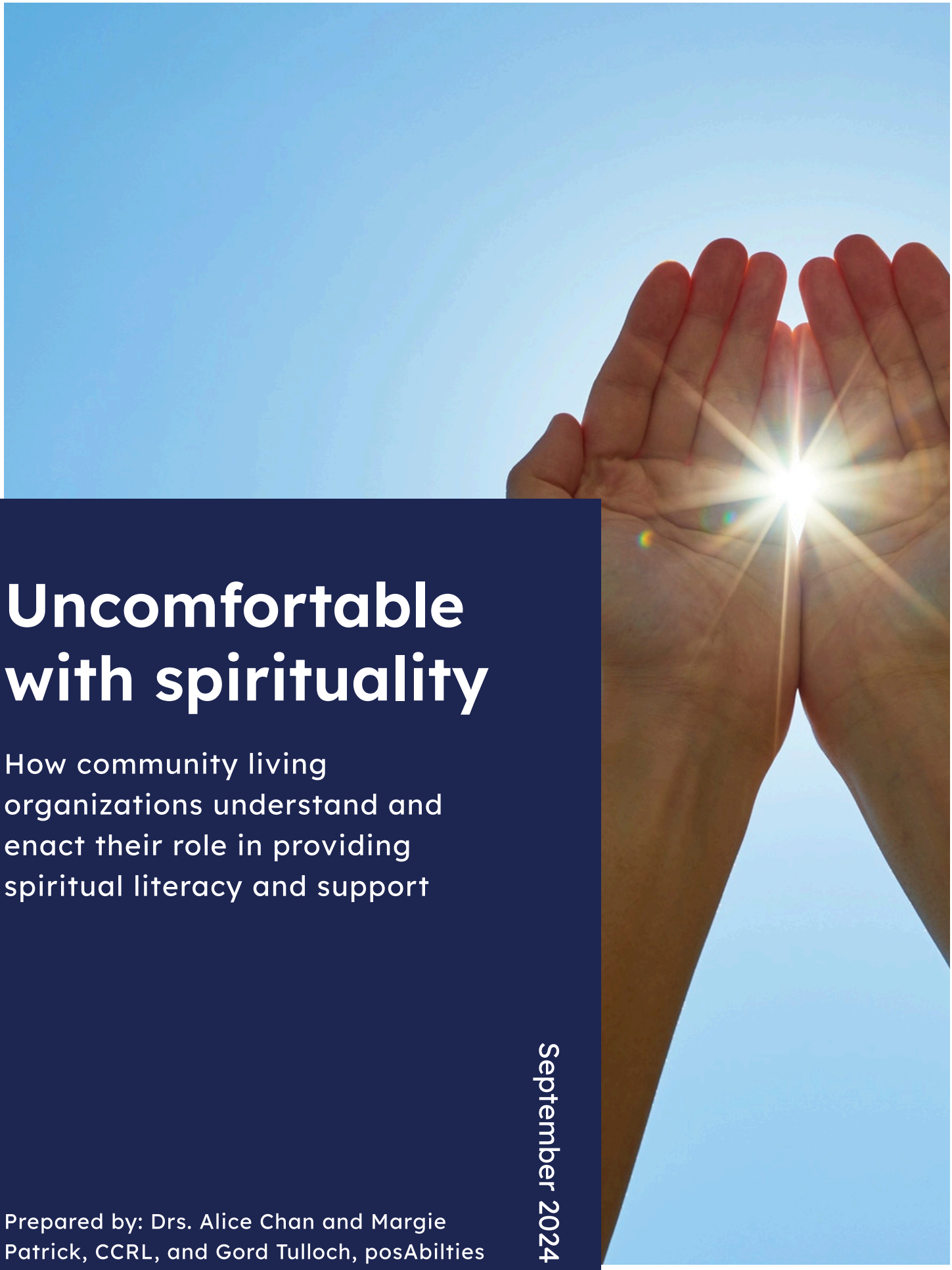

Uncomfortable with spirituality

How community living organizations understand and enact their role in providing spiritual literacy and support

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Background

This project is a partnership that explores how adults with intellectual and developmental disabilities (IDD) learn about and engage in spirituality and how agencies currently understand and enact their role in spiritual literacy and support. Ethics approval was provided through the Research Ethics Board at The King's University in Edmonton, Alberta, where Dr. Margie Patrick is a Professor in the Faculty of Education.

This report summarizes Phase 2 of a study that is part of an evolving, four-phase research project:

- Phase 1: Literature review (Jan - Mar 2024)
- Phase 2: How community living agencies understand and enact their role in spiritual literacy and support (Apr - Sept 2024)
- Phase 3: How people with IDD learn about and engage in spirituality (Oct 2024 - Mar 2025)
- Phase 4: Family perspectives on spirituality and agency roles (April 2025 – Apr 30, 2026)

Summary of findings

Generally, agency staff are unclear about what is involved in providing spiritual literacy and support, including what is expected of them and how to ethically and practically provide it. Four key themes illuminate this conclusion:

1. "Spirituality" is an ambiguous concept
2. Managers and frontline staff tend to have different starting places
3. The treatment of sexuality and spirituality is similar
4. Guidelines and training are needed

Setting the stage

To talk or write about belonging in an inclusive way requires the recognition and incorporation of spirituality. [1]

Project overview

Organizations working with people with intellectual and developmental disabilities (IDD) do a good job caring for things like physical safety, security, coping, stability, skill-building, and productivity. What receives less attention is the inner life: who one is and wants to become

as a person, how one fits in the story of one's family and society, and where one fits in the story of the world. Remedying that disparity and grappling with the spiritual needs of persons with IDD is integral to the vision of "good lives in welcoming communities" and an inclusive society:

> *Rather than confining spiritual curiosity to narrowly defined religious beliefs or cognitively-biased conversations, counselors, chaplains, faith leaders, and support professionals must shatter existing expectations as we seek to understand meaning and spirituality in diverse and scattered places. A world where the spiritual and therapeutic needs of people with intellectual disabilities are constantly undermined and left unmet is broken indeed. The answer is a genuine openness to the variety of religious and spiritual experiences of people with intellectual disabilities. This posture helps to "restore the world", or at least this particular aspect of the world, as the spiritual needs and contributions of people with intellectual disabilities are no longer discounted but are valued and respected in equity with the needs of non-disabled people.* [2]

But what are the implications for community living service providers, particularly those situated in geographies with diverse populations such as Metro Vancouver? That is what this phase of research explores.

We use the term "spirituality" because it can encapsulate both religious and secular inflections, as well as the many ways that people might describe their beliefs, practices, or points of connection. That said, everyone enters this conversation with their own philosophical and experiential bias around the meaning and importance of spirituality. For example, a Western bias may prioritize "primary needs" for survival and safety over more "esoteric" ones like growth, beauty, and spirituality[3]. Thus, with limited time and resources (constructs similarly rooted in a Western framework), attending to spiritual needs may be regarded as a "luxury" [as expressed by a staff research participant], or at least, as something that can't be attended to until more fundamental needs are met. Yet within an Indigenous worldview or Eastern philosophy, spirituality is more likely to be seen holistically and cannot be bracketed or compartmentalized. These varying and often unstated starting points can make conversations more challenging.

While research seems to confirm that spiritual needs play an important role in flourishing for persons with IDD, how it is expressed may be difficult to ascertain, especially given the continuum of ways that disability might manifest. Beyond the challenges of understanding what spirituality might look and feel like for those receiving services, it leads to two different and distinct practical challenges:

1. How should organizations support those with more conspicuous beliefs and practices, and;

2 How should they support those with undeclared, less visible (and ostensibly absent) beliefs and practices?

This is compounded by the possible imposition of personal or sectoral ideals on those who are less able or less confident to expressly articulate who they are or what they want. In one focus group with CEOs someone posed a question around the degree to which people with IDD have spiritual needs versus the degree to which staff presuppose they do based on an ideal around what a "fulsome life" looks like. Another added: "… How do we support and how can we support in a way that is not reflective of our desires and our needs as the person doing the supporting or the agency doing the support, but rather the desires and needs and wants of the individual…. And so, is there an element of transference there that's happening? And that to me is very concerning."

Geographical context

BC has the largest secular population (52.1%) among all the Canadian provinces, in contrast to a religiously diverse Metro Vancouver. This contrast may present a challenge for the agencies due to differing norms and practices that may exist across local areas.

Table 1: The seven most common religious affiliations in BC in contrast to affiliations where BACI, Kinsight, and posAbilities' serve (Statistics Canada, 2021)[4]

2021 Census	Canada	BC	BBY	Coq.	Port Moody	Port Coq.	New West.	Vanc.
Christian	53.3%	34.3%	35.2%	39.6%	40.7%	42.2%	41.1%	29.8%
Sikh	2.1%	5.9%	2.8%	1.3%	1.4%	2.3%	4.8%	2.5%
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%
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%
No affiliation	34.6%	52.1%	48.4%	47.6%	48.4%	46.6%	44.6%	55.8%

Cells shaded in violet indicate local populations that exceed the BC population for a designated group.

The prevalence of religiously non-affiliated residents may enhance a public stigma towards religion, spirituality related to a religion, and those who are religious. In this vein, with one exception, we observed that focus group participants who self-identified with a religious affiliation self-disclosed much slower than those who are non-religious. This may also be the result of a pervasive cultural norm that discourages talk of religion, sex, and politics in polite

conversation or “at the dinner table.” At the same time, stigma towards the non-affiliated can also occur, depending on the context within the Metro Vancouver.[5]

Cultural trends suggest that the largest adult population, the Millennials, are quite secular and increasingly raised in homes that have no religious traditions.[6] They are the “cradle” non-religious.[7] Some frontline staff echoed this trend and noticed that younger persons served (PS) have made fewer requests to attend houses of worship.

Community living sector

A number of observations were made about the community living sector in BC, including that PS who come from institutional settings had fewer experiences with spirituality than those who come from family settings. Additionally, educational programs didn’t adequately prepare students to address this topic. For example, a frontline staff who graduated from a local 2-year program said they hadn’t received much education about religion. This echoes what Patrick and Chan[8] found in their previous research and suggests that agencies cannot rely on local training/education programs to introduce frontline staff to issues related to religion and spirituality.

Two recurring observations that explicitly and implicitly informed all discussions were:

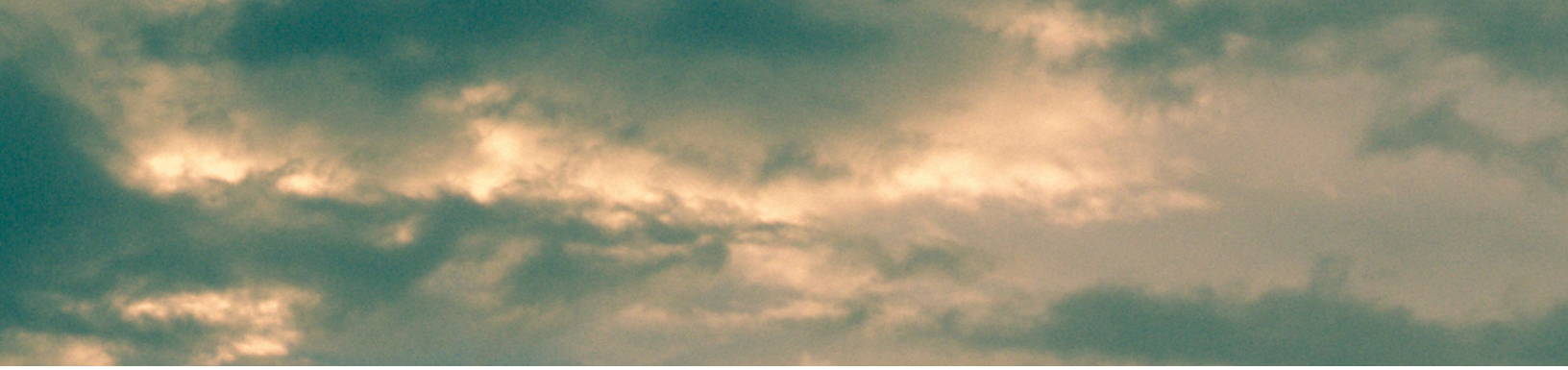
1. **The sector’s history and legacy of institutionalization led by religious groups**. One participant described the legacy as “the violence of evangelism in the past.” Such practices of evangelism in former care facilities have contributed to the secularization of the sector and perhaps exacerbated commonplace associations between “spirituality” and organized religion among wary professionals. Both the literature review and focus groups revealed complicated and conflicting views on the impact of organized religion. On the one hand, it was recognized as a potentially positive resource that could enhance the emotional well-being of people with IDD and provide coping mechanisms and support in times of loss.[9] On the other hand, it was also seen as violent and harmful regarding the self-perceptions of PS (e.g., seeing their disability as God’s punishment for sin).[10] Perhaps unsurprisingly, positive references were typically made by participants who identified as being religious, and negative references were typically made by participants who identified as being non-religious.
2. **Power dynamics complicate the work**. Staff conversations described a range of power dynamics: management—staff, staff—staff, staff—support network, and staff—PS. These dynamics complicate what, how, and if support is given in certain areas. Demographics can further compound imbalances, such as those between newcomers and longer-term citizens, particularly when newcomers are unfamiliar with local regulations, norms and sensitivities.

Agency context

The agencies provide a broad range of services to adults with intellectual disabilities, including residential support (e.g. staffed residences, shared living), outreach (e.g. life skills, support to live independently), a range of community integration programs, and employment. Service models were a factor in whether PS accessed religious events or activities. For example, residential care staff would find it routine to take PS to a sacred space for Friday prayers, Sunday service, Synagogue, etc., but "if you're an outreach worker and you're only seeing somebody a couple of hours a week, that, again, might be very different from if, like, you're a residential support person" [manager]. Programs with daytime schedules and/or reduced staffing were less likely to provide this support.

Services and support are provided to PS across a broad continuum of abilities/disabilities. While co-analysts (staff who helped analyze the research findings with us) shared that the majority of PS are less verbal, lack exposure to others, and tend to engage in segregated activities, those participating in research from Curiko in a subsequent phase of our research were articulate individuals engaged in a variety of social groups and networks. The diversity of abilities and disabilities is a complicating factor and will doubtless inform differences in staff survey responses and their personal perceptions and approaches to the topic.

Uniquely, the agencies have a history of investing in social R&D to tackle complex topics such as social isolation (resulting in an organization called **Kudoz**), and friendship, dating and intimacy (resulting in **Real Talk**[11]) and have demonstrated an ongoing ability to iterate in response to learning (e.g. the transition from **Kudoz** to **Curiko**). In the words of a board member, "paralysis by analysis" is not in the culture of the agencies. This purposeful movement towards human flourishing, including regular reviews of evidence-based literature, has led them to investigate spirituality more fully.



Research method

The survey, focus groups, and co-analysis meetings were based in Critical Communicative Methodology (CCM)[12], a methodology that aims to amplify vulnerable voices. It is based on egalitarian dialogue and communicative action that values the validity of different forms of reasoning and knowledge. CCM aims to minimize hierarchy and positions of power, e.g. between researchers and project participants, to unpack and understand life experiences. It promotes collaboration that refrains from coercion and creates empowering opportunities for traditionally vulnerable groups.

In July 2024, we conducted a preliminary analysis of survey responses to identify themes and patterns and hosted focus groups to obtain perspectives of people across agencies and roles. We then co-analyzed findings with selected staff to better understand what was behind the patterns. This process is critical because CCM assumes the capacity of participants to reflect and self-reflect in ways that could lead to transformative action.

Stage 1: Literature and document review

A literature review was conducted, consisting of 25 journal articles and 5 books/reports, as well as a review of organizational and sectoral documents relating to the provision of access to and support for spirituality. These included: codes of ethics; handbooks for staff, volunteer, and shared living providers; regulations; policies and procedures; strategic and operational plans; person-centered planning templates and goals, etc.

Stage 2: Survey (May 2024)

A 21-question survey (Appendix I) was distributed to staff over two-weeks in May. Communication about the survey was distributed internally with support from the CEOs. We had 133 survey respondents from approximately 1300 staff across Burnaby Association for Community Inclusion (n=60), posAbilities (n=55) and Kinsight (n=24), which was roughly proportionate to their respective sizes.

The survey began by asking questions about respondents' background, perspectives, and role, and was designed to unpack the relationship between the personal and professional self. This data was analyzed in various ways.[13]

Stage 3: Focus groups (June 2024)

Focus groups lasted 1–3 hours and were held with groups from across the three agencies, according to positions held: board of directors (n=5), CEOs (n=3), directors/senior leaders (n=5), managers/supervisors (n=2), and front-line staff (n=2; 1 in each focus group).[14]

Some participants were asked to participate, others volunteered.[15] There were 17 representatives across the three agencies: BACI (n=7), Kinsight (n=5), posAbilities (n=5). Initial survey findings were shared during focus groups and discussed in a semi-structured format to explore key ideas and new observations together. This data was analyzed thematically after each conversation was transcribed.

All focus groups ended on a positive note, with participants excited about beginning this conversation across the agencies.

Stage 4: Co-Analysis (August 2024)

We convened two 2-hour online sessions, six days apart. There were five co-analysts across the three agencies: BACI (n=2), posAbilities (n=2), Kinsight (n=1). Most co-analysts were asked or invited to participate.

Our two co-analysis meetings with staff delved deeper into our preliminary survey analysis and focus group findings to understand how our observations, questions, and new learnings resonated with staff, and explore what we may have missed or misunderstood in our analysis so far.

Four thematic findings

1. “Spirituality” is an ambiguous concept

Every focus group discussion explored the meaning of “spirituality” at considerable length. Not only did participants find it challenging to define, but they could not find agreement on substitute terms or descriptions; no single definition worked for everyone. For example, some thought that the term “connection” was equally abstract, while others liked it. Terms such as “awe” and “wonder” were not embraced. Several participants preferred the term “belonging,” while others thought spirituality could be linked with community and feeling loved, or connection with nature, or a cultural experience. This denotational difficulty is reflected in the literature, where scores of definitions are suggested.

It is because of this murkiness that we avoided supplying a definition in the first place: we didn’t want to arbitrarily constrain possible meanings. Unsurprisingly, when we asked, “what words came to mind when you think of spirituality,” there was a vast and varied response.

We have segmented them below using Word Cloud[16] based on whether respondents self-identified as religious or nonreligious.

Figure 1: Affiliated with Religion
Word Cloud for "What words come to mind when you think of spirituality?" (Q6)

Figure 2: Affiliated with Non-Religion
Word Cloud for "What words come to mind when you think of spirituality?" (Q6)

Discussion highlighted the need to bridge these different understandings with the ways PS may understand or engage in spirituality. This is especially relevant given "the considerable diversity of avenues through which young people with autism and/or intellectual disability express their spirituality and faith commitments."[17]

As much as staff used different language to describe spirituality based on whether one was religious or not, there was also some overlapping language.

Table 2: Word Count of Most Commonly Cited Words Shared by Both Religious and Non-Religious for "What words come to mind when you think of spirituality?" (Q6)

	"Religious" (69 written responses)	"Non-Religious" (51 written responses)
Shared words	Believe/Beliefs (14x) Faith (13x) Religion (12x) Peace (6x) Soul (5x) Connection (3x)	Believing/Belief(s) (9x) Faith (3x) Religion (6x) Peace (3x) Soul (4x) Connection (7x)

Given the abstract nature of spirituality, focus group participants noted the difficulty PS may have in understanding the term, especially those who are nonverbal. While this suggests a cognitive bias around understanding spirituality (e.g. beliefs), some participants proposed embodied or experiential ways to understand and explore it (e.g. describing an experience where the hairs on the back of your neck stand up, feelings of awe, etc.).

Conflating Spirituality and Religion

It isn't unusual for people to confuse "spirituality" with "religion" and to think they are more-or-less the same thing. While the two can intersect, they can also diverge, and it is spirituality that seems to have the more salubrious effects.

> *"Many of the studies and scholarship in the IDD literature tend to merge religiousness and spirituality and assume an integration for individuals. The larger literature has revealed that while there is overlap, the distinctions matter as spirituality has been shown to have more well-being and growth benefits than religiousness.[18]"*

As Dow notes, "Spiritual beliefs, practices, and experiences extend beyond religious boundaries" to encompass the personal search for meaning, purpose and connection[19].

That said, confusing the two terms was evident with co-analysts who acknowledged that they and their colleagues tended to see them as the same thing.

Despite making the conceptual distinction, it will be difficult to operationalize it. Focus group participants noted that "religion and spirituality are so intertwined" that it will be difficult to tease them apart. An implication is that negative or positive experiences with religion can colour how staff (and likely PS) respond to the term "spirituality." For example, Q6 asked "What words come to mind when you think of spirituality?" Open survey responses included everything from "bogus" and "fundamentalism, war, bigotry" to "meditation, presence, practice, love."

2. Managers and frontline staff tend to have different starting places

There is a sharp contrast between the religiosity of frontline workers and the increasing levels of non-religiosity of those in higher levels of management.

Table 3: Responses to Q8 based on role and religious and non-religious affiliation

Q8: Which of the following best describes your religious or spiritual (religious or nonreligious) identity(-ies)? (Check all that apply:)	Religious & Eastern philosophy affiliations[20]	Non-religious[21]	Prefer not to answer	Total
A frontline worker	48 (67.5%)	21 (28.7%)	4 (5.4%)	73
I am a contracted caregiver	7 (53.8%)	5 (38.4%)	1 (7.6%)	13
I supervise front line-workers	9 (37.5%)	14 (58.3%)	1 (4.1%)	24
I oversee supervisors or contracted caregivers and would be considered a manager	4 (36.3%)	5 (45.4%)	2 (18.1%)	11
I am a senior manager or director	2 (20%)	8 (80%)	0 (0%)	10

This contrast extends to the relative importance of spirituality in their lives:

Table 4: Responses to Q7 based on role

Q7: How important is spirituality to you?	Very important	Important	I am indifferent to it	Un-important	Very un-important	Blank	Total
A frontline worker	36 (48%)	25 (33.3%)	10 (13.3%)	2 (2.6%)	2 (2.6%)	1 (1.3%)	76
I am a contracted caregiver	5 (41.6%)	2 (16.6%)	4 (33.3%)	1 (8.3%)	0 (0%)	0 (0%)	12
I supervise front line-workers	5 (22.7%)	10 (45.4%)	4 (18.1%)	2 (9%)	1 (4.5%)	1 (4.3%)	23
I oversee supervisors or contracted caregivers and would be considered a manager	2 (20%)	6 (60%)	2 (20%)	0 (0%)	0 (0%)	0 (0%)	10
I am a senior manager or director	1 (11.1%)	4 (44.4%)	3 (33.3%)	0 (0%)	1 (11.1%)	1 (10%)	10
Response or blank	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (100%)	1

This contrast may help elucidate why, when asked “Should staff in your type of role be supporting people with their spiritual development and expression?” (Q13, Table 5), frontline staff predominantly said “Yes, very much,” (36.8%; 28 of 76), while higher levels of management were more cautious[22]. Anecdotal evidence supported the finding that frontline staff tended to be more religiously affiliated (for example, a long-serving frontline worker said that most staff they work with are Catholics/Christians).

Table 5: Responses to Q13 based on role

Q13: Should staff in your type of role be supporting people with their spiritual development and expression?	Yes, very much	Yes	Somewhat/ Unsure	No, not really	No, not at all	Blank	Total
A frontline worker	28 (36.8%)	26 (34.2%)	17 (22.3%)	4 (5.2%)	0 (0%)	1 (1.3%)	76
I am a contracted caregiver	4 (33.3%)	6 (50%)	0 (0%)	2 (16.6%)	0 (0%)	0 (0%)	12
I supervise front line-workers	6 (27.2%)	12 (54.5%)	3 (13.6%)	1 (4.5%)	0 (0%)	0 (0%)	22
I oversee supervisors or contracted caregivers and would be considered a manager	3 (30%)	6 (60%)	1 (10%)	0 (0%)	0 (0%)	0 (0%)	10
I am a senior manager or director	2 (22.2%)	3 (33.3%)	1 (11.1%)	1 (11.1%)	2 (22.2%)	0 (0%)	9

Differences in religiosity levels among staff, and between staff and management, whether real or hypothesized, surfaced frequently in conversations and illuminated possible tensions between the religiously affiliated and nonaffiliated, and between management and frontline workers. On the one hand, managers were more likely to have misgivings around religion and/or spirituality. Their professional experience made them more cautious about broadening permissions around spirituality for fear it would lead to evangelization in the programs. They recalled “some really difficult conversations” with frontline staff about not evangelizing, including to co-workers, and needing to park their personal beliefs at the door. A CEO acknowledged that such “parking” is “a really big ask.” Consequently, they were concerned that some staff would use such permissions to try to convert others to their beliefs. Interestingly, there was no concern voiced about the imposition of secular worldviews, revealing an unstated assumption that secularism is a morally neutral or preferred worldview. Additionally, leadership was also concerned that it would produce ethical conflicts when the religious and cultural viewpoints of staff and PS were misaligned.

On the other hand, frontline staff seemed to be aware of the dangers of imposing their views on PS. In Q19, the survey asked: “If you feel uncomfortable discussing spirituality or supporting people with their spiritual interests/ development, why is this the case?”

The most common answer was: “People with disabilities can be impressionable, and I don't want to influence them.” This would seem to indicate a high level of regard for PS agency and autonomy, and an awareness of the importance of boundaries—something that is further illustrated through requests for more training and guidelines.

3. The treatment of sexuality and spirituality is similar

The agencies have been advancing sectoral conversations, resources and support around addressing the intimacy needs of persons with IDD. Participants from most (if not all) groups frequently mentioned this and drew parallels to spirituality: both topics are morally and culturally sensitive and involve important needs that are often overlooked.

> *So, one thing I see very similar is like, Real Talk. Like 10 years ago, the whole sexual thing was the same; taboo, on the side, nobody talks about this. Now it's mainstream [board member].*

Participant ideas to address spirituality were patterned off Real Talk and ranged from creating a tailor-made platform to address spirituality to providing training that enabled staff to become more confident, approachable, and better equipped to handle spirituality-related needs. As with Real Talk and sexuality, the goal would be to normalize spirituality within services to PS.

4. Guidelines and training are needed

This study revealed that thinking and practice around spirituality is very much in its infancy among the participating agencies and within the broader community living sector. Despite broad agreement that spirituality is important and should be supported (for example, 75% of survey respondents thought their role should include supporting PS in their spiritual development and expression [Q13][23]), there was a recognition that this was a complex topic that would require careful consideration.

Table 6: Majority responses to Q11 and Q12 from all respondents, regardless of religious or non-religious affiliation[24]

	Yes, very much	Yes	Somewhat/ Unsure	No, not really	No, not at all	Total
Q11: Do you consider some of the people you support to be "spiritual" people?	35 (27.1%)	59 (45.7%)	25 (19.4%)	9 (7%)	1 (0.8%)	129
Q12: Do you believe people with intellectual and developmental disabilities should be supported to make their own decisions around spirituality?	77 (59.7%)	46 (35.7%)	5 (3.9%)	1 (0.8%)	0 (0%)	129

One CEO acknowledged that agencies are "not being as explicit and in part because we don't necessarily know how to be explicit about it." There is wide agreement that direction is needed, but what sort of direction?

Navigating the tensions between the personal and the professional self

There are staff across all roles who indicate that spirituality is not personally important to them, who either agree or are unsure about whether the people they support have spiritual needs (Q10)[25], and who still consider some of the people they support to be spiritual people (Q11). This suggests that staff are able to bracket their personal dispositions and beliefs in order to support individuals wherever they're at.

But doing so isn't always easy for them. Attending a house of worship with a PS can be difficult if they find the theological messages objectionable or triggering. One staff shared that a misalignment around values made it difficult for them to ongoingly support a PS to attend a local Salvation Army Church: "That was a journey for me to sort of navigate, those, yeah, feelings of discomfort in that situation." This tension surfaced many times in discussions, with guidelines often sought as remedies.

Making the right choices

Addressing spirituality can present a range of moral quagmires. These quagmires are already encountered by employees, despite lacking a clear set of guidelines around how to approach them. This produces a number of risks, including that it leaves matters to individual staff or staffing teams to discern what is appropriate, and this can lead to inconsistent, problematic or confusing practices.

Additionally, without a sense of how one is supposed to traverse the ethical terrain, staff will be more reticent to offer support. As one director noted: “We tend to be silent about it. So, if we’re silent about it, then staff are going to say ‘no’; I mean, we communicate by not communicating.” A staff person confirmed this silence: “The people from management never say too much about this topic. We can talk, or we cannot talk?—It’s unclear, we don’t know.” The staff added that “if we know it’s okay, I think we will have more conversation, more situation about this, about the religious, we will do some activities based on the religious. That’s my understanding.” In the absence of guidelines, it’s unlikely spirituality will receive more than cursory and sporadic attention.

It also means that current practices will be conserved because they are assumed to be acceptable, and managers will be reluctant to end or change them, or to introduce something new. For example, a manager talked about a scenario where a devout Christian staff in a licensed home had everyone pray before every meal and at bedtime, despite the fact that many of the residents were not particularly devout. The manager went on to say that a common reaction for many in oversight roles might be to leave it alone: “it’s just safest and best for everybody if I just don’t even touch this topic because there’s so many ways to put my foot wrong and if I put my foot wrong I’m gonna get into trouble, but if I just say nothing and it’s never a topic that ever gets discussed then I won’t be reprimanded for that.” Thus, the danger is not simply that staff won’t make space for prayer when they should, but that they will continue to require it when they shouldn’t.

Also, confusion around roles and boundaries can lead to conflict between PS, staff, managers, families or faith communities. What sort of support is required, and of whom? For example, “Are you asking me to support someone to attend church, or are you asking me to support them by teaching them?” (CEO). Should this be the purview of families rather than agencies, as one board member felt, or was it something that should be addressed in conjunction with families, which another board member believed? Networks and families were frequently identified as key partners in caring for the spiritual life of PS. Ideally, conversations around spiritual needs would occur with the family present, but PS and family perspectives may not align, and “lots of people in adulthood change denominations, change paths, and reevaluate” (manager).

Staff can feel caught in the middle: “Because we don't have the training, we don't know how to talk about it. And then, the other side, we don't have the permission, if their family is happy to talk about their religions or not. We don't know. We don't know the information.” And, as one participant said, to introduce a PS to a new food is doing one’s job well; to introduce them to a mosque down the street is fraught with danger, as it could upend family traditions. Overstepping one’s role can lead to conflict, especially on the topic of spirituality and in the context of support to vulnerable people. This can also have the effect of further disincentivizing staff from engaging at all. The importance of clarifying roles and responsibilities was a recurrent theme.

One's spiritual beliefs can have implications around how one wants to be supported in other parts of their lives, too. For example, what if supporting their spiritual wellbeing ostensibly conflicts with their physical wellbeing (which is sometimes a consequence of belief systems)? As a manager noted: "So, say if that person explores being a Jehovah's Witness and then changes their health care directives. So, what about those situations where there may be life or death consequences of their choice around spirituality? I can see why staff would be like, ah, I need… training."

Lastly, beyond making the best possible decisions, guidelines would also alleviate staff duress, fear and discomfort around navigating this topic and their role in supporting PS.

Moving from principles to practice

While agencies have policies and documentation that recognize religious freedoms and the right of PS to engage in religious practices (or to not engage), there is little reference to how these freedoms are practically understood, or to how spirituality is generally considered and supported. This disconnect between principle and practice was also evident with staff. Although the majority of staff believe that spirituality is important, that the PS they support are spiritual people, and that they have a role in supporting people with their spirituality, the majority were also skeptical or uncertain if PS were expressing their spiritual needs or preferences.

Table 7: Responses to Q14 by role

Q14: Do the people you support express their spiritual preferences and needs?	Yes, very much	Yes	Somewhat / Unsure	No, not really	No, not at all	Total
A frontline worker	6 (8.5%)	21 (30%)	20 (28.5%)	19 (27.1%)	4 (5.7%)	70
I am a contracted caregiver	1 (8.3%)	5 (41.6%)	2 (16.6%)	4 (33.3%)	0 (0%)	12
I supervise front line-workers	3 (13.6%)	8 (36.3%)	8 (36.3%)	3 (13.6%)	0 (0%)	22
I oversee supervisors or contracted caregivers and would be considered a manager	0 (0%)	4 (44.4%)	3 (33.3%)	2 (22.2%)	0 (0%)	9
I am a senior manager or director	2 (22.2%)	2 (22.2%)	2 (22.2%)	1 (11.1%)	2 (22.2%)	9

Table 8: Responses to Q14 by service area

Q14: Do the people you support express their spiritual preferences and needs?[26]	Yes, very much	Yes	Somewhat / Unsure	No, not really	No, not at all	Total
Residential (n=67)	7 (11.4)	19 (31.1%	15 (24.5%)	19 (31.1%)	1 (1.6%)	61
Community inclusion/day program(s) (n=43)	1 (2.4%)	15 (36.5%)	15 (36.5%)	6 (14.6%)	4 (9.7%)	41
Independent Living, Outreach, Life skills, Supported Living (posA) (n=9)	1 (11.1%)	4 (44.4%)	1 (11.1%)	3 (33.3%)	0 (0%)	9
Building Caring Communities, Explore (PosA), LIFE (Kinsight/BACI), Stitch (BACI) (n=9)	1 (11.1%)	4 (44.4%)	4 (44.4%)	0 (0%)	0 (0%)	9
Employment (n=9)	0 (0%)	2 (25%)	2 (25%)	3 (37.5%)	1 (12.5%)	8
Shared Living/Life Share (n=13)	2 (18.2%)	4 (36.4%)	3 (27.3%)	2 (18.2%)	0 (0%)	11

As one CEO reflected, these responses may be due to PS not expressing their spiritual desires or staff not recognizing it when they see it, especially if it doesn't involve attending a house of worship.

One way that spiritual preferences might be addressed is through person-centered planning (PCP). A review of PCP processes revealed a scant number of goals related to faith-based services or activities. And, even with those, several staff questioned whether they reflected spiritual needs or whether they might be attending a house of worship because it includes a meal, or because it's primarily about meeting people, or because the home share provider attends them.

There were many more goals that might have a spiritual basis, but there is no way to know because the process doesn't elucidate what's beneath them (e.g. walking might be about connecting to nature, volunteering about connecting to something transcendent, family meals about connecting to others, and music therapy about connecting to oneself).

A CEO anticipated that while planning processes have mechanisms that should be able to capture spiritual needs and preferences, the process may lapse into a perfunctory exercise over time: "I would question too, how well it's addressed through planning because certainly, you know, if planning is to go through the years and some of the questions can drop off or just be really skimmed over. Yeah, it really depends on the skill, I guess, on the comfort of the facilitator." They went on to say that a review of policies and practices related to individual learning and planning was needed "to ensure that we're asking questions and providing opportunities through that process in a way that will surface in these things."

Staff confirmed this hunch that spirituality is generally disregarded in personal growth and goal setting, especially if the staff conducting the processes or facilitating the conversations is not religious or spiritual themselves: "If you're not an experienced person, you wouldn't necessarily think about that." They went on to say that when it comes to planning, it's "not a norm to have [spirituality] as part of the conversation." This absence is a lost opportunity to get traction on organizational commitments to accommodating PS religious or spiritual needs and preferences.

A need for training

Question 19 on the survey asked: "If you feel uncomfortable discussing spirituality or supporting people with their spiritual interests/ development, why is this the case?" The top four (of 25) 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%)

To address these concerns, survey respondents,[27] focus group participants, and co-analysts overwhelmingly said that more guidelines and training are needed. This desire was echoed at all levels in the agencies. While guidelines can provide information and direction, training helps to translate them into everyday practice. Co-analysts described historical benefits of training in improving how staff engage with PS. Further, studies in nursing and among healthcare workers have shown that the differences in spiritual care were due to staff attitudes linked to training and the particular ethos of the services.[28]

Examples of some of the topics that were identified for training included:

- Staff are not "spiritual conduits" or spiritual guides
- Spirituality is not missional, evangelical or about impressing certain views
- Boundaries between staff, circles of support, and places of worship
- Applicable statutory, regulatory and contracting frameworks

Practical training would also be needed around (1) religious and spiritual literacy for staff, especially given the diverse terminologies, lenses, and approaches used by staff and PS (one

staff suggested that management could send out emails with information about local programs and events) (2) navigating sociocultural conflict and complexities, because staff were worried about worldview clashes amongst themselves and with families[29]; and (3) tools and strategies to support those across a broad range of abilities and disabilities, including those who are nonverbal, and that provide staff with "the comfort and the permission to do the work…and to do it within certain guidelines" [manager].

Also, there were questions around whether training would need to look different for employees in different programs or who were occupying different roles within the agencies. Spiritual literacy and support might look different in a residence, day program, or employment service, for instance. There was also a question around whether progressive levels of training might be required based on the support needs or plans of individuals, though it might also be envisioned for employees who transition into more senior roles.

But there may be limits and drawbacks to training, too. A long-term staff felt that "to support someone … with their spirituality, there has to be some emotional connection, emotion[al] relationship with the other person, because if they don't have that… I see it as just work. …There's nothing person-centered about it." If the quality of the relationship is important to supporting someone with their spiritual expression and development, it's unclear to what extent conventional training can foster it. One suggestion was to provide training to both staff and PS, thereby positioning them both as co-learners and avoiding the teacher-student binary. Undertaking a shared journey of spiritual exploration could dissolve power dynamics and lead to the sort of mutuality conducive to spiritual support.[30]

One recurring concern was that training might lead to an overly "transactional", "checkbox", or "program" approach to spirituality (descriptions are from focus group discussions). Leadership, particularly, were concerned that by introducing more structure and training around spirituality, it's organic essence could be lost.

> *But the focus is: I need more training, I need guidelines, I need policies, I need procedures, right, in order to engage in this, in this work, in this line. And, yet the notion of spirituality, to me anyway, is so counter to the notion of policy and procedures [director]. …because as soon as you…system it, you train it, you package it up in documentation, then something gives, right? Like…then it becomes a program… which is not what you want [with] spirituality. You want it to be natural and, in its moment, and there's going to be different times in your life it's more important to you and why it's more. You know, and for us when we're in that service delivery, we have to put things in place to sort of make sure it gets done too. Right? And so, it's just always that fine line of like, making sure it gets done, but making sure that it's not just getting done, because they're two different things [CEO].*

Conclusion

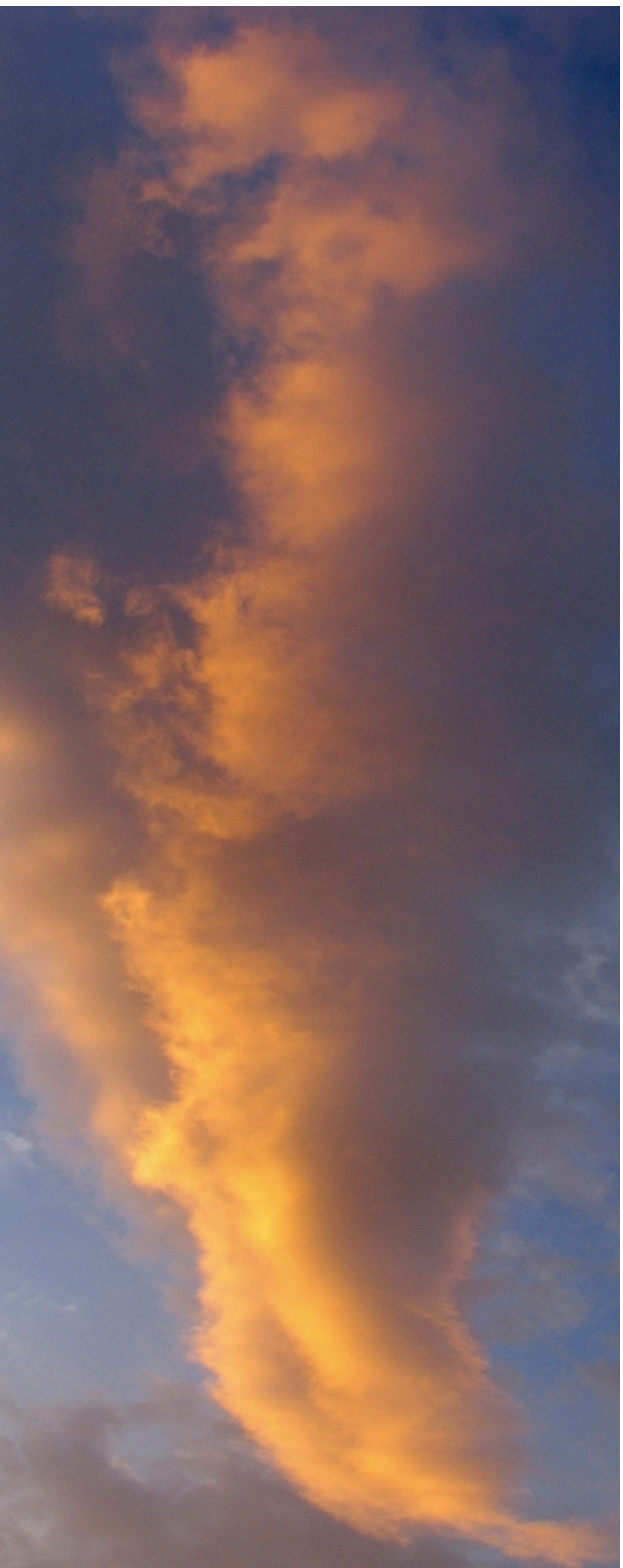
The literature review, survey responses, interviews/focus groups and co-analysis sessions all pointed to the importance of spirituality in the lives of people with intellectual and developmental disabilities. However, what that means or looks like can be different for everyone, and there is no universal understanding of what spirituality is. More often than not, people tend to conflate it with institutionalized religion, inheriting all the related objections, associations and stigma, while also excluding consideration for the many nonreligious forms of spirituality. But establishing a clear definition of spirituality comes with a double edge. On the one hand, without a clear definition, agencies may have trouble developing a coherent strategy and measuring progress towards it. On the other hand, tightening its meaning could exclude some of the diverse interpretations and approaches held by PS, staff, and families.

The research also illustrated a gap between ideals/expectations and actual practice. Agencies struggled to identify PS spiritual needs or preferences, or to address them in their programs and services. Fears around doing the wrong thing, whether imposing a belief, breaching protocols or overstepping roles, meant that employees at every level were reluctant to do anything beyond responding to explicit requests for support (e.g. attending religious events or activities). This led to frequent calls from research participants for more guidelines and training, though there are concerns that treating this as a skills-and-programming issue will miss the essence of spirituality.

Lastly, we note that organizational liaisons remarked on existing feelings of being overwhelmed around the volume of work facing staff, managers, and leaders. Capacity and resources are already stretched thin, and it was hard to imagine how agencies might undertake to meaningfully address such a complex and challenging topic. Kinsight, BACI and posAbilities are probably not alone—we imagine other providers in the sector are in a similar place. One idea was to engage the willing—those employees from across the agencies (or the sector) who resonate with this topic, and who can be jointly supported to grow and share learning around practice.

Either way, agencies face a difficult choice: to translate the perceived (and evidence-based) importance of spirituality into more strategic action, which will be a challenging undertaking, or to accept that the spiritual needs and preferences of persons served are quite possibly not being met. While it's reasonable to conjecture that some gaps exist, it's also possible that confusion around the term "spirituality" could also mean that the spiritual needs of PS **are** being met, but that they are not being recognized as such (e.g. walks in nature, time spent with family and friends, art projects, and so on). More work would be needed to get a sense of what spirituality "on the ground" looks like, but resources might be better expended on developing a spirituality strategy and implementing it.

On the promising side, the vast majority of staff believe in the importance of spirituality for themselves and PS, and they are ready and willing to be engaged. Most would probably agree with author Carolyn Myss that “Every life has a spiritual purpose, and every person plays a role in the spiritual development of others.” Certainly, the majority of staff respondents believe they should be available to support the spiritual journeys of PS and are looking for direction around how to do that well. In the end, staff do play a role, whether witting or unwitting, supportive or not, available or unavailable, and so the more discerning question is probably not **if** they should be involved, but **how**.



Limitations

Some of the limitations of this phase of the project include:

- The researchers haven’t worked in the IDD-serving sector and may not have picked up on nuances around its unique character and challenges (the assignment of organizational liaisons and co-analysts were intended to help mitigate this)
- Survey respondents and some focus group participants self-selected based on existing interest in the conversation.
- The higher rates of religiosity among frontline respondents could reflect a self-selection bias in that those who find spirituality and religion important may be more likely to complete the survey, thus skewing the results.
- Only two frontline staff members participated in focus group discussions. This added insight to our survey findings but did not let us explore the survey findings with frontline staff in greater detail.
- Staff responses were informed by their work with particular individuals, but insofar as PS represent a very broad spectrum of abilities and disabilities, it is problematic to generalize.
- Despite our efforts in the survey preamble to clarify that spirituality can be religious or nonreligious, this conflation is likely to have influenced survey responses.

Appendix I: Survey questions

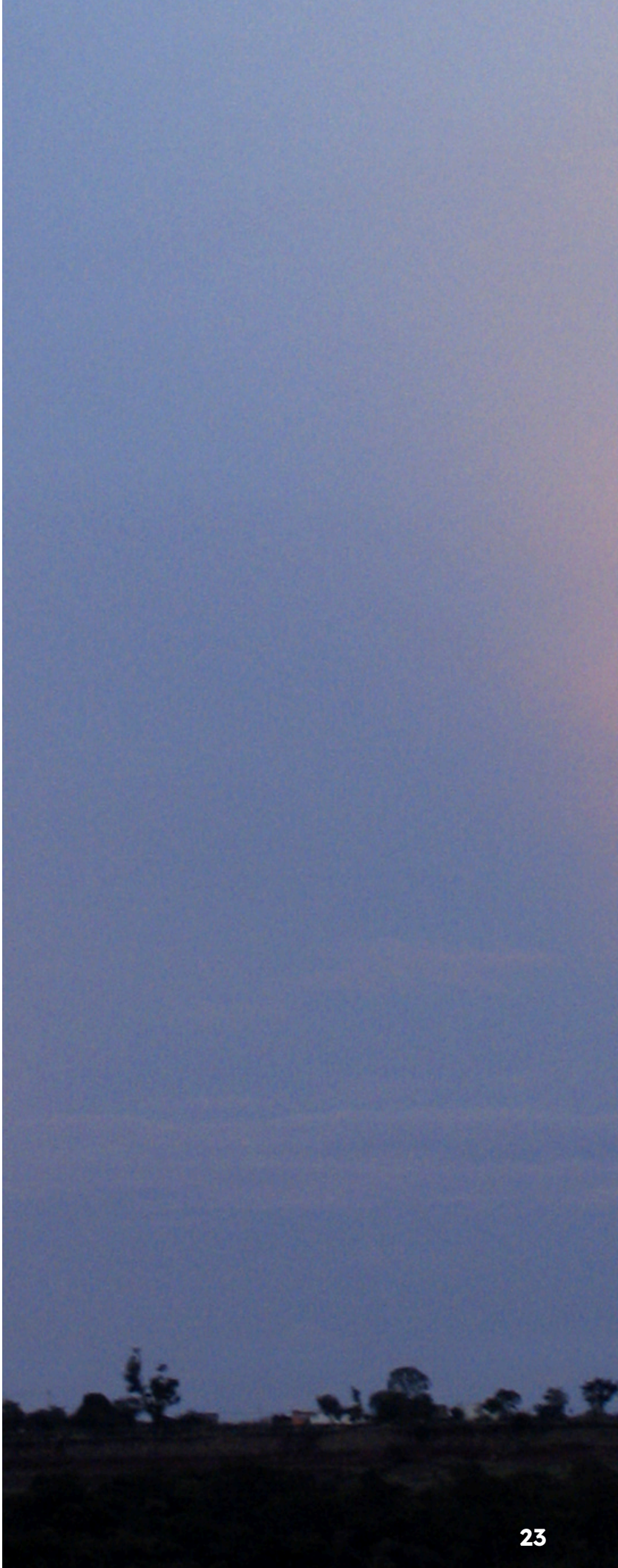
Note: Survey questions consist of check boxes with the exception of questions 5, 6, 15 and 21, which invite comments.

1. I work for (Check all that apply):
2. I work in the following service area(s): (Check all that apply)
3. My role is:
4. My work is:
5. Which race(s), ethnicity(-ies), and/or cultural origin(s) do you identify with?
6. What words come to mind when you think of spirituality?
7. How important is spirituality to you?
8. Which of the following best describes your religious or spiritual (religious or nonreligious) identity(-ies)? (Check all that apply):
9. Do you see your work as some sort of “calling” in life (whether in religious or non-religious terms)?
10. Do you believe people with intellectual and developmental disabilities have spiritual needs?
11. Do you consider some of the people you support to be “spiritual” people?
12. Do you believe people with intellectual and developmental disabilities should be supported to make their own decisions around spirituality?
13. Should staff in your type of role be supporting people with their spiritual development and expression?
14. Do the people you support express their spiritual preferences and needs?

15. Please elaborate:
16. In your experience, spirituality has been an important part of a person with intellectual and development disability's:

- employment
- social relationships
- community participation
- mental health
- self-determination

17. Are you comfortable discussing spirituality with the people you support? Or, if you are on the management or leadership team, are you comfortable supporting your staff to discuss spirituality with the people they support?
18. Are you comfortable supporting people with their spiritual interests or development? Or, if you are on the management or leadership team, are you comfortable having your staff support the people they support with their spiritual interests or development?
19. If you feel uncomfortable discussing spirituality or supporting people with their spiritual interests/development, why is this the case? (Check all that apply):
20. 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?
21. Thank you for your thoughts. Please use the space below to ask any questions, add more details to responses above, or share additional comments that you have on this topic. All comments are welcome.



Appendix II: Focus group questions

Focus groups were organized in a discussion and conversational approach with semi-structured and open-ended questions. Questions changed slightly as each focus group conversation informed discussions and considerations for the next one. However, our discussions initiated with these main points:

- How do you define spirituality?
- Are the survey findings consistent with how you understand your role?
- Are the survey data consistent with your experience?
- How do you respond to what staff shared about what they need to support adults with IDD in their exploration of spirituality?
- Are there key takeaways from the survey data or the focus group conversation for you and/or your organization?

High-level findings from Q5, 7, 8, 10, 13, 16, 17, and 19 in the survey were shared to inform the conversation.

Endnotes

[1] Gaventa, B. (2021). Whose am I? Spiritual pathways into the heart of belonging. In J. L. Jones, K. L. Gallus (eds.), *Belonging and Resilience in Individuals with Developmental Disabilities*. Springer, p. 81. doi.org/10.1007/978-3-030-81277-5_6.

[2] P. 2 from Dow, K. (2023). Thousands of glittering shards: Spirituality as resonance in the lives of people with intellectual disabilities. *Religions,* 14, 886. 11pp. doi.org/10.3390/rel14070886. We also appreciate the sentiments expressed by Huggins & Copeland (2023) who wrote "It is time for faith and disability research to move beyond questions of *if* people with IDD have faith or faith experiences that are valuable or important and move toward questions of *how* to support the important and valuable faith experiences of people with IDD who would like to have them."

[3] A common misunderstanding of Maslow's Hierarchy of Needs, a theory of human motivation oft-cited in Canadian education, social work and business, is that safety needs must be more-or-less satisfied before higher-order needs can be pursued. This is not a categorical progression as needs can be contemporaneous, and sometimes higher order needs for things like purpose, meaning, love, forgiveness, and beauty are more pressing than survival needs. Interestingly, Maslow developed his hierarchy based on time spent with the Siksika Nation (Blackfoot People) of southern Alberta. Although the experience profoundly impacted him, resulting in a shift away from behaviourism to humanist psychology, he did not understand their worldview and his hierarchy does not represent it. See "Reconsidering Maslow and the hierarchy of needs form a First Nations' perspective" (2022) by Elder Roy Bear Chief – Oom Kapisi (Big Coyote), Peter W. Choate, Gabrielle Lindstrom for more details: doi.org/10.11157/anzswj-vol34iss2id959.

[4] All data sets are available from Statistics Canada Census 2021.

[5] "Recognize discrimination against nonreligious." (2017). BC Humanist Association. bchumanist.ca/recognize_discrimination_against_nonreligious.

[6] In 2023, Millennials overtook the Baby Boomers as the largest population cohort, due in part to immigration. (Statistics Canada, 2024, www150.statcan.gc.ca/n1/daily-quotidien/240221/dq240221a-eng.htm).

[7] Wilkins-Laflamme, S. (2023). *Religion, spirituality and secularity among Millennials: The generation shaping American and Canadian trends*. Routledge.

[8] Patrick, M. & Chan, W.Y.A. (2022). Can I keep my religious identity and be a professional? Evaluating the presence of religious literacy in education, nursing, and social work professional programs across Canada. *Education Science*s, 12(8), 543. doi.org/10.3390/educsci12080543.

[9] Dow, K. (2023). Thousands of Glittering Shards: Spirituality as Resonance in the Lives of People with Intellectual Disabilities. *Religion*s, 14(7), 886, doi.org/10.3390/rel14070886.

[10] Same as above.

[11] Real Talk (real-talk.org) is a platform that emerged from social R&D investments by Kinsight, BACI, posAbilities and InWithForward.

[12] Gómez, A., Puigvert, L., & Flecha, R. (2011). CCM: Informing real social transformation through research. *Qualitative Inquiry*, 17 (3), 235–245. doi.org/10.1177/1077800410397802; Gómez, A., Racionero, S., & Sordé, T. (2010). Ten years of critical communicative methodology. *International Review of Qualitative Research*, 3 (1), 17–43. jstor.org/stable/10.1525/irqr.2010.3.1.17; Puigvert, L., Christou, M., & Holford, J. (2012). CCM: Including vulnerable voices in research through dialogue. *Cambridge Journal of Education*, 42 (4), 513–526. doi.org/10.1080/0305764X.2012.733341.

[13] Survey analysis considered:

- Which questions were skipped most often? Why?
- Exclusionary elements, in accordance with the aims of CCM
- Transformative elements, in accordance with the aims of CCM
- How do staff understand themselves? (Q5)
- Do “religious” staff and “non-religious” staff hold different personal perspectives?
- Analysis by roles (Q10, 11, 13, 14, 17, 18)
- Analysis by service areas (Q10, 11, 13, 14, 17, 18)
- Analysis by agencies (Q10, 11, 13, 14, 17, 18)
- Analysis between personal perspectives and professional perspectives
- For those who are “uncomfortable” supporting or discussing spirituality, what are their most common reasons for discomfort?

[14] Three staff RSVPed to the first focus group but only one attended. Two RSVPed for the second focus group and only one attended. We decided to proceed with those who attended despite the low numbers.

[15] Some focus group participants and co-analysts were asked or appointed to participate. In certain research approaches, this can be seen as a limitation because participants did not join the conversations voluntarily. However, for the aims of this project, it was important to ensure particular perspectives were included, such as those of HR Directors and the Program Directors. All provided insight into the discussion and became collaborators towards project goals.

[16] For those who are unfamiliar with word clouds, the more frequently a word is cited by respondents, the larger the font. The frequency is also clustered into different colour tiers. In this case purple is tier 1 (most cited), blue is tier 2, yellow is tier 3, and orange is tier 4 (least cited).

[17] Page 67 from Carter, E.W. (2013). Supporting inclusion and flourishing in the religious and spiritual lives of people with intellectual and developmental disabilities. *Inclusion*, 1(1), 64-75. DOI: 10.1352/2326-6988-1.1.064

[18] Niemiec, R.M. & Tomasulo, D. (2023). *Character strengths and abilities within disabilities: Advances and practice*. Springer, p. 184.

[19] P. 2-3 from Dow, K. (2023). Thousands of glittering shards: Spirituality as resonance in the lives of people with intellectual disabilities. *Religions*, 14, 886. 11pp. doi.org/10.3390/rel14070886.

[20] For categorization purposes in this report, “Religious & Eastern philosophy affiliations” refers to those who identified as Buddhist, Sikh, Hindu, Baha’i, Christian, Indigenous Spirituality, Jewish, Muslim, Pagan, Rastafarian, Taoist, Unitarian, Catholic, Karma, and Religious AND Spiritual (as these terms are not mutually exclusive).

[21] Similarly, “Nonreligious” refers to those who identified as Atheist, Agnostic, Humanist, New Age, Spiritual, But Not Religious, and No Religious Affiliation.

[22] Every focus group wrestled with the meaning of “support” and indicated that it was vague and could be understood in many different ways, and that confusion around its meaning may have led to the variety of responses we received.

[23] Respondents in leadership roles were significantly less likely to see a role for themselves though this may be attributed to a combination of how they interpreted “support” and how they perceived their role (e.g. HR directors, board members, etc.).

[24] This is true across all agencies, although more Kinsight respondents tended to answer “somewhat/ unsure.”

[25] Q10 asked: “Do you believe people with intellectual and developmental disabilities have spiritual needs?”

[26] All questions were optional, so some questions had less responses than others. The sample number in this chart indicates those who self-identified their service area in Q2: “I work in the following service area(s): (Check all that apply).”

[27] Q20 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?”; 68% of respondents identified training.

[28] Page 157 in Sango, P.N. & Forrester-Jones, R. (2019). Spiritual care for people with intellectual and developmental disability: An exploratory study. *Journal of Intellectual and Developmental Disability*, 44(2), 150-160. doi.org/10.3109/13668250.2017.1350834.

[29] Covenantal Pluralism is one framework that may be useful: templetonreligiontrust.org/areas-of-focus/covenantal-pluralism/.

[30] Note: This is the approach that Curiko takes, and it has produced valuable outcomes and learning for a subsequent phase of our research.

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