

An Investigation of Spirituality in Person-Centered Planning for Adults with Intellectual/Developmental Disabilities

Introduction

In a joint position statement, the American Association on Intellectual and Developmental Disabilities and the ARC state, “People with intellectual and/or developmental disabilities have the right to choose their own expressions of spirituality, to practice those beliefs and expressions, and to participate in the faith community of their choice or in other spiritual activities” (AAIDD, 2015). Despite this best practice stance from national expert organizations, inclusion of people with disabilities in faith communities remains sub-optimal; this is a problem since participation in a community of faith contributes to personal well-being, belonging, and sense of purpose for many individuals in our society, including those with disabilities (Gaventa & Carter, 2012). To change this, four groups must come together, (a) individuals with disabilities; (b) faith communities; (c) families of people with disabilities; (d) support service providers (Carter, 2013). Current literature describes the efforts of faith communities and families relative to spiritual inclusion; however, little is known about how support service systems are addressing this topic (Carter et al., 2012).

Literature Review

Over the past 40 years, inclusion of people with disabilities has changed substantially. People with disabilities have moved along a continuum from being segregated and isolated (excluded), to being merely present in their communities (without involvement), to being fully included (welcomed, accepted, and involved with others who do not have disabilities) in educational, vocational, residential, and recreational activities (Mank & Grossi, 2013; Ryndak et

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al., 2013). Like other areas of life, faith community inclusion tends to progress along a continuum from exclusion to full inclusion as illustrated in Table 1.

Table 1

Faith Community Continuum of Inclusion

Level	Description
Exclusion: <i>Apart from</i> communities of faith.	Individuals with disabilities are (a) left out of faith communities; (b) not welcomed or accepted.
Physical presence: <i>At</i> communities of faith.	Communities of faith are architecturally accessible. Individuals with disabilities (a) are merely present in faith communities; (b) do not participate in separate or regular programs; (c) do not belong or contribute.
Separate programs: <i>Alongside</i> communities of faith.	Individuals with disabilities attend segregated programs designed only for those who have a disability.
Integration: <i>In</i> communities of faith.	Individuals with disabilities attend regular programs and participate but do not contribute.
Full inclusion: <i>With</i> communities of faith.	Individuals with disabilities' spiritual interests are respected and valued by disability support providers and communities of faith. Individuals with disabilities (a) belong; (b) are supported to develop and express their spirituality; (c) engage in spiritual life; (d) use their unique spiritual gifts to contribute to the life of the faith community.

While people with disabilities have advanced along this continuum in many areas of their lives, their full inclusion in communities of faith lags significantly behind.

Systems of support are driven by a deep commitment to empowering people with disabilities to flourish. The experiences and interactions that contribute to thriving will vary from

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one person with disabilities to another. For one person, meaningful employment, a safe and comfortable place to live, enduring friendships, and strong community connections may all be important aspects of flourishing. Another individual may value good health, a strong support system, and intimate relationships. For many people with disabilities, “spirituality and opportunities to worship, learn, serve, and fellowship alongside others within a community of faith also contribute substantially to their own flourishing” (Carter, 2013, p. 64). Even though people with disabilities indicate that expression of faith and spirituality is important to them to flourish, most of the research in this area focuses on how faith communities and families can support the inclusion of people with disabilities in their congregations. While faith communities and families obviously play a key role in the equation, direct-support service providers are also crucial. Meaningful opportunities for inclusion in communities of faith are most likely when all four of these stakeholders work together with each other (Carter, 2013).

Some disability support agencies and service providers include spirituality and religious participation among the consumer rights that they endeavor to support. Unfortunately, this commitment is seldom put into practice. Studies show that resources and education for disability support agencies relative to spiritual expression and inclusion in faith communities is uneven or altogether absent (Ault et al., 2013). Unlike other domains of life, many disability service agencies have been slow to develop inclusive models of involvement in communities of faith communities; while not validated, Ault et al. (2013) offer several potential barriers that may prevent disability support personnel from addressing this topic, including

- minimizing the importance of faith in the lives of the individuals they support;
- undervaluing the contributions of faith communities to people with disabilities;

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- limiting opportunities for individuals to explore places of worship of their own choosing;
- confusing roles and discomfort of staff related to supporting individuals with disabilities in faith communities (especially if the beliefs and spiritual interests of the staff differ dramatically from those of the individual being supported);
- worrying about crossing the line of separation between church and state;
- failing to schedule adequate staff on the weekends to support individuals with disabilities in communities of faith.

There has also been a mistaken belief among many disability support providers that individuals with disabilities do not have the capacity to deepen or express their spirituality (Gaventa, 2005). Many people believe the premise that a disability limits a person's ability to be meaningfully engaged in his or her faith community. In one of the few studies on this topic, the authors indicated that, "almost two thirds of the Canadian service providers in the study said spiritual activity was not applicable to the adults they served, and less than one quarter of these providers reported that the spiritual needs of these adults had been identified and supported through involvement in their community" (Minnes et al., 2002). In addition, an article by Baca and McNair in the *Journal of the Christian Institute on Disability* (2013) indicated that 77% of the disability support staff who participated in a survey had, "little or no training in building effective and sustainable relationships with faith communities" (p. 38).

Disability service providers who are asked to support the inclusion of people with disabilities in religious and spiritual life "likely have had limited formal preparation to do so" (Carter, 2013, p. 65). Disability professionals may receive training in effective planning and supports in areas of life such as employment, independent living, community inclusion, and

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recreation/leisure activities. These same providers, however, are often less comfortable and confident in their ability to support people with disabilities to express their spirituality and participate in faith communities (Gaventa & Carter, 2012). As service systems acknowledge that spirituality and inclusion in a community of faith play an important role in the lives of the people to whom they provide support, they are in an optimal position to empower people with disabilities to thrive in all aspects of their lives. When disability support professionals “understand the beliefs and relationships people draw on for strength, their sense of calling or purpose in the world, the gifts they possess and which to share, and the ways in which they view and related to others, service providers can do a much better job of designing supports and creating opportunities that incorporate these values” (Carter, 2007, p. 153).

It is important to identify information to guide service systems in attending more fully to the spiritual support needs of the people with disabilities to whom they provide services. Carter et al. (2012) assert that, “Descriptive studies exploring whether and how providers are addressing spiritual supports within their written policies, assessment processes, person-centered planning approaches, service delivery, staff training, and evaluation efforts could provide insight into the development of recommended practices” (p. 33). Therefore, the purpose of this study was to investigate the beliefs, perceptions, and practices of direct support professionals (DSPs) regarding spirituality and its role in the person-centered planning process for people with disabilities.

Methods

Participants

A total of 62 DSPs from across the nation responded to the survey. Thirty five percent of the DSPs worked in the upper Midwest, 27% on the Eastern coast, 18% in the Midwest, 8% in

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the Southeast, 8% in the Southcentral region, 2% in the Southwest, and 2% on the Western coast. Sixty one percent worked in urban settings while 39% worked in rural communities. The ages of the DSPs were represented relatively evenly with 31% between 36 and 50 years of age, 27% between 25 and 35 years, 27% over 50 years, and 15% younger than 25 years old. All but two of the respondents indicated they supported adults or both children and adults with disabilities.

Materials

A researcher-developed survey instrument was used to investigate the perceptions, beliefs, and practices of DSPs and Qualified Intellectual/Developmental Disabilities Professionals (QIDDPs) regarding spirituality in person-centered planning for adults with disabilities. Face validity of the instrument was established through a) careful alignment of each item to a specific aspect of spirituality identified in the relevant literature: and b) review by two outside experts in the DSP/QIDDP field. The final survey instrument consisted of 39 total items and is included in the Appendix. Five items pertained to the demographics of the professionals completing the survey; six items pertained to the professionals' own spirituality; 13 items were specific to the professionals' perceptions of spirituality and persons with disabilities; four items pertained to policy issues that impacted spirituality and person with disabilities; and 11 items were related to practices related to addressing spirituality for persons with disabilities.

Procedure

The survey was created for electronic distribution on Microsoft Forms® and was sent via the email and social media pages of public and private organizations in the U.S. who support individuals with disabilities and employ direct support professionals. Organizations were identified through membership in the National Alliance for Direct Support Professionals

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(NADSP), the American Network of Community Options and Resources (ANCHOR), and the Association of University Centers on Disabilities (AUCD) and other agencies found through online search engines. The survey was open for a period of three weeks.

Results

Direct Support Professionals' Perceptions of Their Own Spirituality

The DSPs were asked five questions pertaining to their perceptions of their own spirituality; 74% considered themselves religious people and 63% indicated they participate in a religious community. Additionally, the majority of DSPs (87%) said they hold beliefs that help them enjoy life and 48% said they had strong personal beliefs that guide their decisions. Thirteen percent of DSPs said they are uncomfortable discussing spirituality because they themselves are not religious and 10% of DSPs indicated they are uncomfortable attending a religious activity with a person who has a disability if it differed from their own religious affiliation.

Direct Support Professionals' Perceptions of Spirituality for People with Disabilities

Perceptions of DSPs relative to the importance of spirituality for people with disabilities were highly favorable with 100% indicating they believe spirituality is part of self-determination and 98% percent saying spirituality can add to quality of life for people with disabilities. Further, 98% recognized that spirituality could be expressed not only through worship but through service, friendships, employment, hobbies, and nature and that serving others could be a meaningful activity for people with disabilities. While 94% of DSPs believe it is their responsibility to address spirituality for people with disabilities, 26% believe people with disabilities may lack the capacity to express spirituality.

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Policy and Agency Factors

DSPs were asked about agency policy and procedural factors that either facilitated or posed barriers to the inclusion of spirituality for the people with disabilities they supported. Only 8% said they were not permitted to address spirituality at their agency. Sixty three percent of DSPs indicated the domain of spirituality was on the person-centered planning form at their agency and 53% reported that spirituality goals appeared on person-centered plans at their agency. When asked if their agency included the aspect of supporting the spiritual needs of people with disabilities when discussing agency values and practices, for example in the agency mission statement or strategic plan, 58% of DSPs indicated yes, 29% said no, and 13% did not know.

Practices and Implementation Factors

Survey participants were also asked about their regular practices regarding the implementation of support for the spiritual needs of people with disabilities. The majority of DSPs (95%) indicated they know how to use natural supports for spirituality needs and 81% said they do promote meaningful relationships between faith communities and the people with disabilities they support through education and communication. However, when asked about the consistency of supporting people with disabilities in spiritual activities, only 29% indicated “regularly” while 56% said “sometimes.” Additionally, 35% of DSPs reported that their agency does not have the necessary resources, such as staff and transportation, for them to support spirituality needs of people with disabilities and more than half (53%) said they had not received adequate training to address spirituality needs. Further, 48% of DSPs indicated that family disagreements about faith may factor in to their ability to address spirituality for the people with disabilities they support.

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Participants also had the opportunity to indicate what they would need to support the spiritual needs of people with disabilities. Staff training and self-advocacy training for individuals with disabilities were both ranked as the top need by 23% of participants. The next highest need was regular and accessible transportation identified by 21% of participants. The third and fourth most needed resource identified by participants were curriculum and materials and more staff at 17% and 16% respectively.

Finally, DSPs were given an opportunity to comment on any aspect of the role of spirituality in their support of people with disabilities. The small number of comments (n=9) did not allow for thematic analysis; however, these comments do offer confirmation and expansion of the quantitative results. For example, nearly all respondents indicated they believed spirituality was important for the well-being of people with disabilities (PWD). One DSP further explained,

I recognize that spirituality rarely means exactly the same thing to each person and want to celebrate and enhance the unique spirituality attributes each person values. We are always conscious of these things as we carry out tasks of daily living, write unique supports and ensure follow through with a person's wishes in this area.

In the same manner, another DPS said,

I think that spirituality is important to PWD if they understand the benefits and what it would do for them. It could be something as little as hearing music at church. Spirituality is more than religion and knowing and understanding what is being said. It's about being in tuned with things going on around you and that is important to all people not just PWD.

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Some of the DPS's comments also reflected some of the barriers to including spirituality in PCP identified in the literature such as hesitancy due to separation of church and state issues as in,

Sometimes in an attempt to be neutral, this aspect of PWD is overlooked by an agency.

We often wait for the person to suggest an avenue instead of exploring options. We don't want to look like we're pushing a PWD into spiritual activities, because some of them are agreeable to anything proposed.

Research has also indicated agency barriers, which was also mentioned by one DSP,

Once I was able to get permission to have a psychologist attend the PWD's church and work with the congregation. It was great. Lots of good ideas for other church members (e.g., scripture in cartoon format as PWD was 12; hymns on disc so PWD could play and learn them, etc.) But hard to get approval for supporting PWD from supervisor.

Finally, while attitudes regarding the inclusion of PWD in faith communities have evolved, attitudinal barriers may still exist in faith communities themselves. One professional noted,

I am finding that through visiting many different denominations and speaking with their pastors/church leaders, that they are not genuinely welcoming to those people with disabilities. Even after explaining to them our mission and our work to get people as fully integrated into the community as possible, some say they don't have the volunteer support or that they need to call before they come. In my opinion if you want to go to church on a Saturday/Sunday, you have the free will to show up when you want. It shouldn't matter if the person has a disability or is accompanied by staff, or you are someone without a disability. This is something that has surprised me greatly and I hope that this can be corrected through proper education.

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Discussion

The purpose of this study was to explore perceptions of DSPs and provide some initial descriptive data that can inform continued efforts to ensure this component of life is accessible for people with disabilities and offer direction for future research. Results of this study both validate and challenge assumptions of how support professionals perceive spirituality for PWD.

Views of families, professionals, and the general public related to access for PWD has significantly evolved over the past 30 years since the passing of the Americans with Disabilities Act. Current best practice dictates a person-centered planning approach that supports a PWD to explore their own choices and determine their own goals, also known as self-determination. Historically, aspects of life such as vocation and sexuality were considered “not applicable” or off limits for PWD. Of course, now we realize such aspects of life are essential to all humans and this has led to preservice and in-service training standards for professionals and vocational and sexuality goals are routinely included in person-centered planning for PWD. The aspect of spirituality appears to be experiencing the same evolution. Previous research has suggested that lack of awareness and misconceptions about the relevance of spirituality for PWD as possible reasons it was not being addressed in person-centered planning (Ault et al., 2013; Carter, 2013). The professionals in the current study believe spirituality is vital to the quality of life for PWD and that this area is part of self-determination; they further believe it is their responsibility to address spirituality needs. However, there is a discrepancy between professionals’ beliefs and their practices. The reasons for this appear to parallel inclusion research in K-12 education. In the years after PL 94-142, and then IDEA were passed, the challenge was to address professionals’ attitudes and beliefs that were negative toward inclusion (Ryndak et al., 2013); however, current research indicates the majority of teachers strongly support inclusion but face

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barriers in carrying it out (Somma, 2020). Similarly, the current study concludes that professionals want to include the aspect of spirituality in person-centered planning for PWD, but two main barriers were identified: a) lack of training for both professionals and for PWD; and b) limitations in staffing, transportation, and other tangible resources. A limitation of the current study is its exploratory nature and relatively small sample size (n=62). While respondents from around the country were represented, it is possible that professionals who had a particular interest in the topic due to personal values and/or their experiences in supporting PWD chose to respond, which may have skewed the results. Additional research with larger samples could serve to strengthen the conclusions based on these initial results.

As service systems acknowledge that spirituality and inclusion in a community of faith play an important role in the lives of the individuals to whom they provide support, they are in an optimal position to empower individuals with disabilities to thrive in all aspects of their lives. Efforts to increase awareness of spirituality inclusion in person-centered planning for PWD can begin at the preservice level. For example, Minot State University is using the information gained from this study to develop curriculum modules for their existing Community Staff Training Program and career ladder of Human Services degrees. It has also given cause to examine our Special Education teaching programs to ensure the aspect of spirituality is included in methods coursework for transition planning; Ault (2010) found that this topic is usually not addressed in special education.

Future research should investigate the impact of such preservice or inservice training modules on the implementation of assessing and including spirituality when supporting PWD through the person-centered planning process. We echo the recommendation of Carter and Boehm (2019) that focus on refining existing person-centered planning assessments and

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processes that incorporate spirituality is needed. Some tools for accomplishing this are identified in the literature: The Faith, Importance, Community, Address (FICA) tool (Puchalski, 2014), Including Spirituality in Assessment, Evaluation, and Person-Centered Planning Processes (Carter et al., 2015), and Protecting Religious Freedom: The Caregiver's Responsibility (Hoeksema, 1994). Additionally, several models exist in the literature (e.g. Rahman et al., 2018) that have examined the efficacy of training on other aspects of community inclusion and these could be used as the design for establishing effective methods of equipping teams to include spirituality and ameliorate barriers.

Gaventa (2002) advised that the commitment of service providers to ensuring the aspect of spirituality is addressed for PWD was more important than the particular assessment tool or method used. Efforts to regularly engage the key stakeholders of individuals with disabilities and their families, faith communities, and support professionals in the capacity building process must continue in order to build a collaborative system of support that allows people with disabilities access to and full participation in meaningful spirituality.

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Appendix: Spirituality in Person-Centered Planning Survey

1. I have been a DSP or QUIDDP for

0-2 years, 3-10 years, more than 10 years

2. My work setting is

Rural, Urban

3. I currently work in the

Upper Midwest, Midwest, South Central, Southwest, Southeast, Eastern Coast, Western Coast

4. I currently serve

Children, Adults, Both Children and Adults

5. My age is

18-25years, 26-35 years, 36-50 years, 50+ years

6. I currently support PWD in spirituality activities

regularly, sometimes, never

(All of the following questions should have a Likert Scale of Strongly Agree, Agree, Disagree, Strongly Disagree)

7. I consider myself a religious person.

8. There are spirituality goals and objectives on PCP plans at my agency

9. I have strong personal beliefs that guide my decisions.

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10. The aspect of spirituality is not relevant to PWD.
11. I participate in a religious community.
12. I have spiritual beliefs that help me enjoy daily life.
13. I am not comfortable attending a church activity with my client if it differs from my own church affiliation.
14. My agency has a policy explaining the domains that must be discussed at a PCP meeting.
15. I haven't given much thought to the role of spirituality for PWD.
16. Addressing spirituality needs for PWD is not my responsibility.
17. I don't have the time to support spirituality activities with the PWD I support.
18. Spirituality can be expressed not only through worship but through service, friendships, employment, hobbies, and nature.
19. The right to explore and choose participation in a spiritual community is part of a person's self-determination.
20. I feel uncomfortable supporting spirituality activities with the PWD I support because I am not a religious person.
21. I use natural support systems: individuals with family and friends who want to attend worship and other faith community activities.
22. My agency does not allow me to attend spirituality activities with the PWD I support.
23. Faith can be a source of inspiration and excitement for a PWD.

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24. Spirituality is included on the PCP planning form at my agency.
25. My agency does not have the resources (training, materials, transportation, staff etc.) to address spirituality needs for PWD.
26. There is often disagreement between the PWD and their family about the level of participation in spirituality activities.
27. I have received adequate training on supporting PWD in exploring their spirituality interests.
28. PWD often don't have the capacity to express their spirituality.
29. Spirituality is not applicable to the clients that I work with.
30. Connection to a spiritual being can provide comfort/reassurance to PWD.
31. Serving others can be a meaningful spiritual activity for PWD.
32. It is my responsibility to support opportunities for PWD to realize their personal spiritual goals.
33. I promote meaningful relationships between faith communities and PWD through education and communication.
34. Spiritual strength allows a PWD to have a better quality of life and enhanced well-being.
35. Supporting self-determination must include consideration of PWD spiritual experiences as well as their choices about how or if they wish to express their spirituality.
36. Spirituality is an important dimension of quality of life for everyone.

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37. My agency includes supporting the spiritual needs of clients when discussing agency values and practices (e.g. mission statement, strategic plan etc.).

38. To include spirituality in PCP and carry it out, I would need: (Check all that apply)

Staff Training

Training materials/curriculum

Self-advocacy training for consumers and staff

Regular transportation

Additional staff

Permission & support from my agency supervisor

Other... (specify)

39. Is there anything else you want to tell us about the topic of spirituality and PWD?