

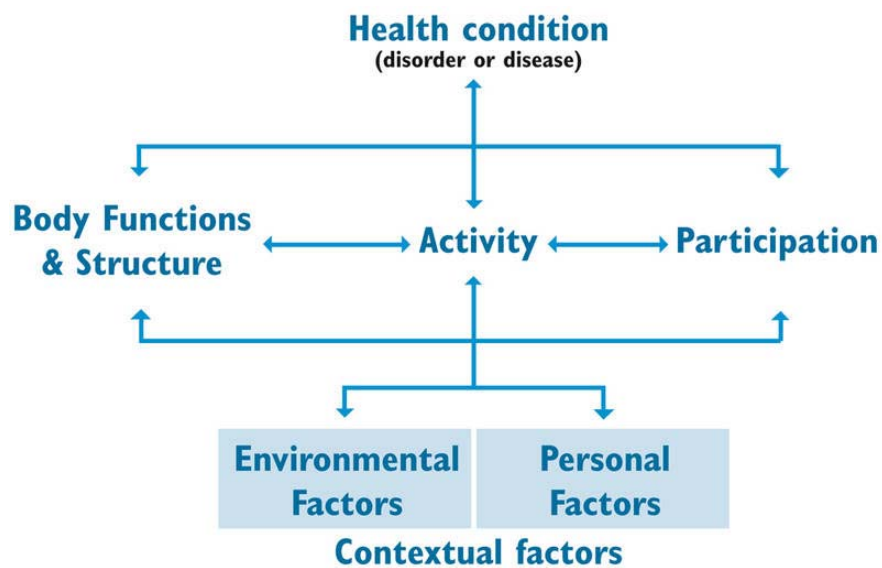
Deep and Wide: Spirituality, Quality of Life, and Participation that Leads to Belonging

In the United States, there is an old church camp song called [Deep and Wide](#) that goes like this, with hand motions:

Deep and wide, deep, and wide
There's a fountain flowing deep and wide.
Deep and wide, deep and wide,
There's a fountain flowing deep and wide.

The fountain, is, of course, the fountain of life and of God's love. Now, just keep that in the back of your head as we look at spirituality, quality of life, and people with disabilities.

First, let's define disability and spirituality. My favorite definition of disability is the one you probably know coming from the World Health Organization.ⁱ Disability, in this organic, inter-related diagram is condition originating in a health condition or disease related to body functions and structure that impact activities of daily living.



The abilities needed for those activities of daily living also occur in a social-ecological context, in which environmental factors, such as architecture and design, social attitudes, and culture also shape physical and mental ability in those activities, and, secondly, by personal context, which includes an individual's particular circumstances, culture, family, financial status, and attitudes about one's disability. All of them together work together to impact participation in the life of the community and society.

Second, one can define spirituality in many ways, but the most succinct I know is by Dr. Christina Puchalski at the George Washington University Institute on Spirituality and Health.

Spirituality is the dimension of a person that seeks to find meaning in his or her life. It is also the quality that supports connection to and relationship with the sacred, as well as with each other.ⁱⁱ

Finding meaning in one's life: the depths. Finding connections and relationship with God and with each other: the width. Deep and Wide.

Spirituality also impacts, or is expressed by, how we answer the core questions of human life:

- ❖ Identity: Who am I?
 - Meaning, passions, values, what one considers to be sacred, my core story.
- ❖ Purpose: Why am I?
 - From passions, interests, and gifts, what am I to do, make a difference to others, vocation, employment, calling, "social role valorization."
- ❖ Connection and culture: Whose are I? Who are my people?
 - Connections with others, place, sacred, past, or future, nature, culture, sense of home, etc.

At a conference workshop I led once in the United States, a young Jewish autistic man, resident of a group home, talked about the relationship that home had with a nearby Catholic church. *"I am Jewish, I like going to this Catholic Church. It helps me know who I am and shapes my identity."*

So, note again the places where spirituality might most directly impact disability, through shaping the cultural context of values and images about disability and one's personal social and value context, and in ways it may impact participation. For example, a noted hospitality and welcome for people with disabilities in a parish will impact someone's social context, as well as their own beliefs about whether that will be a positive and worthwhile experience. Spirituality can also shape a body's response to disease or health conditions, as has been demonstrated in multiple research studies in psychology and healthcare, with most results pointing to the way it impacts personal attitudes, social supports, coping skills, and meaning.

Now, in the United States, and in most western cultures, the values driving services and supports for people with disabilities the following. Note how those cultural and treatment values relate to the fundamental spiritual questions we just outlined.

- ❖ **Independence** (Who am I?), i.e., a person's core values, meaning, and identity, including what is sacred.
- ❖ **Productivity** (Why am I?), i.e., a sense of purpose, call, vocation, or obligation, being able to contribute.
- ❖ **Inclusion** (Whose am I?), i.e., connections and relationships, to self, others, the sacred, time, and place.

- ❖ **Self-determination:** “What kind of control or power do I have over what happens to me?”
- ❖ **Cultural competence:** “Will my personal uniqueness and cultural heritage be respected?” At the heart of self-determination is the question of preferences, choices, power, and control.

And there are specific policies and practices that line up with these values and questions:

Practice and Policy Values in Health Care and Human Services	Fundamental Human/Spiritual Question	Core Spiritual Theme	Practices
Independence	Who am I?	Identity/Meaning	Spiritual supports as part of person-centered care and planning. Toward a “new normal.”
Productivity	Why am I?	Purpose, Calling, Vocation	Gifts and strengths that can be used toward employment, volunteering, making a difference, helping others
Community Inclusion	Whose am I? Who do I belong to? (Also closely related to culture, below)	Community Connection to others Connection to divine	Community inclusion, participation, memberships, friendships, long term supports
Cultural Competence	Where have I come from? Who are my people?	Cultural traditions, preferences, ways of understanding	Person-centered and family centered health care, connections, honoring choice, and uniqueness
Self Determination	How do I shape my own destiny? Why do bad things happen?	Choice, Responsibility, Control, Power	Advocacy, rights empowerment, and belief systems, including right to religion.

Thus, the rationale for including and addressing spirituality in services and supports is, I think, also both deep and wide. The problem is that people usually ignore it or don’t know how to. That rationale includes:

- Tapping the power of the sacred in people’s lives
- Meaning, resilience, support, identity
- Cultural competency/cultural humility
- Self Determination and Quality of Life
- Rights
- Dealing with grief and loss, not just at end of life
- Natural, generic supports/community participation

One could say, as a friend of mine does, that if support or person-centered planning that does not pay attention to the spiritual dimensions of one’s life and what they think about it, then it is not as person centered or holistic as it claims to be.

Even further, to bring in another dimension to deep and wide, i.e., long, different parts of spirituality are especially felt and experienced at different stages over the length of one’s life:

- Spiritual supports at diagnosis for families or individual with acquired disability.
- Opportunities for early and ongoing inclusion in faith communities.
- Rites of passage as building community such as First Communion, confirmation, etc. Blessings of relationships through marriage and more.
- Transitions and ports of entry: The power of immigrant/ethnic religious organizations as sanctuary
- Adult Services: A place to contribute, learn, socialize, recreation.
- Social capital and connections (employment)
- Support in grief and loss throughout life, as well as in times of celebration.

Quality of life is research construct aimed at trying to get at the question of whether a person and/or others is living a good life. As a scientific construct, it faces challenges, for a commitment to objectivity and measurement makes it hard to capture how people feel about their own lives. Good, in science, is something you can observe. It’s true when you can measure it. It is beautiful when you can replicate it. But as you know, there are other ways to look at goodness, truth, and beauty. The values one uses to evaluate parts of their lives are both objective and subjective, heavily influenced by one’s culture, and by the meaning (i.e., the spirituality) that people both bring to and take from their life experiences.

There is, of course, no universal acknowledgement of one way of addressing Quality of Life. I am aware of three major models:ⁱⁱⁱ

WHO	QOL Research Unit, University of Toronto	Schalock, et. al.
1. Physical Health	1. Physical Being	1. Personal development
2. Psychological	2. Psychological Being	2. Self-determination
3. Level of Independence	3. Spiritual Being	3. Interpersonal relations
4. Social Relations	4. Physical Belonging	4. Social Inclusion
5. Environment	5. Social Belonging	5. Rights
6. Spirituality/Religion/ Personal beliefs	6. Community Belonging	6. Emotional Well-being
	7. Practical Becoming	7. Physical well-being
	8. Leisure Becoming	8. Material well-being
	9. Growth Becoming	

Spirituality and religion are included in the WHO model of quality of life, but it is focused on more on what one believes, and how it impacts their life.

Robert Schalock and others have developed a model for Quality of Life that is well-known in intellectual disability circles. I have talked with him about it, and about the fact it does not explicitly mention spirituality. He says that it can be addressed under categories like emotional well-being, social inclusion, etc. My response is that if it is not explicit, people will not learn how to address it, and two, I could outline for him how spirituality can relate to and impact every one of the eight dimensions of his model.

As you might guess, my favorite theoretical model is the one from University of Toronto that looks at Quality of life as an interplay between being, belonging, and becoming, in which spirituality can dynamically relate to many of those parts.

Some systems like the Core Indicators of Quality of Life for adults in the United States, which talks to thousands of adults, are including questions like the number of times they attend a faith community. There are, in fact, correlations, between that and whether one is more connected in the community, employed, and more. The problem is that a disabled person's level of participation in the community is more than just the number of times one is present.

In English, think of the roots of the word "participation":

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- Be part of...
- Have a part in...
- Take part in...
- Do our part...
- Be given a part...
- Ask for a part...
- Be a valued or critical part...
- Be a key part...
- Be or have part-ners...

As you know, far too often, people with disabilities feel "apart from." Being and living in the community does not mean one is a part of the community. But taking seriously the many dimensions of identity, what one loves, how one can make a difference, and the many ways that people can be connected to others and a sense of the sacred, all speak to the ways that paying attention to spiritual needs, interests, and dimensions of someone's life can improve their quality of life. We have too often thought that quality of life depended on where one lived: a mantra of location, location, location. However, quality of life really depends on the depth, width, length, and types of one's relationships. The mantra should be "relationship, relationship, relationship."

In the United States, we who have been working on spiritual inclusion have for a while talking about what is beyond inclusion. The spiritual and theological answer is “Belonging.” Let me end by sharing a model developed by my colleague Erik Carter who did a research project surveying 500 family members and people with disabilities about their interest and involvement in spirituality. There have been many lessons learned, including the sober one of how little attention is paid to their interest by both secular services and religious organizations.

But out of the research, Erik heard individuals and families talking about what it would mean to them to belong to a faith community. Here, collectively, is what they said:^{iv}



There is much richness here, but notice two things:

Those ten factors are all part of the capacity of churches, synagogues, and other religious organizations. Not every faith community is good at all of them, but historically, as the families note, they are part of the expectations and hopes of what one may find in a faith community.

Second, this is a model of belonging that comes of out spiritual research, but one that is applicable to any form of belonging in a community, in other organizations, clubs, groups, and the community itself.

For professional service providers, our challenges are several:

- We need to be able to reinterpret the role of “professional” to include honoring and fostering community relationships.
- We need to recognize spirituality as a dimension of life for people we support, their families, and ourselves as professionals.
- We need to discard the myth of the “value-free” professional and move to one where we are “value-clear.”

- We need to be more honest about the mutuality of helping relationships, and how we as professionals learn, grow and receive from the people we support as well as the other way around.
- We need new versions of the ancient vows of “professing” commitment to a religious order, ones that affirm steadfastness, loyalty, equity, and justice.

And together, working with individuals, families, churches, advocates, and friends, we have a better chance of building churches and communities which.

- Value human life and the importance of lifelong support, as desired and needed.
- Enable people with disabilities to live lives not solely defined by deficit or impairment, but also by strengths, gifts, and passions.
- Have lives full of purpose and contribution.
- Journey through life closely connected to friends, communities and their preferred faith and spiritual traditions.

Or, in other words, lives that full of meaning and love: Deep and Wide.

ⁱ World Health Organization. 1993. *International Classification of Impairments, Disabilities and Handicaps*: a manual of classification relating to the consequences of disease, published in accordance with resolution WHA 29.35 of the Twenty-ninth World Health Assembly, May 1976 (reprinted with foreword). Geneva: World Health Organization.

ⁱⁱ <http://smhs.gwu.edu/gwish/>

ⁱⁱⁱ Gaventa, William. *Disability and Spirituality: Recovering Wholeness*. Waco, Texas: Baylor University Press. Pp. 22-35.

^{iv} Carter, Erik. *Inclusive Practices*. TASH Journal. Vol. XX. No. X.

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