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Engaging in Difficult Conversations: Supporting the Spiritual Needs of People with Intellectual and/or Developmental Disabilities

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ABSTRACT

This article joins the existing conversation about the place and importance of spirituality for persons with intellectual and/or developmental disabilities (IDD). While the conversation is marginal and predominantly informed by US-based studies, we present findings from a study based in Metro Vancouver, Canada that continues a decade of research by three local community living organizations, which discovered an egregious lack of attention to supporting the inner needs of human life and wellbeing. With an understanding that spirituality is largely omitted from discussions of wellbeing but can be a powerful component of human life, we explored how "spiritual literacy"—described as an ability to engage with religious and nonreligious spiritualities in our study—can further support well-being for adults with IDD. Specifically, we examined staff and management perspectives concerning their role in supporting the spiritual literacy and journeys of persons with IDD. Through a survey across the three organizations; sense-making sessions with frontline staff, managers, CEOs, and board members; and, co-analysis with staff to further analyze the data, we learned that: 1) everyone defines "spirituality" differently which makes an organizational strategy difficult to devise; 2) staff lack training around religion and spirituality and feel ill-equipped to provide literacy or guidance; and, 3) clear guidelines are needed to navigate ethical dilemmas. We discuss each finding in this article and offer practical implications for agencies. While it provides findings from stage one of our project, another article will present findings from conversations with adults with IDD to provide further insight into this discussion.

1. Introduction

The "community living" sector refers to a constellation of organizations, funders, professionals, caregivers, and others, who work with adults with

intellectual and/or developmental disabilities (IDD). Although they share a vision around inclusion, citizenship, and quality of life, the focus is on health and safety and on developing skills that lead to more independence and self-reliance. Service emphasis is on what is happening in the visible world—bodies, behaviors and environments. Less attention is spent on what is happening on the inside, on personal meaning, growth and development.

posAbilities, Kinsight, and Burnaby Association for Community Inclusion (BACI) are nonprofit service providers located in Metro Vancouver, British Columbia (BC), Canada. In 2014, they partnered with InWithForward, a social research and development studio to engage in ethnographic research to better understand social isolation for people with IDD. They discovered an egregious, if unsurprising, lack of novelty in their everyday experiences, personal growth, and sense of purpose. Continued research over the last decade has emphasized the disconnect between sectoral aspirations of "meaningful lives," a goal outlined by Community Living BC (CLBC, n.d.a) and reflected in the vision statements of affiliated agencies, and the lived reality of people with IDD. Human needs for meaning, purpose, beauty, hope, love, reflection, and creativity, are not merely secondary or concurrent needs, they argued, but often primary ones—without them, skills or physical wellbeing can be pointless. Thus, if service providers are serious about their aspirations, they need to address the inner life (Tulloch & Schulman, 2020).

In 2023, as part of an effort to address "soul" needs, Curiko (www.curiko.ca), a platform co-created by the four organizations to connect people and create meaningful experiences, invited persons with IDD to use images from magazines to create a collage of what spirituality meant for them. At the conclusion of the experience, the facilitator was discouraged by the lack of meaningful engagement with the topic and felt she had failed. But the team surmised that this had less to do with the facilitator or the exercise, and more to do with a failure of the sector to properly address spiritual needs (Figure 1).

Figure 1. Daniel's response from the Curiko experience in 2023.

From this experience, posAbilities and its partners approached the Center for Civic Religious Literacy (CCRL), a Canada-based non-religious nonprofit, to collaboratively explore the question: "How do we introduce religious literacy as a means to further support wellbeing for adults with IDD?"

In Canada, as part of polite culture and social stigma around religion, there is a strong tendency in secular social service organizations to suppress conversations related to spirituality. This is especially true when it comes to persons with IDD, for fear of impressing beliefs on them (Pederson & Webster, 2022). But such suppression can be harmful.

Research indicates that spirituality is a pre-determinant of significant benefits related to physical wellbeing (e.g. cardiovascular and coronary health, recovery and coping with addictions, chronic illness and pain, longevity, etc.), mental wellbeing (e.g. increased sense of meaning/purpose, hope, gratitude, empowerment, ability to cope with stress, and lower levels of depression/anxiety and loneliness, etc.), and social wellbeing (e.g. marital adjustment and satisfaction, social connectedness, more prosocial behaviors, etc.) (Bożek et al., 2020; Fry, 2024; Koenig, 2009; Ryff, 2021). Despite this evidence, spirituality is often absent from Western wellness frameworks, including the provincial Quality of Life tool mandated by Community Living BC, the provincial government funder of services to adults with IDD (CLBC, n.d.b)

It is in this context that we join an existing if limited conversation about the place and importance of spirituality for persons with IDD (Carter, 2023; Dow, 2023; Gaventa, 2021). Various researchers and practitioners (Carter, 2021; Niemiec & Tomasulo, 2023) have expressed the value of a network in the spiritual support and development of an individual (Figure 2). This article shares findings and perspectives from one
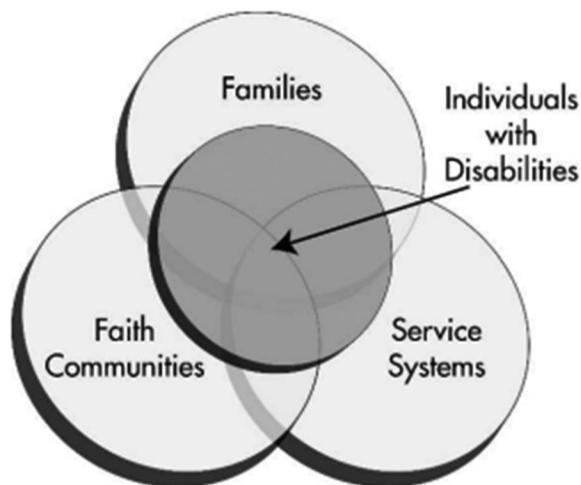

Figure 2. Framework for research, policy, and practice to support the spiritual expression and religious participation of individuals with intellectual and developmental disabilities (Carter, 2013, p. 66)

vital group within the network: professional caregivers. Particularly, how do service agencies understand and enact their role in supporting spiritual literacy for adults with IDD?

This research was made possible with funding from Redleaf Family Foundation. Ethics approval was obtained from The King's University. A subsequent phase of the project focuses on the perspectives of adults with IDD. The related findings will be published separately.

The following sections present key findings from our literature review and some relevant characteristics of the local context in Metro Vancouver, Canada. Understanding the local context is particularly important when comparing our findings with the research base, especially given most of the literature comes from the United States, which has its own unique composition, culture, and history. We then provide an overview of our methodology, a summary of our findings and a discussion of how these findings map onto the literature review. We conclude with some implications for organizations supporting adults with IDD.

2. Literature review

2.1. Religious literacy

We chose religious literacy as our conceptual schema because the term "literacy" involves an ability of "reading the world" and "naviga[ting] a complex range of social practices" (Biesta et al., 2019). Literacies are indispensable, and to lack them "is to experience a serious deprivation that hinders human flourishing" (p. 6). People with disabilities often face numerous challenges to acquire literacy, whether that be health literacy (Hourston, 2004) or digital literacy (Venkatasan, 2024). Those who are non-verbal develop non-speech ways of reading the world and navigating social practices, using assistive technology, picture-based communication, visual aids, body language, touch, eye contact, and facial expression (Developmental Disabilities Association, n.d.).

Like media literacy and financial literacy, 'religious' literacy is an equally complex term, especially in countries like Canada where fewer people are involved in organized religion (Wilkins-Laflamme, 2023). Despite the popular belief that religion has disappeared from modern societies, religion, belief, and spirituality continue to be everywhere. As one scholar states, religion is a "chain of memory" (Dinham, 2015) impacting everything from identities to traditions to controversial issues and more. As such, religious literacy needs to be understood in relation to local histories and cultures, expressed by scholars such as Prothero (2008), who insists that the primary purpose of religious literacy in the US is to have knowledge about the Bible and world religions in order to participate meaningfully in America's religiously inflected public debates.

The conceptual framework that guided our project understands religious literacy as a series of ways to make sense of and engage with the diversity of religious, spiritual, and non-religious identities, perspectives, and traditions from a context-specific intersectional lens (Patrick & Chan, 2022). Its ability to provide context, concepts, and language with which to express and describe spirituality corresponded with the gap that the partner agencies noticed in the community living sector and its goals to promote human flourishing.

Yet, there are assumptions built into the framework of religious literacy as a set of knowledge and skills. Content is typically shared and discussed via written and spoken language, with less attention paid to sensory, visual, embodied, and/or relational forms of communication. As Justine Ellis (2020) argues, the field of religious literacy privileges "intellectualized and 'linguisticized' conceptions of religion" at the cost of affective and embodied dimensions (iii). When conventional approaches to religious literacy are conjoined with civics and democracy-building goals, they emphasize rationality and text, which mask a deep distrust of the body and "an apparent fear of the non-cognitive" (122). Ellis argues that a civics-oriented religious literacy fosters views of religion that align with specific liberal values (e.g. individual autonomy and choice, the primacy of rationality, etc.). In contrast, affect theory, with its focus on the nonlinguistic and the para-cognitive, highlights the transmission of affects like emotions. Ideas and knowledge are never transmitted distinct from affect, and decision-making is not a solely cognitive endeavor. A project like ours is mindful of this and aims to be more open to the affective and embodied components of religious literacy. When we interacted with people with IDD, we attempted to adopt more relational forms of communication and place less focus on rational forms of communication.

Though our conceptual framework was grounded in one conception of religious literacy in Canada (Figure 3), and we used it in our analysis of findings, we transitioned our terminology in this project to focus on "spiritual literacy," understanding it to encompass religion and nonreligion. The term reflects (1) the definitions and use of "spirituality" in the existing literature, (2) the demographics of BC, and (3) the desire to counter Canada's colonial practices that historically omitted Indigenous spirituality.

2.2. Choosing the term "spirituality"

2.2.1. Existing literature

We found that spirituality, rather than religion, resonated most within the literature we reviewed. Two particular definitions summarized perspectives and findings across several studies:

In Canada, religious literacy can refer to:

- Understanding the internal diversity within worldview groups;

- Understanding the external diversity across worldview groups;

- Recognizing the influence that socio-cultural, political, and economic aspects of society have on worldview groups, and vice versa, in the past and present;

- Recognizing the need to include religious, spiritual, and nonreligious worldviews in the full conversation;

- Recognizing that worldviews hold a significant personal meaning to the religious, spiritual, and nonreligiously affiliated individuals. This leads us to discuss these worldviews from an individual or community's distinct lens and not from the worldview of another person/group, and know that individuals who share the same worldview may have diverse beliefs, expressions, interpretations, and terminology to describe it based on a number of factors (such as personal circumstance, place, political context, etc.).

Figure 3. One conception of religious literacy in Canada (Chan et al., 2020)

"The word that seemed to sum up the essence of people's understanding of spirituality was connections [sic]. People felt spirituality had to do with being connected with friends, with a community and for some people with God. Friendships gave people a sense of meaning for their lives and offered them purpose and hope for a positive future. Friendships affirmed people's sense of value and provided them with a feeling of acceptance and being loved. These things are all important aspects of spirituality" (Swinton & Powrie, 2004, p. 3).

"Framed broadly, [spirituality] often refers to the sacred and transcendent aspects of people's lives, the search for meaning and purpose, and/or the things that bring people life and joy" (Carter, 2023, p. 1).

The first definition is based on a project that engaged people in the UK with IDD to define "spirituality." The second definition is from a researcher who studies intersections between individuals with IDD and spirituality. Each definition allows for religious practices, rituals, and relationship with a divine, as well as for a spirituality that can be found and experienced outside of religion, e.g. in relationships, joy, and meaning.

2.2.2. Demographics

The context of BC required that we use the broader term "spirituality" as it is home to the largest nonreligious population among all Canadian provinces (at 52.1% compared to the national average of 34.6%), while

Table 1. The seven most common affiliations and Indigenous spirituality in BC in contrast to affiliations where BACI, Kinsight, and posAbilities' primarily serve (Statistics Canada, 2023a).

2021 Census	Canada	BC	Burnaby	Coquitlam	Port Moody	Port Coquitlam	New Westminster	Vancouver (City)
Christian	53.3%	34.3%	35.2%	39.6%	40.7%	42.2%	41.1%	29.8%
No affiliation	34.6%	52.1%	48.4%	47.6%	48.4%	46.6%	44.6%	55.8%
Muslim	4.9%	2.6%	5.6%	6.2%	4.5%	4.4%	3.3%	2.7%
Hindu	2.3%	1.7%	3.1%	1.3%	1.3%	1.2%	2.5%	1.9%
Sikh	2.1%	5.9%	2.8%	1.3%	1.4%	2.3%	4.8%	2.5%
Buddhist	1%	1.7%	3.7%	2.4%	1.9%	1.6%	2.0%	4.0%
Jewish	0.9%	0.5%	0.2%	0.2%	0.6%	0.4%	0.3%	1.7%
Indigenous Spirituality	0.2%	0.2%	0.1%	No data	0.1%	0.1%	No data	0.1%

also being very religiously diverse (Statistics Canada, 2023a). For example, Metro Vancouver has large Buddhist, Christian, Jewish, Hindu, and Muslim populations that exceed the provincial average (indicated by the yellow highlight in Table 1). Additionally, cultural trends suggest that the largest adult population, the Millennials (those born between 1981 and 1996), are quite secular (Statistics Canada, 2024), and younger cohorts are increasingly "cradle" nonreligious, meaning that they are raised in homes with few or no religious traditions (Wilkins-Laflamme, 2023).

2.2.3. Creating space for Indigenous spirituality

Vancouver has the third largest population of Indigenous peoples among the census metropolitan areas in Canada (Statistics Canada, 2023b). Within this group, 43% indicated affiliation with the main world religions but the majority of individuals, 57% (371,075 people), self-identified as having "a traditional North American Indigenous spirituality", "other religions and spiritual traditions", or "no religion and secular perspectives." Given Canada's history of colonialism toward Indigenous peoples, where potlatches, powwows, smudging, and other Indigenous ceremonies and sacred practices were banned, our project aims to counter and challenge this history by creating the space to include Indigenous Spirituality and engage with various types of spirituality writ large.

3. Methodology

This project was guided by the Critical Communicative Methodology (CCM), informed by the theoretical frameworks of Jurgen Habermas' (1984) deliberative democracy and communicative action, and Paulo Friere's commitment to conscientization. As a result, CCM aims to include and amplify vulnerable voices through dialogue and communication that unpack life experiences, resulting in analysis which identifies elements that promote inequality and those that transform it. CCM dictates that dialogue must

be egalitarian, where the experiences and lifeworlds of the participants are based on the validity of their reasoning rather than the positions of power they hold. Additionally, social actors are understood within their contexts. As one researcher noted, "CCM promotes dialogical procedures, as researchers trust that every participant, particularly those belonging to vulnerable groups, has the capacity to reason" (Puigvert et al., 2012, p. 4). This is critical because it assumes the capacity of participants to reflect and self-reflect in ways that lead to transformative action. Although this phase of research did not directly involve persons with IDD, we believe CCM to be well-suited for this entire project because the capacity to reflect and self-reflect exists in varying degrees across the IDD community. Moreover, we interpret reason and reflection to encompass embodied ways of making sense of the world and subsequently incorporated learning from (1) multi-modal conversations in which persons with IDD explored the topic while engaging with art materials and (2) from curated experiences where they walked labyrinths, arranged flowers, held religious artifacts, and so on. On such occasions, embodied, relational, affective and non-linguistic forms of exploration were invited and supported.

Further, because CCM explicitly acknowledges that there are different ways of making sense of the world, it provides epistemological and methodological space for practically engaging with people who may be non-verbal or rely on other forms of communication or expression. The implied emphasis on verbal dialogical procedures is a natural bias, but it is not essential or required.

With respect to this phase of research with the organizations themselves, we found CCM helpful in creating the sort of invitational space that would enable employees and volunteers participate openly. This was important because social service organizations are traditionally hierarchical with centralized decision-making and controls, which could lead to staff participation being more performative.

As an explicitly dialogic approach, CCM aims to de-center researchers and Western research methods in data collection and analysis, creating empowering opportunities for participants who become agents of their own transformation (Freire, 1970). By encouraging participants and researchers to share lived stories, discuss issues without coercion or hierarchy in communicative focus groups, and reflect on insights from previous discussions (Gómez et al., 2010)—the three methods specific to CCM—CCM makes space for multiple experiences and ways of knowing, allowing for transparency to foster trust in research as a shared process.

We recognize that within organizations, measuring knowledge "is not bound to one part of the organization [but] resides within the individuals,

the organization's culture, workplace, standard operating processes, and structure" (Dam et al., 2022). Consequently, we sought perspectives from across organizational contexts in order to better understand a topic that is contentious, and that is in regards to a population where even conventional determinations of understanding or awareness are difficult to assess. These issues could be the subjects of an article on their own, but for the purposes of this paper, we can only acknowledge their complexities.

3.1. Process

Using CCM values and practices, the project included liaisons from community organizations to co-develop the survey questions. This ensured the inclusion of relevant contextual details and topical insights. CCRL developed a short video introducing the project, and CEOs and management from the organization circulated it to their employees and contracted caregivers along with an invitation to participate. A link to a 21-question survey was then sent to approximately 1,300 staff across posAbilities, Kinsight, and BACI, which rendered 133 responses over a two-week time period.

CCRL researchers analyzed the data, identified trends, and, alongside organizational liaisons, crafted some semi-structured questions for use in conversations with employees and contracted caregivers who volunteered to help make sense of survey results. CCRL then facilitated six sense-making sessions with these volunteers and invited them to jointly reflect on and interpret the data. Four of these groups were in-person and two were online. Each sense-making group lasted between one to three hours. Seventeen representatives participated, including five Board members, three CEOs, five senior leaders, two managers/supervisors, and two staff.

Survey data and transcribed group conversations were then analyzed thematically by the CCRL researchers and an intern, and prepared for co-analysis with five organizational staff invited by and from the three agencies. They included a manager, supervisor, coach, team lead, and front-line staff who were knowledgeable and passionate about the sector, agencies, and people they served. The co-analysis took place in two, 2-hour online sessions, six days apart.

The CCM analysis is purposely collaborative, engaging members of a community to deepen collective understanding of an issue, and to understand and identify the "exclusionary" and "transformative" elements that exclude participants from a phenomenon or context, or the possible elements that can lead to positive change. This form of analysis was exceptionally valuable for the project because the two CCRL project researchers and coauthors have never worked in the IDD-serving sector. There was

only so much they could ascertain from their teaching experience with students and from the literature review.

Nevertheless, the project findings are limited because participation in the survey and sense-making discussions was voluntary. Also, because the majority of frontline workers who responded to the survey self-identified as religious, our survey responses may be skewed toward those who are interested in the topic of spirituality and religion, while those who do not view spirituality as important chose not to participate. Likewise, only two frontline staff participated in our sense-making groups; others had confirmed interest but they did not join at the scheduled time. Their perspectives added insight to our survey findings, but did not let us explore the survey findings with frontline staff in greater detail. Additionally, staff across the three agencies support individuals with a spectrum of abilities, where some are more verbal than others. Staff may have interpreted and responded to the survey questions based on the particular individuals they supported.

4. Findings

This phase of the project specifically explored the research question: "How do agencies (and their staff) understand and enact their role in spiritual literacy and support?" Our overarching finding was that staff were reluctant to engage adults with IDD in a conversation about spirituality or to support their spiritual development. There were many reasons for this, including underlying questions and confusions around what spirituality means, how they are supposed to address it (or not), and to what extent.

4.1. Everyone defines "spirituality" differently

Every sense-making conversation had a significant discussion about the definition of spirituality. We deliberately did not include a definition of spirituality in the survey because there is no consistent meaning within the literature and we did not want to arbitrarily constrain it. However, leaving the term undefined created its own problems. Without a shared understanding of what "spirituality" means among participants, what it might mean for the agency, or for adults with IDD and their families, staff were unsure of what it would mean to support it.

Those who self-affiliated with a religion or Eastern tradition (53% of staff [70 of 131]) used the words in Figure 4 to describe "spirituality", while those who were unaffiliated (40% [53 staff]) used the words in Figure 5. The Word Clouds in Figures 4 and 5 reveal similarities and differences in how both groups conceptualize spirituality. Some words appear for one group but not the other. For example, "transcendent/
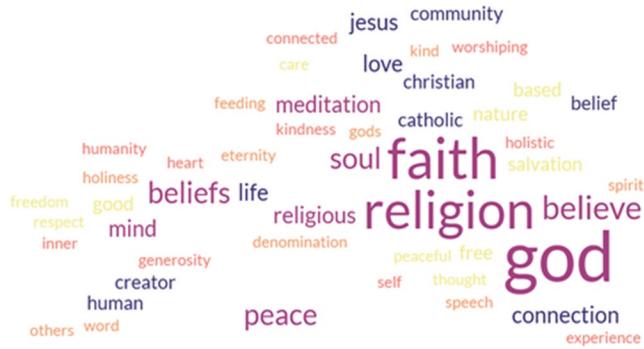
Figure 4. Responses from religiously affiliated staff to the question: "what words come to mind when you think of spirituality?"

Figure 5. Responses from religiously unaffiliated staff to the question: "what words come to mind when you think of spirituality?"

transcendental" were part of four survey responses from unaffiliated staff, but not mentioned by religiously affiliated staff. Likewise, "free/freedom" was part of three survey responses from affiliated staff, but not mentioned among unaffiliated staff. Table 2 shows the prevalence of shared words.

"Believe/beliefs/believing", "faith", "religion", "connection", and "peace" are the most common words among both groups by count, noted by the larger font size and purple color in Figures 4 and 5. It is worth noting that both groups tend to see belief as a central feature of spirituality. Lastly, the language that staff used to describe spirituality sometimes overlapped with definitions in the literature and sometimes diverged from them.

Despite the lack of a shared definition of spirituality, there was general agreement that it was important. Overall, 75% of staff (97 of 130) said that spirituality is "very important" or "important" to them, and 74% (96 of 129) said that staff in their type of role should "yes, very much" or "yes" be supporting people with their spiritual developmental and expression. These findings indicate that spirituality is valued by staff with and without religious affiliations, and that the majority of them feel that staff in their role should be supporting the spiritual wellbeing of people with

Table 2. Most common words to describe spirituality by count and percentage, among survey respondents affiliated with a religion or Eastern philosophy, and unaffiliated respondents.

Affiliated with a religion or Eastern philosophy (69 written responses)	Religiously unaffiliated (51 written responses)
Believe/Belief(s)/Believing (14 times, 20%)	Believing/Belief(s)/Believing (9 times, 18%)
Faith (13 times, 19%)	Connection (7 times, 14%)
Religion (12 times, 17%)	Religion (6 times, 12%)
Peace (6 times, 9%)	Soul (4 times, 8%)
Soul (5 times, 7%)	Peace (3 times, 6%)
Connection (3 times, 4%)	Faith (3 times, 6%)

IDD. However, given the lack of a shared definition, they did not know what that should look like.

4.2. Training is needed

As sense-making discussions and co-analyst meetings dug deeper, they surfaced many questions:

- To what degree is spirituality important for flourishing, i.e. Is spirituality a prerequisite to flourishing?
- If I don't believe in the same form of spirituality as [the person I support], am I introducing the "wrong" belief to [them], one that can harm their wellbeing?
- If I support [someone] in their spiritual development, will it be considered proselytizing?
- If spirituality is based on belief, which requires a mental connection, how or to what degree can [the person I support] engage with spirituality?

Underpinning these questions are a variety of assumptions around the meaning of spirituality, its significance for people with IDD, and the role of staff and agencies.

To better understand staff challenges, the survey asked: "If you feel uncomfortable discussing spirituality or supporting people with their spiritual interests/development, why is this the case?" Staff were invited to choose from among 25 responses that we collated from our literature review. Their top four responses were:

- People with disabilities can be impressionable, and I don't want to influence them (24%)
- Their family members or my colleagues could have a problem with it (22%)
- I don't have adequate training about how to talk about religion and spirituality (20%)
- There are insufficient guidelines around how to engage with spirituality (20%)

In addition to differences in the interpretation of spirituality, these responses reveal some of the tensions occurring among staff, between staff and management, and between staff and family members. These tensions, along with fears of violating professional standards of conduct, help to illuminate staff unease around *how* to discuss spirituality with the individuals they are supporting.

Following this question, the survey asked: "Which type of program/ training/tool would be the most helpful for you to learn more about how to support people with intellectual and developmental disabilities in their religion/spirituality?" The majority of staff (68%) said that more training is needed.

The study consistently revealed that staff feel ill-equipped to provide spiritual literacy to the people they serve. They recognize that there are many forms of religious literacy that fall outside of their knowledge, skills, and experience, and that in addition to those practical considerations, they need training to navigate a socially and politically charged space, especially where power imbalances exist.

4.3. Clear guidelines from agencies are needed

Beyond practical training, staff expressed the need for guidelines that provide clear ethical boundaries and a common approach to providing spiritual literacy and support. Such guidelines are thought to protect everyone, especially the wellbeing of individuals with IDD. One CEO acknowledged the need for better communication with staff because agencies are "not being as explicit [around spirituality] and in part because we don't necessarily know how to be explicit about it" (CEO2). This relates to our first finding about a lack of common language for and understanding about "spirituality," which translates into a lack of appropriate standards to address it.

Staff sought guidance on overarching questions about themselves and their role, summarized as:

- How do I address personal and professional tensions? For example, what if I do not support what an individual with IDD believes, but they are asking me to do something based on that belief?
- What am I allowed to do and how far am I supposed to support spiritual development in the people I serve?
- How do I support a person's spirituality if they don't express it?

The lack of definition, guidelines or training around spirituality help contextualize the conundrum facing many staff. On the one hand,

spirituality is important or very important to the majority of survey respondents, and they recognize the potential place that spirituality can have in the life of an individual with IDD. On the other hand, they were reluctant to engage people with IDD in a conversation about spirituality or to support their spiritual development because they do not know how to discuss it in an environment (and sector) where spirituality is not commonly raised or discussed, where there is virtually no education around spiritual literacy nor navigating spiritual support in a pluralist context, and where there are no professional guidelines for conduct.

5. Discussion

Our findings resonated with four themes from our literature review.

First, studies found that there are inadequate resources for addressing spiritual needs of people with IDD. These include: limited opportunities for individuals to explore places of worship of their own choosing; a lack of regular and accessible transportation to sacred spaces, or challenges to organizing transportation; a lack of curriculum and materials; and a need for more staff, especially when agencies fail to schedule adequate staff on the weekends to support individuals with disabilities in communities of faith (Carter, 2023; Pederson & Webster, 2022; Sango & Forrester-Jones, 2019). In our study, a lack of curriculum and materials was discussed most frequently, though all the resources in the list were also raised.

Second, staff lack sufficient knowledge or skills to support people with their spiritual needs. They are confused around the vast number of spiritual traditions and expressions; lack an established set of professional guidelines and practices that keep others from being hurt by inappropriate constructs and/or approaches (e.g., proselytizing, manipulation, coercion, exploitation, and more); lack skills in how to collaborate effectively with spiritual leaders and communities; and lack training though courses of related offerings on this topic. Furthermore, staff are confused about their roles and what to do about their own discomfort or disquiet, especially if their beliefs and spiritual interests differ dramatically from those they are supporting. They also wondered how they are supposed to support faith leaders and religious group members who feel unprepared to support and engage with people with IDD (Carter, 2023; Pederson & Webster, 2022; Sango & Forrester-Jones, 2019).

Third, there is social stigma around religion and spirituality. Staff were hesitant to arrange support or engage with religion because of social stigma around it, and because of discomfort or fear around the power wielded by religions in cultures and communities (Gaventa, 2013). Though our project is about religious and nonreligious expressions of spirituality, the

dominant population in BC is nonreligious and this may translate into higher stigma toward religion and religious people, and to anything having to do with "spirituality" insofar as it tends to be conflated with "religion." In this vein, with one exception, we observed that sense-making participants who affiliated with a religion self-disclosed much slower than those who were nonreligious. This may be a result of stigma and/or a result of cultural norms at the national, regional, sectoral, or agency level where there is "no talk of religion, sex, and politics at the dinner table" (Chan et al., 2023). Interestingly, in discussions that expressed concern around the imposition of religion on persons with IDD, there was no concern voiced about the imposition of secular worldviews. This suggests an unstated assumption that secularism is a morally neutral and socially preferred worldview.

Fourth, research indicates that staff minimize discussions about spirituality and religion in an effort to minimize tensions between staff and families (Pederson & Webster, 2022). Although this was not a dominant theme in our findings, survey responses and co-analysts expressed that tensions between staff and families do occur. This provides another clear rationale for why training and guidelines are needed.

Studies in our literature review revealed that staff also tended to minimize or downplay the importance of faith in the lives of the individuals they support. They worried about the "taboo" nature of religion, and American-based studies observed a separation of church and state in public service roles, which implicitly discouraged them from discussing religion and/or spirituality (Carter, 2023; Gaventa, 2013; Pederson & Webster, 2022). While these sentiments were not explicitly raised or discussed in our findings, it would not be surprising to find them within the BC context, even though Canada does not have a constitutional separation of church and state like that of the United States.

Nonetheless, it is difficult to see how there can be standardization to guidelines, training, or support around spirituality until there is first some agreement on what it means. Especially because, despite the literature's use of the language of "spirituality," and offering definitions that incorporated nonreligious significance to it, the practical examples and applications often drifted toward faith-based ones (usually Christian). Figure 2 in this article makes this conflation visible: "spiritual expression" is coextensive with "faith communities." This habitual assumption was replicated in our sense-making conversations with staff, though spiritual expression applies equally to the nonreligious search for meaning and purpose, and for finding peace and experiencing joy. Beyond casual mention in the literature we reviewed, or in survey responses and our sense-making conversations with staff, the nonreligious dimension of spirituality, and the significance

of meaning, purpose, joy and connection outside of religious commitments, were largely unexplored. How does this influence staff conceptions of spirituality for persons with IDD and the kinds of support that should be provided, especially in a predominantly nonreligious context like BC?

5.1. Practical implications for agencies

The community living sector seems caught in a bind. On the one hand, staff look to persons with IDD for explicit direction around goal-planning and what they want support with. On the other hand, unless people with IDD are given exposure to spiritual beliefs and practices, and invited to reflect on them, they are unlikely to become aware of the role that spirituality does or could play in their wellbeing, or know how to ask for it. Organizations might begin addressing this bind by recognizing the important role that spirituality plays in "the meaningful life." If their aspirations include human flourishing, they might begin with Quality of Life instruments and/or wellbeing frameworks that include the spiritual dimension of wellbeing. Currently, the agencies in BC are required to report on outcomes aligned to with Schalock's Quality of Life framework, which does not include spirituality (CLBC, n.d. b). Some additional concrete steps can be taken to incorporate spirituality into their service and support frameworks, though they will not be easy:

1. Define "spirituality." Current variability creates confusion among staff and makes individual action and the coordination of a common approach difficult. Organizations might consider the research of de Brito Sena et al. (2021), who conducted a metastudy of definitions of "spirituality" in healthcare literature, and Michaelson (2020) who conducted a study among Canadian youth. They both propose frameworks that incorporate religious and nonreligious orientations to spirituality.
2. Provide general training to staff (or create specialized roles) that equip them to provide spiritual literacy and support. Not only does spirituality take many forms, but literacy would need to look quite different for persons with IDD given the broad range of cognitive abilities. This training could also assist staff to navigate sociopolitical minefields.
3. Establish a set of ethical guidelines. Staff and managers are worried about imposing worldviews on vulnerable people. A process needs to be enacted that would explore ethical tensions such as: What is the difference between providing literacy and persuading or converting someone? For example, would any of the following be considered inappropriate and if so, in what circumstances and why: explaining

one's faith, performing the salat, offering to pray for someone, hanging an amethyst to help relieve stress and anxiety, saying grace or thanks for one's meal, etc.? Also, should staff be expected to provide spiritual support related to beliefs, rituals, or traditions at odds with their own? What does it mean to "park" one's beliefs at the door, and do such organizational expectations impact their capacity to assist people with spiritual exploration and development?

These steps will require organizations to grapple with a variety of questions, including: (1) How do perceptions of vulnerability, impressionability, and power and control, inform how spiritual literacy and support is provided? (2) How should family members and circles be involved? (3) What resources are needed (e.g. staff training; time for staff to reach out to spiritual leaders and communities, participate in community events, plan reflective experiences, coach individuals, etc.)? (4) What are the spiritual support needs of someone who is non-verbal and has significant cognitive delays?

6. Conclusion

Although there is abundant research that shows the importance of spirituality to human flourishing, and although the majority of surveyed staff and managers personally recognize its importance, it remains to be seen whether community living organizations will be able to move beyond simply identifying and responding to religious preferences to supporting spiritual literacy and development more broadly.

One hurdle will be prevailing norms and assumptions that publicly funded organizations should be secular spaces. While that may make sense in many instances, it ceases to make sense when organizations are tasked with human wellbeing. In such cases, spirituality cannot be minimized or ignored.

But organizations face an uphill battle: defining "spirituality" in broad yet practicable terms, determining their role in supporting it, expanding community partnerships, capacity and participation, providing practical training for employees, developing tools and approaches that might be used across a continuum of abilities, grappling with complex ethical challenges and providing a set of coherent professional guidelines for employees, navigating sociocultural and political tensions, and continuing to honor relationships with families and circles. To undertake all this without drawing away resources from what they already do will not be an easy or straightforward journey. But of course, the ones that matter rarely are.

One approach that is showing some promise are Curiko's experiences to explore spirituality. In its efforts to advance human flourishing by

providing moments of connection to the self, others, land/place, culture, the human project, and the sacred, and by catalyzing these moments as "momentum" leading toward positive growth and development, Curiko has hired a Peer Spirituality Explorer (someone who identifies as neuro-diverse) who creates experiences that are posted on their website, available online or in-person, and are open to people with and without disabilities. Research into their learning is ongoing and will be shared in future presentations and projects. However, early results indicate that people with IDD *want* to have conversations about spirituality. The problem is that few people in their lives, if any, have asked them about this important part of themselves or created the space for them to explore it—an impetus, we hope, for organizations to embark on this challenging journey.

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