempowerment (e.g., structurally disempowering policies that, in practice, are impacted by practical events such as staffing shortages, budgetary changes, access and proximity to support services, etc., which unintentionally further disempower PWID). In the DSP, structural disempowerment is masked by a façade of extending choice and control to

PWID. DSP's maintenance of control over PWID living in support options result in sustained poverty, limited choice, and forced adaptation to the system – a reality of disempowerment in their daily living.

Care Coordinators

An example of structural disempowerment observed in DSP policies includes the heavy reliance on Care Coordinators. This role is situated at the administrative level with the DSP and maintains contact with program participants. In the DSP Program Policies Glossary, this role is defined as "*responsible for financial and functional assessments, case planning and case management*" (Department of Community Services, 2016, p. 97). The Care Coordinator is the primary and ongoing contact for the administration of DSP supports to participants throughout all stages of the program, from application, to placement, and for re-evaluations and key decision-making as support needs evolve over time.

Care Coordinators hold a profound degree of responsibility and influence with respect to changing support needs of program participants. The Care Coordinator is the point person for any changes or requests made by a participant or their home. They administer all program changes required by an increase in support needs, with occasional significant decisions under the direction the Casework Supervisor. Their influence over such widespread aspects of their clients' lives impacts how much – or little – they empower PWID to have control over their life. An example of structurally disempowering policy involving the Care Coordinator role pertains to service requests, specifically when an applicant or existing participant is awaiting either a new or different

support option placement. Some of these requests include participants whose needs can no longer be supported in their current option and must move to a different support option. As the DSP policy states, the Care Coordinator is responsible for compiling all necessary information and determines where a participant can be placed; however, while awaiting a placement, participants are not allowed to know where they sit on the "list" and remain in the dark until a placement is made (Department of Community Services, 2016, p. 20). Remarkably, there is no further explanation as to why DSP cannot disclose information about an individual's position on the service request list. Not only is it a profound form of disempowerment for individuals to be completely removed from the process of choosing their place to live (and knowing how long it will take to get there), but it is also a violation of the rights of PWD (UNCRPD, 2006). DSP's prescribed reliance and power of the Care Coordinator role is an example of the structural disempowerment of PWID living in SOHs with changing needs may experience.

The disproportionate power held by the Care Coordinator creates a risk of secondary disempowerment on PWID with increasing support needs based on Care Coordinator philosophies towards "ageing/remaining in place." Care Coordinators possess a high degree of influence over decisions made about participants since they liaise between participants and the DSP administration, performing duties such as conducting assessments, making placement decisions, and granting funding requests. For PWID living in Coa SOH experiencing increasing support needs, their Care Coordinator's beliefs about how DSP can support the individual to remain in their home will directly influence the participant's future living circumstances, and how much the

participant or their advocates can weigh in on such matters. This assertion aligns with the more detailed discussion from Webber, Bowers, & Mckenzie-Green (2010), who discussed group home supervisors' outlooks and responses to age-related health changes in their participants. Although all supervisors expressed that they were acting in the best interest of the participant, their philosophies typically fell into one of two categories: "active engagement" (i.e., a move to residential care when they can no longer be supported in the home) and "ageing in place" (i.e., augmented supports should be provided to allow them to remain in home as long as possible). The same could be said for Care Coordinators; specifically, that their philosophy regarding 'active engagement' or 'ageing in place' in combination with the degree of power and influence they hold directly impacts how empowered (or disempowered) participants with increasing support needs will be to have their wishes met as they adapt to their health-related changes.

Chronic system overload and high demand on Care Coordinators also poses a risk for PWID to face forms of secondary disempowerment when experiencing changes in support needs. As of 2023, Care Coordinators had a participant ratio of 1:83. As the HR Remedy acknowledges, this ratio is far too high for a Care Coordinator to fulfill the vast and demanding responsibilities placed upon them (Bartnik & Stainton, 2023, p.40). The DSP system has experienced chronic system overload, especially with respect to waitlisting times with a total of 1834 requests as of 2022; 1245 of those requests are for people already being supported by DSP and are waiting for their preferred option (Bartnik & Stainton, 2023). There is a risk that needs of PWID with increasing support needs may go unmet until their needs reach a critical level, which also may increase the

potential outcome of a participant needing to move to a different home. Any time a matter is delayed until it becomes a more critical need effectively removes the impacted individual from having input and control over their outcome.

The HR Remedy recognized the problematic structure of the Care Coordinator role and put forth significant directives to improve this system and shift the power dynamic to participants. The Remedy directed DSP to remove the Care Coordinator role from being situated as a government role and instead position it within the community. The role will be broken into two separate roles that serve to support DSP participants: Local Area Coordinators, who support individualized planning, coordination, and self-management, and are removed from (but work in conjunction with) Eligibility and Assessment Coordinators. Moving forward, Care Coordinators will have a participant ratio of 1:50, and there are no specified ratios or scope of work for Eligibility and Assessment Coordinators in the HR Remedy (Bartnik & Stainton, 2023). Coupled with the independent funding system the HR Remedy puts forth, participants should have significantly more control over their placement and lifestyle decisions. Grindrod & Rumbold (2017), Spassiani et al. (2019), and Webber, Bowers, & Mckenzie-Green (2010) all point to the impact that staff in leadership roles can have on individual participant experiences. Their discussions primarily focus on leadership roles from the organizational side; however, they mirror external leadership roles (such as the Care Coordinator) with respect to the influence that their philosophies have on participant outcomes. Although the HR Remedy advances progress in the right direction by dismantling the Care Coordinator from the all-encompassing role it was before, the new

structure still relies on two people (Care Coordinator and Eligibility and Assessment Coordinator) to make significant decisions, which are influenced by individual philosophies. Alternatively, more attention should be directed toward collaborative work amongst a team of individuals to support the best interest of a participant, rather than the decisions still falling in the hands of the powerful few.

Controlled Funding

Another aspect of structural disempowerment that participants with changing support needs may experience is through the limited and controlled funding for supports and 'Special Needs' requests. The DSP Program Policy stipulates that any participant behavioural or medical support needs that cannot be met within the home are to be sought through Standard Community Resources (SCRs). Should supports not be met through SCRs, the Care Coordinator may consider whether they can be met with funding through the Basic and Special Needs Policy. The Basic and Special Needs Policy outlines the provisions for basic and special needs granted through DSP and contains provisions that restrict the degree of power PWID have to make decisions about their financial supports.

There are many examples within Basic and Special Needs Policy of DSP's priority to save money over promoting participant choice and independence. Allocations for general items such as clothing allowance ($30 monthly) or day activities (up to $40 monthly) are strikingly low and demonstrate how DSP maintains the impoverishment of their participants. A DSP participant that may need to access Special Needs funding due to increasing support needs may experience even less choice and control over their supports. Appendix A of the DSP Policies, which outlines Basic and Special Needs

Rates, is littered with specifications that funding will only be granted for the "most economical option." Specifically, participants and their support options are only funded for the most economical option of any special needs "that meet their individual health and support needs" (Department of Community Services, 2016, p.70), some of which may greatly impact an individual's experience and quality of life during a time of transition and change with evolving support needs. Examples of items that are only funded as the most economical option include special clothing, attending medical appointments outside the community (for costs associated with travel, lodging, and food), hearing aids, medical equipment, medical supplies, nursing care, and eye care. To remove choice from supports that will be such a crucial element to an individual's well-being and quality of life effectively disempowers them from having control and autonomy to adapt to increasing support needs.

The DSP's responses to accommodate changes in participant support needs through 'Special Needs' funding are done in a manner which supports the financial conservation of the program over the participant's best interest. For example, should a participant experience an increase in support needs that cannot be accommodated within the scope of services provided in their support option, the participant can be eligible for funding for Special Needs supports (e.g., extra staffing, nursing care) *only until an appropriate support option becomes available* or such care can be provided through Standard Community Resources (SCRs). In other cases where a participant can remain in their support option with the use of medical equipment, they are required to submit medical documentation supporting the need and must opt for the most economical

purchase. Similarly, if a participant needs to access medical rehabilitation services, such services will only be funded until available through Standard Community Resources; however, they are only to be provided short term (6 months up to 12 months) with ongoing documentation. Any exceptions made are in favour of cost-conservation to DSP. Finally, structural modifications to the home of a participant with a change in support needs *are not covered* under the Basic and Special Needs Policy. The nature of these provisions demonstrates how deeply rooted historical institutional frameworks (i.e., the believed 'low worth' of PWID and prioritization of functioning of the facility over resident needs) remain within the present DSP system (Burghardt, 2018).

Restrictive and minimal funding amounts are consistent with findings of Smith-Carrier et. al (2017) in their critical analysis of the Ontario Disability Support Program (ODSP) and Ontario Works (OW). They highlighted the meagre funding amounts allocated to participants and restrictive eligibility criteria associated with certain special funding streams, including a $250 per month allocation for a Special Diet Allowance, which was only available to participants who had one or more of the 38 listed conditions. This amount contrasts with NS's maximum allowable amount of up to $150 per month if eligible from a list of 19 conditions. Consistent with Smith-Carrier et. al's assertion that the ODSP funding structure reinforces the "antiquated hierarchy of the 'deserving' and 'undeserving' poor" (Smith-Carrier et. al, 2017, p. 1578), DSP's reliance on the "most economical option" for purchasing supports and the strikingly low rates for special needs funding demonstrate the implicit maintenance of tiered power structures in NS, thus further disempowering PWID with increasing support needs from pursuing meaningful

and personalized supports during times of significant change. Further, it demonstrates the low perceived value and economic burden of PWID in the eyes of decision makers, which aligns with the same societal beliefs that contributed to the development of historical institutions (Burghardt, 2017).

Years of proposed reform to Nova Scotia's DSP resulted in the inclusion and stated promotion of empowerment through person- and client-centered language in their policies and programs. A deeper look into their policies reveal that the structures imposed within the DSP create a different reality for PWID accessing DSP supports. Specifically, the heavy reliance on Care Coordinators and restrictive funding structures are mechanisms to reinforce the disempowerment, and ultimately, oppression of PWID in NS. The unilateral constructs through which PWID are understood in DSP policies are further complicated by colonial ideologies underlying policy provisions.

Colonial Systems

Despite existing as the primary program to provide social services and funding for community living to PWID in Nova Scotia, DSP policies are markedly absent of any considerations for the diversity of participants accessing the program and how their experience in homes (including SOHs) may differ based on their identities. Although the HR Remedy makes efforts to improve intersectional considerations made within the DSP program, it remains at a more superficial level than what is needed to truly promote an inclusive and empowering experience for all PWID in the province.

As discussed in '*Reactivity of Supports'*, the DSP policies employ a reactive approach to supporting PWID. Consistent with that theme, these policies demonstrate a

lack of proactive consideration for how PWID from various backgrounds and identities may differentially experience the program and neglect measures to ensure an inclusive experience throughout program participation. Any specific identity groups that are mentioned in DSP policies (e.g., PWID who live with chronic illness, who are ageing, or who require end of life care) are done so in response to a problem rather than to promote a proactively inclusive environment for those individuals. Nova Scotia has a rich and diverse population including Black Nova Scotian, African Nova Scotian, Acadian, Francophonie, and Mi'kmaq communities, as well as a growth in newcomers in recent years. All communities possess varying cultural beliefs and practices with respect to disability, ageing, and illness, which are also impacted by varied experiences of systemic and overt racism (Etowa et al., 2007; Hollinsworth, 2013; Province of Nova Scotia, 2010). The DSP neglects to factor a range of cultural beliefs, practices, and historical oppression into their policies and, in turn, continues to elevate the inclusion of white PWID in NS over non-white communities. These structural limitations demonstrate that the NS government's assumption that intellectual disability is the sole defining feature of individuals accessing the DSP, and that all PWID navigate and experience the world in the same way. Although these assumptions have been challenged in various sectors with other identity groups (e.g., Indigenous communities; Province of Nova Scotia, 2010), it remains largely unchallenged with disability groups and as they intersect with other identity groups.

Several recent provincial reports detail intersectional barriers experienced by residents accessing services. The HR Remedy detailed feedback from Indigenous,

African Nova Scotian and Francophone communities, including the lack of DSP supports available on-reserve, the lack of cultural representation in DSP services, and the jurisdictional barriers associated with accessing them (Bartnik & Stainton, 2023). It is worth noting that the scope of the HR Remedy did not include Indigenous persons with disabilities living on reserve, which neglects a crucial voice that should inform the shape of DSP's future. In 2010, the province released *Aboriginal Long-Term Care in NS* (Province of Nova Scotia, 2010). Although not directly relating to PWD, given the close ties between LTC and DSP support options from an institutional and demographic perspective, information from this report is also applicable to the present topic. This report details the barriers to accessing LTC for Indigenous communities in NS as of 2010 and what is needed to improve access. Feedback primarily detailed distrust with the present LTC system and resistance to accessing those services. Reasons cited included the traumatic historical experiences of institutionalization from residential schooling and a lack of cultural representation and practices within facilities, including language barriers with staff and only having non-Indigenous residents. It also discussed the need for having on-reserve LTC facilities, or at a minimum, dedicated wings for Indigenous people to reside in. The NS Health Equity Framework highlighted feedback from African Nova Scotia, Francophone, and newcomer, and Mi'kmaq communities, including how current health services and service providers show no cultural competency or humility of the populations they serve. Many also detailed language barriers while accessing health services (NS Dept of Health and Wellness, 2023). Although the HR Remedy's inclusion of voices from other identity groups is a positive starting point, the

overall absence of intersectional representation in DSP policies and reports reinforce the assumption that individuals accessing the DSP possess the central identifying feature of having a disability, and that persons with disabilities are uniform in identity.

There are many systemic factors impacting the barriers to accessing provincial services, such as health services or supports through DSP, for non-white communities in NS. Centuries of ongoing systemic and overt acts of racism has led to generational poverty, trauma, and distrust in the system, which create attitudinal and socioeconomic barriers to accessing services. This is especially in areas such as NS, where most services are located in the city of Halifax (Etowa et al., 2007; Hollinsworth, 2013). Race and ability are key factors in health disparities (Dorsey Holliman et al., 2023), and may impact how some communities qualify 'disability'. Some communities may recognize only physical impairments, such as the loss of a limb, as a disability (Dorsey Holliman et al., 2023; Hollinsworth, 2013; Province of Nova Scotia, 2010). Alternatively, some communities push beyond a 'colonized' way of understanding disability; specifically, that the effects of colonization of Indigenous communities 'disabled' their way of knowing, being, and living. Physically, this is evidenced through decades of poor social determinants of health leading to generational illnesses (Stienstra, 2018). There are a multitude of cultural, historical, and socio-political considerations that should be made to support any individual living in a SOH experiencing changes in health needs; however, the landscape of support for a white individual may look vastly different from that of a non-white individual. The DSP, and broader provincial government, has a responsibility to account for those factors in their policies and practices to ensure all DSP participants

have inclusive and equitable access to services, especially during periods of change in health or well-being.

Although some HR Remedy recommendations may improve the landscape of access to supports, the recommendations fell short of what is needed to address feedback gathered by Indigenous, African Nova Scotian, and Francophone communities in NS. The HR Remedy noted the importance of including culturally appropriate and responsive services situated in the proposed regional "Regional Hubs," (Bartnik & Stainton, 2023, p.54) but did not specify any concrete steps that will be taken to ensure diverse communities are represented in these Regional Hubs. Additionally, under Key Direction 6 (Bartnik & Stainton, 2023, p.66), the HR Remedy notes that all initiatives the DSP undertakes are to be aligned with other provincial initiatives, such as Anti-Black racism efforts and the provincial Mental Health Strategy, but once again does not detail concrete steps for how that will be accomplished. Although the HR Remedy loosely addresses how community supports will be culturally appropriate with changes to the DSP, deeper and more meaningful engagement with what DSP support options may look like to best serve participants who face unique and complex intersectional barriers is absent. This absence perpetuates the risk of DSP support options continuing to remain as they are: to elevate and meet the needs of white PWID in NS, while suppressing those from other communities.

The marked absence of intersectional consideration within DSP policies reinforces the assumption that PWID are a uniform group whose central identity is having a disability. Further, the lack of consideration in DSP policies for barriers to

accessing services, such as health care, due to racial differences continues to elevate access to these services for White Nova Scotians, while simultaneously suppressing access for non-White Nova Scotians. Although the HR Remedy took a positive step to gathering feedback from various intersectional communities across NS (e.g., Indigenous disability groups), the recommendations lack the depth needed to require DSP to implement policy reform needed to ensure equitable and person and community-centered access to DSP services across identity groups.

Composite Stories: Connecting Policy to the Person

This section follows up on the lives of Heather and Johnny as they each navigate life with evolving support needs while living in SOHs. A brief section thereafter connects elements of their stories to the themes identified in 'Analysis'.

Heather

One year after Heather was diagnosed with early onset dementia, she had to retire from her job. On her better memory days, she occasionally called out names of her friends from work, who she no longer saw. She spent a lot of time at home so that her support staff could care for her and her housemates, but Heather still enjoyed having her hair and makeup done by support staff.

The increasing number of medical appointments were very upsetting for Heather and her support staff to attend. Because she developed greater difficulty regulating her emotions, it took a long time for Heather to be seen by medical professionals. Sometimes it took so long that they ran out of time; on other occasions, medical professionals turned her away because they didn't have the capacity to assist her that day. Heather's sister,

Jean, was very concerned about her treatment by medical professionals, and the type of treatment she was receiving. Whenever Jean could make the drive, she tried to advocate for Heather at her appointments, but felt her advocacy was viewed as an extra burden by medical professionals. Anytime she visited Heather, Jean also tried to bring some traditional remedies cultivated from the Medicine Trail back home. She instructed Heather's support staff on how to prepare the remedies, but Jean felt resistance from staff and would find the medicines unused during the following visit. The support staff, on the other hand, felt it was one more thing added onto a team that was already spread far too thin. Jean wished she could bring Heather closer to home.

As Heather's dementia progressed, she required an increasing amount of support at home with daily activities like getting dressed and eating meals. She also needed help regulating her emotions and with getting back to bed during the night when she wandered. Heather eventually needed support almost round the clock for her own safety. Accommodating Heather's safety needs put a large strain on the support staff, and Heather's housemates felt the impact of the decrease in care and attention they received. At that point, the supervisor of the SOH worked with Heather's Care Coordinator to identify solutions, where it was decided they would apply for funding to hire in home-nursing support on a temporary basis until she could be transferred to a LTC facility, since she had an age-related illness. It took months to secure this funding, and in that time Heather, her housemates, and support staff all felt the impacts.

Heather's sister strongly advocated against moving her into LTC. Beyond removing Heather from her home, the medical-like structure strongly opposed her

family's values of community and interconnectedness that is lost in a large facility. As Heather's dementia progressed and she found herself living in memories of her earlier life on-reserve, Jean feared for her sister's well-being with being isolated even further from people she knew and loved by transferring to LTC. Heather's support staff also felt strongly against moving her to LTC; although she would receive adequate dementia care, she would not receive the same quality of disability supports as in her present home.

Heather received in-home nursing care for three months before being placed in a LTC facility. Jean and the support staff fought against this decision, but the SOH supervisor did not want to spend further money to delay an inevitable move to a facility. Thankfully, they negotiated a placement closer to Heather's hometown, so Jean and her aunties now visited more regularly.

Presently, Heather's life in LTC is one of confusion and fear. She isn't familiar with anything around her, including the people assisting her throughout the day. Sometimes she reaches for her makeup, but she can't find the person who normally does it at home. Although Heather no longer recognizes people by their name, she feels incomparable happiness and warmth when her sister visits her. Those visits are the single thing that brings her happiness, and thankfully Jean is now able to see her several times per week. Jean wishes she could bring Heather home with her, but for now, this is the best they can do.

Johnny

Since Johnny's symptoms began six weeks ago, it became apparent that his current living situation did not meet his new support needs. Four weeks ago, he had a

bad fall after walking to the bathroom at night: losing his balance, he fell into the tub and hit his head off the faucet, causing a large gash. The single support staff working that night did their best to apply first aid to Johnny but couldn't leave the house to seek any further medical attention due to Johnny's housemates remaining in the home. The following day Johnny was brought to the emergency room by one of the day support staff, where he received treatment to attempt to relieve his symptoms. Unfortunately, Johnny's stroke-like symptoms did not go away. It was deemed no longer safe for Johnny to go back home, as the inaccessibility of his home and lack of available staff to support him was a threat to the safety of himself and others around him. Johnny was forced to remain in the hospital while the home Supervisor worked with his Care Coordinator to determine what to do.

Johnny struggled deeply with being stuck at the hospital. During the day, one of the support staff from home stayed with him. This was manageable as his home had two people staffed during the day; however, there was only one overnight staff. Johnny relied on his support staff or his mom to be able to communicate his needs to medical professionals and got very upset when they weren't around. He also looked to them for comfort and felt scared and isolated without them. While Johnny's Care Coordinator determined what additional funding for support staff could be provided, his mom took on nights at the hospital until she needed a break after a couple of weeks. The hospital refused to provide any extra staffing support, and Johnny was instead supervised by a hospital-appointed security guard outside his room at night. This arrangement only lasted for one night; Johnny attempted to get out of bed in the middle of the night (something

that wouldn't have happened with a known support person in the room) and had a fall. Finding support for Johnny suddenly became a very urgent concern.

As time passed, Johnny's Care Coordinator and house supervisor were very concerned about Johnny's DSP funding for his SOH placement. They understood that after one month in the hospital, DSP will no longer fund the placement. They worked tirelessly to come up with a solution in that time. They considered what it would take to make Johnny's home accessible for him, but DSP policies did not fund modifications to accommodate participant accessibility needs. There was no way the organization could afford to front the cost of home modifications, which amounted to over $20,000. Simultaneously, they were working to secure extra funding for staff to be with Johnny round the clock. DSP was able to grant this request quickly, but due to the high number of service requests, the question surrounding Johnny's funding eligibility took over four months to be processed. During that time, Johnny remained in the hospital unnecessarily, but at least he was able to always have a support person with him.

Over the course of the four months, Johnny became a shadow of his former self. All he wanted was to go back home, see his housemates, and share a Tim Hortons coffee with Sherry. At home, he was familiar and comfortable with his support workers and house mates. Everyone here at the hospital were strangers. In the beginning, despite his frustration with all the unfamiliar people at the hospital, he mostly maintained his jokey attitude and played activities like bingo with his support staff. But now, Johnny remained silent most of the day. He sunk deeper into sadness with every day that passed. He was frequently offered his favourite things, such as his bingo daubers or coffee to bring him

back to his happy state – but those things stopped working long ago. Not even his mom could coax him into happiness now. His mom saw the impact that this experience had on Johnny; week by week, she watched his personality fade.

After many long weeks, a decision was finally made; Johnny would move into a nearby group home that was better equipped to meet his support needs. All people involved were saddened by this news; since Johnny relied so much on trusted long-standing relationships for his well-being, he would be gravely impacted by such a drastic move. Unfortunately, in the weeks and months following his move, Johnny never returned to his old self. Everything he once knew was gone, and the only thing that remained the same were the items in his bedroom, visits from his family, and occasionally his old support staff. Nothing compared to being in his old home, with his two roommates he cared for so deeply, and the moments shared with his support workers sitting around the table drinking a coffee, playing bingo, or sharing jokes.

Connecting Policy to Person

Though Heather and Johnny's stories are fictional, they illuminate the life-altering implications that aspects of DSP policies may have on PWID with evolving support needs living in SOHs. There are several themes shared across both characters, and others unique to each of them, which are highlighted in this section.

Both characters were impacted by aspects of the medicalization of DSP supports. All supports were delivered reactively: no health-promoting programs were present prior to the characters' life changes, and all additional supports were initiated after the onset of personal events with no proactive measures to set the characters up for better success in

the future. This problematic approach is especially tangible in Heather's story; with a progressive illness such as dementia, numerous supports could have been arranged to promote her best chance for success and well-being as her illness progressed. Both characters experienced significant wait times to receive additional supports, leading to stress and lack of staffing capacity (Heather) and risk to physical safety, emotional harm, and unnecessary institutionalization (Johnny). The reactive approach that both characters were met with demonstrates the impact of the assumption that persons with disabilities exist as static and unchanging.

The impact of the Service Request List prioritization structure is also observed between the stories: both characters put forth the request for additional staff funding, but Johnny's was granted much faster because it reached a state of crisis (i.e., there was a threat to his safety observed after his fall during the night of supervision by a security guard), whereas Heather and her support staff 'managed' at home while awaiting funding. Further, Johnny's service request to determine his funding eligibility and find a support option took four months while he remained unnecessarily institutionalized. The toll that the hospital stay took on Johnny was substantial given his heavy reliance on familiar surroundings and support persons for his well-being. These events also demonstrate the lack of person-centered consideration in DSP policies (i.e., the decision to allow a security guard to 'supervise' Johnny overnight disregarded his needs to be able to communicate through his support persons).

The impacts of rigid funding structures in DSP policies can be observed in both stories. Johnny and his support network experienced additional stress due to the

impending threat of Johnny losing DSP funding after a hospital stay past 30 days; simultaneously, Johnny could no longer return to his home due to DSP not funding structural modifications to homes to support accessibility needs. Heather, who was classified as having an age-related illness, was transferred to the Department of Seniors and Long-term Care (SLTC) and moved into a LTC home. This decision disregards the lack of disability-informed supports available to her or any consideration for her personal wishes. It is evident that securing funding for in-home care was *possible* (i.e., Heather received in-home nursing support), but only until the more cost-effective option was available (i.e., a LTC facility).

Heather and Johnny's stories also demonstrated the differential impact that Care Coordinators can have on DSP participants' outcomes. Heather's Care Coordinator primarily possessed an "active engagement" approach (Webber, Bowers, & Mckenzie-Green, 2010); once a bed was secured in a LTC facility, Heather was moved out of her home. Alternatively, it was evident that Johnny's Care Coordinator advocated for his personal wishes more (i.e., securing support staffing in hospital, finding him a group home support rather than LTC), but was still working within the bureaucratic constraints of the system. Each story reveals the power Care Coordinators hold; neither Heather or Johnny were the driving force behind their future outcomes; rather, it was their Care Coordinators' ultimate influence and decision.

There are numerous intersectional factors that influenced Heather and Johnny's experiences. It was evident that Johnny received additional financial and material support throughout his life, which contributed to the comfort he felt at home. This reality

contrasted with those of his roommates, who could afford to shop at local used clothing stores only. This point briefly alludes to DSP's restrictive funding structures for their participants (e.g., $30 per month for clothing). More broadly, it demonstrates the reinforced "hierarchy of the deserving and undeserving poor" (Smith-Carrier et al., 2017) in DSP policies, and further, the privilege of having a dedicated and (assumedly) socioeconomically stable family that sets Johnny ahead.

Proximity to family and care were impacting factors in both stories. Johnny had the privilege of living near his family throughout his life and was able to see his family regularly. Heather, on the other hand, was uprooted from her hometown to live in Halifax, where she would have greater access to health services but received fewer visits from her family. She also had complex trauma associated with health services. The story does not specify what type of services she was receiving; however, it raises the question as to whether it was accessed through Standard Community Resources (SCRs), and whether SCRs were prioritized over arranging more personalized supports that could be accessed from a home closer to her family.

As alluded to earlier, age impacted Heather and Johnny differently based on DSP policy provisions. Although Johnny was technically older than Heather, Heather had an age-related illness and was therefore under the jurisdiction of SLTC; she was subsequently transferred to a LTC facility, whereas Johnny was able to remain in a DSP support option (albeit not his original home). These cases demonstrate the binary nature that disability and age are regarded within DSP policies; specifically, that you can either be ageing, or disabled – but not both (Bigby, 2008).

Heather and Johnny had differing experiences resulting from their racial identities. Heather is Mi'kmaw and was raised on a reserve in rural Nova Scotia. It is evident in her story that she does not share similar cultural values with anyone in her support option, leaving her feeling isolated in her identity. This further materializes through Jean's character; she serves as Heather's primary advocate and her attempts at supporting Heather through traditional medicines are dismissed. Jean's discomfort is palpable regarding Heather's dependence on the Western medical system and with being re-institutionalized in LTC. Though it is not stated exactly what led to Jean's discomfort, Heather's trauma around accessing health care services, or why she is met with difficulty from healthcare providers, research has documented the ongoing legacy of colonial violence in healthcare settings, which continues to negatively impact Indigenous people's interactions with institutional settings, such as hospitals or LTC facilities (Latimer et al., 2020). Given Heather and Jean's identities, one can infer that those same forms of oppression have impacted their experiences and attitudes around accessing forms of care.

Although Johnny also shared a difficult experience at the hospital (in his case, it was due to a lack of disability-informed care), he experienced no barriers resulting from his racial identity. The story does not specifically identify him as a white individual, but it is free from details of conflicting cultural values within his home or while accessing medical care, suggesting that his cultural values aligned with other members of his home and with the colonial medical system. The contrast in barriers resulting from racial identity between these two stories demonstrates the potentially harmful impact of the lack of consideration in DSP policies for the varied identities (and, thus, cultural norms,

generational traumas, various worldviews, etc.) shared by PWID living in a support option. It also demonstrates the implicit elevation of white PWID and simultaneous exclusion of other non-white PWID accessing DSP supports.

Discussion

The present study examined how Nova Scotia Disability Support Program (DSP) policies impact PWID experiencing increasing support needs while living in SOHs. A range of DSP policies were analyzed with supporting documents including other NS government reports, strategies, and frameworks. The analysis revealed several themes within DSP policies which were grouped by larger categories including 'Medicalization', 'Dis/Empowerment', and 'Colonial Structures'. These themes are situated in the present discussion section within broader influences of institutional ideology, assumptions about PWID, differing attitudes about the notion of 'ageing in place', and attitudes about what, and how, rights are afforded to PWID.

Analysis of structures within DSP policies revealed static assumptions about PWID; specifically, that there is no diversity within the disability community (i.e., all PWID are the same). There are several reasons why this assumption may persist in public policy. Although the disability rights movement was a significant step in improving understandings about persons with disabilities, the discourse that dominated this movement primarily arose from White PWD; particularly, men (Bailey, 2019). Therefore, it is possible that the notion of 'community living' and the public structure that arose from it was primarily born from the gaze of White (male) persons. Recent preliminary work took place to improve understandings of the diversity of PWD in NS

(Bartnik & Stainton, 2023); however, such initiatives will need to be ongoing and dig deeper than what presently exists to achieve a more accurate and emancipatory understanding of the diversity of PWID in NS, and how varied cultural beliefs may impact individuals' experience of the DSP program.

Meaningfully acknowledging and honouring the diversity of PWD accessing DSP supports would also require DSP policy makers to examine the intersectional factors that share parallel and intertwined histories with the disability landscape, such as the deeply rooted intergenerational traumas associated with residential schooling and colonial mistreatment within the healthcare system; both which are considered 'institutional' forms of care. Present day stereotypic assumptions, language barriers, and lack of cultural knowledge or sensitivity from healthcare providers coupled with worldviews impacted by intergenerational trauma carried from residential schools contributes to the ongoing harms perpetuated against Indigenous people accessing care, contributing to the mistrust toward forms of colonial care facilities (Latimer et al., 2020). This circumstance was observed in Heather's story in the present study, which demonstrates a salient example as to why DSP, which provides various forms of care-related supports, must consider the multifaceted and diverse histories and beliefs PWD carry with them when accessing DSP supports.

The analysis also revealed the assumption within DSP policies that intellectual disability is the sole defining feature of PWID, and that PWID remain the same across their lifespan. Historically, these assumptions could be explained by the ideologies underlying the institutionalization of PWID. The economy-driven market of the

industrialization period prompted the othering of PWID, who were stripped from any identifying features other than disability and categorized as unproductive citizens for their assumed inability to work and contribute to society (Burghardt, 2017). Consistent with the notion that institutional ideologies extend into the community living framework today, this approach to identifying and understanding PWID is evidence of the rootedness and impact of the institutional approach to identifying and characterizing PWID. Practically, this understanding of PWID could also be contextualized by the static and siloed nature of government services, which is a known characteristic of the NS government (Bartnik & Stainton, 2023). Services require individuals to identify (and prove) their membership within a specific group to access services, such as disability supports (person with a disability), long-term care (ageing individual), or employment assistance (un/underemployed person). The unilateral and siloed nature of social supports therefore centers the disclosed identity within accessing a service; in the case of DSP, participants are watered down to their 'disability; identity only.

The siloed approach to social service delivery may also partially account for another theme identified through the present analysis; specifically, that there are differing attitudes and assumptions contributing to the notion of 'ageing in place' for PWID with evolving support needs (i.e., through illness or ageing) than for people without disabilities (Bigby, 2008; Webber et al., 2010). Specifically, one may only possess a disability OR be ageing, but not both. In the NS government, services that are both meaningfully disability-informed and provide age-related care do not exist, which is further evidenced by the DSP policy provision that DSP participants who develop an age-

related illness would be transferred into LTC. Work has been done to identify solutions to some barriers to accessing services for DSP participants, such as practitioner or outreach services (Bartnik & Stainton, 2023); however, more substantial research and initiatives will need to take place to determine empowering and proactive solutions to allow PWID with evolving support needs to make informed decisions about their future with in their home.

Deeper historical ties with institutional ideology and the maintenance of socioeconomically 'deserving/undeserving' individuals may also influence differing assumptions about who is afforded the right to 'age in place.' As stated above, PWID were historically removed from general society and placed in institutions because they were viewed as economic drains on society (Burghardt, 2017), evidencing clear attitudinal differences between who has the right to autonomy over their lives. Parallel behaviours are present today with the funding and administrative structure of DSP, which serve to maintain that PWID remain in poverty and are stripped of the right to self-determination over their own future. Following the logic of historical institutions, persons without disabilities have the ability to 'contribute' economically to society throughout their lives and thus have the right to self-determination over their futures as they age, whereas PWID do not contribute; thus, they are not afforded rights must accept what is given to them (Smith-Carrier et al., 2017).

The discussion around rights afforded to PWID accessing DSP supports highlights an additional tension surrounding beliefs underlying DSP policies. The Province of Nova Scotia outwardly professes to support the rights of persons with

disabilities, but their actions demonstrate the opposite. Structurally, this tension is observed through DSP policies using language that gives the illusion that they honour the rights and autonomy of PWD, while the practical outcomes of the policy provisions demonstrate the opposite. On a much larger scale, it materializes through the outwardly professed support by the NS government of the rights and dignity of PWD, while simultaneously fighting the legal ruling that housing is a human right for PWD. This contradiction demonstrates the further work needed in NS; the province will fail to achieve its goal of deinstitutionalization if it continues to claim that the right to housing does not apply to PWD. In addition to the deep-rooted impact that historical institutional ideologies have on present day community living frameworks, this tension also demonstrates the government's true priorities and beliefs about their role in ensuring the rights of PWID. Specifically, government initiatives will only go so far as to *meet* their legal obligations for disability supports, as evidenced by the carefully worded policy statements containing buzz words such as "independence," "self-reliance," and "social inclusion" (Department of Community Services, 2016, p. 6, 28) to align with legislative requirements such as the UNCRPD (UNCRPD, 2006), rather than *actualize* or *enhance* the rights of PWID in NS. This assertion is further demonstrated through the ongoing failed attempts at improving DSP initiatives (through frameworks containing the same buzz words; NS Joint Community-Government Advisory Committee, 2013), with demonstrative change only beginning after a human rights ruling led to the legally-binding HR Remedy recommendations. Possible explanations for such an approach may include the previously discussed deep-rooted influence of institutional ideology into

today's frameworks, the prioritization of financial conservation of government spending, and prioritizing other government programs (and spending on 'more desirable' people) that contribute to an enhanced economy.

Study Limitations and Future Directions

The present study had several limitations. Firstly, the nature of the study (i.e., policy analysis) subjects the analyses to my individual biases. Though the inclusion of fictional composite stories was useful to contextualize the identified policy issues, they are limited to my scope of knowledge; some of the identities framed within the composite stories pertains to groups whom I do not personally identify with, and the knowledge I apply to the stories does not replace the invaluable contributions of first-person experience. Finally, the subject matter within this study is on an issue that represents a very specific point in time; the DSP landscape is rapidly changing due to the urgent nature of the HR Remedy recommendations, and therefore information about DSP policies presented in the present study may quickly become outdated.

Several bodies of potential future research arose from the present study. Future research on the impact of DSP policy on lived experiences of PWID should consider the importance and value of consulting individuals with lived experience and letting their voices frame the observations gathered from analyses. There were several themes related to the complex intersectional barriers that PWID may experience while accessing DSP supports, including individuals of varying racial and cultural identities. To honour the true and complex nature of the intersectional diversity of PWID, future research should

apply a deeper investigation into how varied intersectional identities, including their parallel and interconnected experiences, impact how PWID access DSP supports.

To demonstrate the potential lived impact that DSP policies have on PWID, the present study contextualized themes revealed in the analysis within the fictional stories of Heather and Johnny. This approach demonstrated the disconnection sometimes present between policy and lived impact. It is therefore imperative that future DSP policies are meaningfully informed by the diverse groups of people accessing those services. Change makers should also center the question "who might this impact, and how?" at all stages of policy reform (Burghardt, 2023).

Conclusion

The Province of Nova Scotia (NS) is at a pivotal point in history with significant changes to the DSP underway, prompted by the legal human rights ruling and subsequent HR Remedy. Initiatives include the elimination of institutions and group homes, leaving SOHs as the remaining congregate-style support option. The structures set in place by DSP policies impact SOH responses to increasing support needs of their participants, ultimately impacting the individual experiences of PWID.

Present research associated with increasing support needs of PWID only exists within congregate care environments, such as group homes or long-term care (LTC) settings (Bowers et al., 2014; Hussain et al., 2019; Northway et al., 2017; Webber, Bowers, & Bigby, 2010). Guided by CDT and intersectionality theory, a text-based policy analysis was performed to examine how Nova Scotia DSP policies impact PWID experiencing increasing support needs while living in SOHs. Identified themes were

contextualized within the two fictional composite stories to demonstrate the lived impacts that DSP policies may have.

The analysis revealed many themes that may impact PWID with increasing support needs living in SOHs. Themes observed within DSP policies included medicalized understandings of PWID, disempowering policy structures, and colonial systems dominating the policies. These themes unveiled broader assumptions and beliefs underlying the DSP, including static understandings of PWID, that intellectual disability is the defining feature of PWID, varied assumptions around who is afforded the right to 'age in place' (Bigby, 2008), and conflict about the province's beliefs about the rights of PWID.

Primary limitations within the present study include the possibility of bias and gaps in understanding from the researcher influencing the present analysis and the inclusion of fictional stories over lived experience. Future research may include lived experiences of PWID. Future research should also apply a deeper investigation into how varied intersectional identities impact how PWID experience the DSP program. Finally, DSP policy reform should be informed by the lived experiences of DSP participants throughout the process, and center the question "who might this impact, and how?" at all stages of change.

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Appendix A

Glossary of Acronyms

AODA	Accessibility for Ontarians with Disabilities Act
CDT	Critical Disability Theory
CPA	Critical Policy Analysis
DCS	Department of Community Services
DHW	Department of Health and Wellness
DRC	Disability Rights Coalition
DSP	Disability Support Program
HR Remedy	Human Rights Remedy
IBPA	Intersectionality-Based Policy Analysis
LTC	Long-Term Care
NS	Nova Scotia
ODSP	Ontario Disability Support Program
PWD	Persons with disabilities
PWID	Persons labelled with intellectual disabilities
SCRs	Standard Community Resources
SLTC	Seniors and Long-Term Care
SOHs	Small option homes
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Endnotes

[i] The composite stories were created by identifying salient themes in the analysis and applying a combination of themes from the literature and inspiration from various individuals with disabilities I encountered in my life into fictional storylines. The storylines were constructed with consideration for intersectional complexities to demonstrate the differential impact DSP policies have on individuals with disabilities varying in their identity groups.

[ii] The following policies were analysed for the present study:

- Disability Support Program (DSP) Policies
- DSP Financial Eligibility Policy
- DSP Basic and Special Needs Policy
- DSP End of Life Care Policy

The following provincial reports were analysed:

- Human Rights Review and Remedy for the Findings of Systemic Discrimination Against Nova Scotians with Disabilities (Bartnik & Stainton, 2023)
- Choice, Equality, and Good Lives in Inclusive Communities: A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program (NS Joint Community-Government Advisory Committee, 2013)
- NS Equity and Anti-Racism Strategy (Province of Nova Scotia, 2023)
- NS Health Equity Framework (NS Dept of Health and Wellness, 2023)
- Aboriginal Long-Term Care in NS (Province of Nova Scotia, 2010)

The following legislation was reviewed to support analyses in the present study:

- Nova Scotia Accessibility Act (Accessibility Act; 2017)
- Accessible Canada Act (2019)
- United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006)

[iii] Standard community resources (SCRs) are defined by DSP as, "*Resources provided by the Department of Health and Wellness, Continuing Care Program or the Nova Scotia Health Authority such as mental health outreach services or home care nursing services. These resources are typically available to all residents of Nova Scotia* (Department of Community Services, 2016, p. 105)*."*