



# Assessing & Addressing Spiritual Interests and Needs in Individual Service Plans of Adults with IDD

MAY 9, 2021 REV. AMY PETRÉ HILL, JD

IRB PROTOCOL # 21-2728

## THE SURVEY

Extensive research has demonstrated that spirituality is a social determinate of health, improving physical and mental health for adults with and without Intellectual and Developmental Disabilities (Koenig, King, & Carson, 2012; Park et al., 2017). Understanding and respecting the spiritual interests and connections to spiritual communities of people with disabilities and their families is an accepted best practice (Carter, 2013; Gaventa, 2005, 2017).

An IRB-approved, 16-questions survey on a Likert scale was developed to measure how often and how significantly human services professionals in Colorado conduct assessments of the spiritual interests and connections to spiritual communities of adults with IDD.

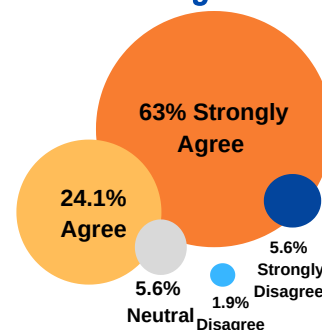
Through JFK Partners, Developmental Pathways, and Autism Society of Colorado listserves, the survey was sent to human services professionals, home-host providers, Arc employees, and parents participating in creating Individual Service Plans (ISPs) for adults significantly impacted by IDD receiving services funded through Medicaid's Home and Community-Based Services Waivers (IDD Waivers). A total of 76 responses were received, including 54 complete surveys. Demographics of respondents include:

- **Gender Identity:** Female (80.6%), Male (6.1%), Prefer not to respond (3.2%), Transgender (0%), Non-binary (0%), Other (0%)
- **Race:** White (88.7%), Prefer not to respond (4.8%), Hawaiian/Pacific Islander (3.5%), More than one race (3.2%), Black (1.6%), Asian (1.6%)
- **Ethnicity:** Non-Hispanic (88.7%), Hispanic (8.1%), Prefer not to respond (3.2%)
- **Education Level:** Participants with College Degree or above (88.7%)
- **Work:** Human Services or Direct Service Professionals at CCBs, PASAs, the Arc (67.7%), Unpaid caregivers (parent, family, friend) (32.3%)
- **Years Caring for Adults with IDD:** Over 11 (58%), 4-10 (17.8%), under 3 (19.4%)
- **Spiritual Background:** Belong to a Faith Community & Regularly Attend (48.4%), Independently Spiritual (17.7%), Belong to a faith community & do not regularly attend (11.3%), Agnostic (16.1%), Atheist (0%)

## SIX KEY FINDINGS

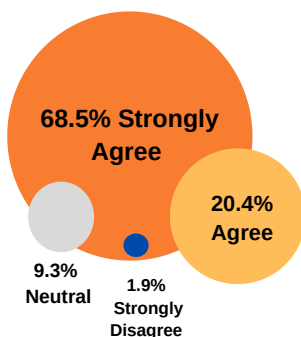
### 1) SURVEY QUESTION: "I believe addressing the spiritual interests of adults with IDD is important to their well-being."

Those who supported addressing the spiritual needs of adults with IDD were professionals, direct care providers, and family members and included people of all races and ethnicities. The respondents who disagreed or strongly disagreed with the importance of addressing spiritual interests identified as white and independently spiritual, belonged to a faith community and attended regularly, or preferred not to respond regarding their spiritual background. Most were case managers in Community Center Boards, one was a CNA, and another a family member of an adult with IDD.



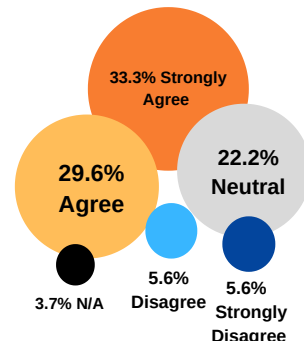
### 2) SURVEY QUESTION: "I believe supporting the participation of adults with IDD in the Spiritual Communities of their choice is important to their well-being."

Only one individual strongly disagreed with this statement. This individual was a family member and also *strongly disagreed* with addressing the spiritual interests of adults with IDD. The individual identified as a person who belongs to a spiritual community and regularly attends. No one *disagreed* with this statement, meaning 88.9% of respondents see participation in spiritual communities as important for adults with IDD. It would be interesting to explore why there are slightly different percentages of support for addressing spiritual interests vs. access to chosen spiritual communities.



### 3) SURVEY QUESTION: "My organization supports the choices of adults with IDD related to their spiritual interests and access to spiritual communities."

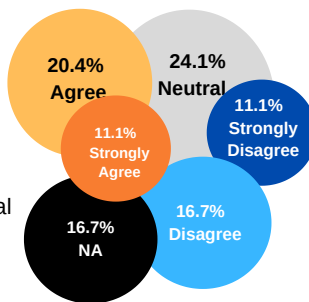
A majority of respondents, 62.9%, see their organization as supportive of adults with IDD's spiritual interests and access to spiritual communities. The significant number of respondents who selected neutral requires further investigation: are these respondents unaware of their organization's way of supporting adults with IDD around spirituality, are there parameters put around staff's ability to advocate for programmatic changes, or do respondents have questions regarding how supporting spiritual interests would look in their setting?



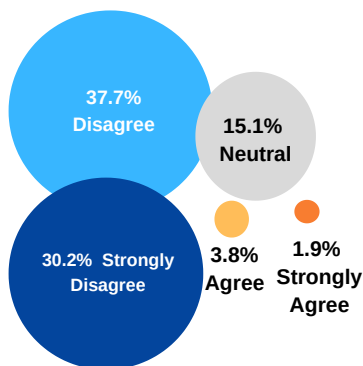
# SIX KEY FINDINGS cont.

## 4) SURVEY QUESTION "My organization has written policies on supporting the spiritual interests and access to spiritual communities for adults with IDD."

A larger percentage of respondents believe support for spiritual interests and access to spiritual communities for adults with IDD important to their well-being. More than half hold that their organizations share this personal belief. However, when respondents were asked about written policies articulating this commitment, the largest single response neutral with almost equal percentages implying there was a policy and wasn't a policy in their organization.



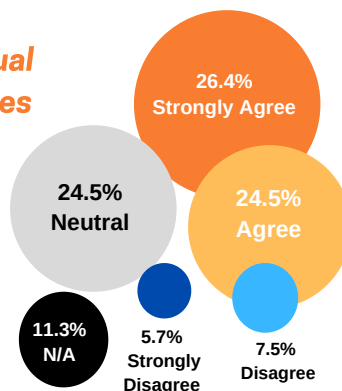
## 5) SURVEY QUESTION "My organization offers training on how to appropriately assess and address the spiritual interests of adults with IDD in their Individual Service Plan."



When respondents were asked about how spiritual interests and access to spiritual communities were captured and implemented in the Individual Service Plans (ISP) of adults with IDD, issues emerged. Adults with IDD receiving services through Home and Community Based Waivers (IDD Waivers) are dependent on this waiver for all their basic needs and may no longer have family alive or in contact with them to advocate for their interests, including their spiritual interests. One solution to this issue is to offer training and resources to support human service professionals in incorporating the spiritual interests and access to chosen spiritual communities in adult's ISPs.

## 6) SURVEY QUESTION "I would appreciate training on assessing and addressing spiritual interests and access to spiritual communities in Individual Service Plans."

A small percentage of respondents who were actively uninterested in spiritual assessment and implementation training was a low 13.2% and only 11.3% responding such assessments are not part of their role. Whereas 50.9% of respondents are actively interested in such training. Those interested in such training had a variety of spiritual backgrounds and professional roles.



## STUDY LIMITATIONS

While this survey uncovered several interesting insights, it also contains several limitations.

- The sample size is very small with only 74 responses and 54 completed surveys.
- The survey was offered for only three weeks through the listserves of only three organizations, limiting the participation to those with connection to email via wireless or internet access and comfort using a smartphone, tablet, or computer.
- The study did offer a good crosssection of leadership--a CEO, EDs, program managers--as well as case managers, clinicians, host home providers, direct care providers, and parents, but those who responded were overwhelmingly white and female. This initial version of the survey was only offered in English and future versions should be offered in other languages.
- Only the most basic analysis was conducted on the survey results using REDcap: further detailed statistical analysis of the results is needed.

## NEXT STEPS

1) Develop model written policies supporting accessing and addressing the spiritual interests and access to spiritual communities chosen by adults with IDD. Such policies would be created in partnership with Colorado disability policy experts, the Colorado Council on Developmental Disabilities, and Community Center Boards.

New York City has developed some processes its human service professionals can utilize to assess the spiritual interests and needs of adults with IDD, including those who are not verbal. This program demonstrates that it is possible to ask about and incorporates spiritual interests into annual Individual Service Plans without violating state or federal regulations maintaining appropriate separation between spiritual communities, faith traditions, and agencies.

2) Develop a curriculum that offers human service professionals and direct care providers information and opportunities to practice conducting quick and simple spiritual assessments. This curriculum will also help human service professionals and parents address interests and needs within intakes and annual Individual Service Plan development.

This researcher is currently partnering with Andrea Morales, Community Resources Program Administrator at Developmental Pathways and LEND Diversity Fellow to provide Mental Health First Aid training to DP staff, related PASAs, and parents. We will use participant feedback from this training as a starting point to develop effective training for busy staff and family members working with adults with IDD on how to conduct spiritual assessments.

3) Future Goal: Create an interfaith community spiritual care non-profit run by the APC-certified chaplains who can serve as a resource and problem-solving partner for agencies, human services professionals, faith leaders, spiritual communities, host home providers, and families living with disabilities at no cost. For more information or to help create such a community spiritual resource, email the researcher at [revamy@mhministres.org](mailto:revamy@mhministres.org).



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