

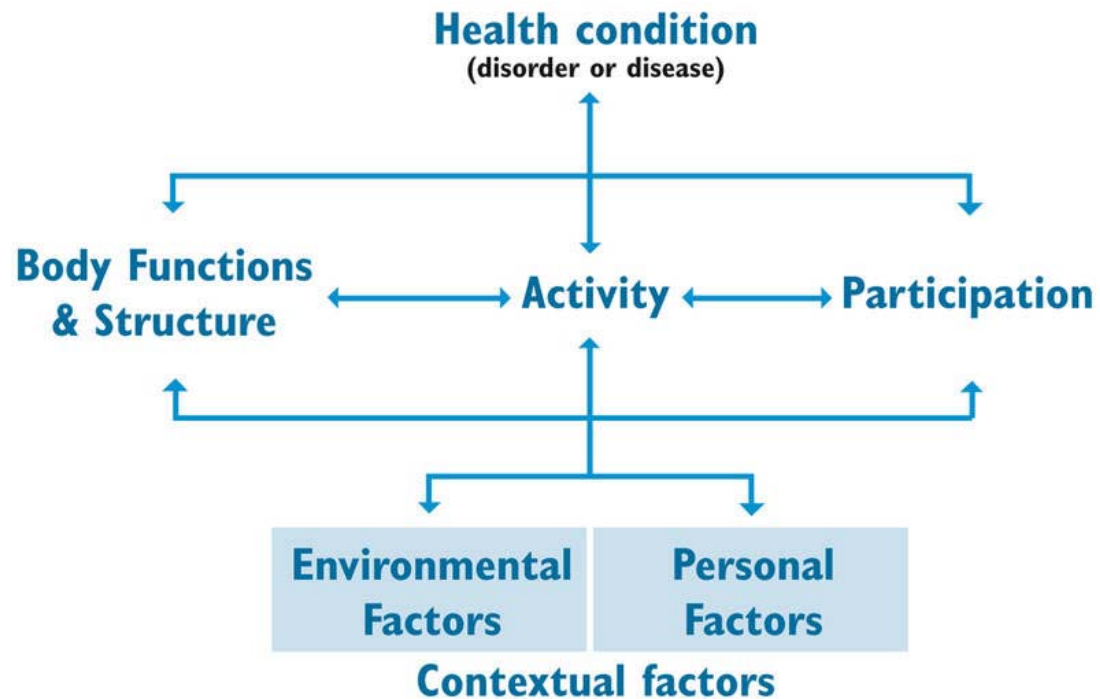
*Deep and Wide:*

*Spirituality,  
Quality of Life and  
Participation that  
Leads to Belonging*

Bill Gaventa, M.Div.



# World Health Organization: Disability Toward A Functioning Definition



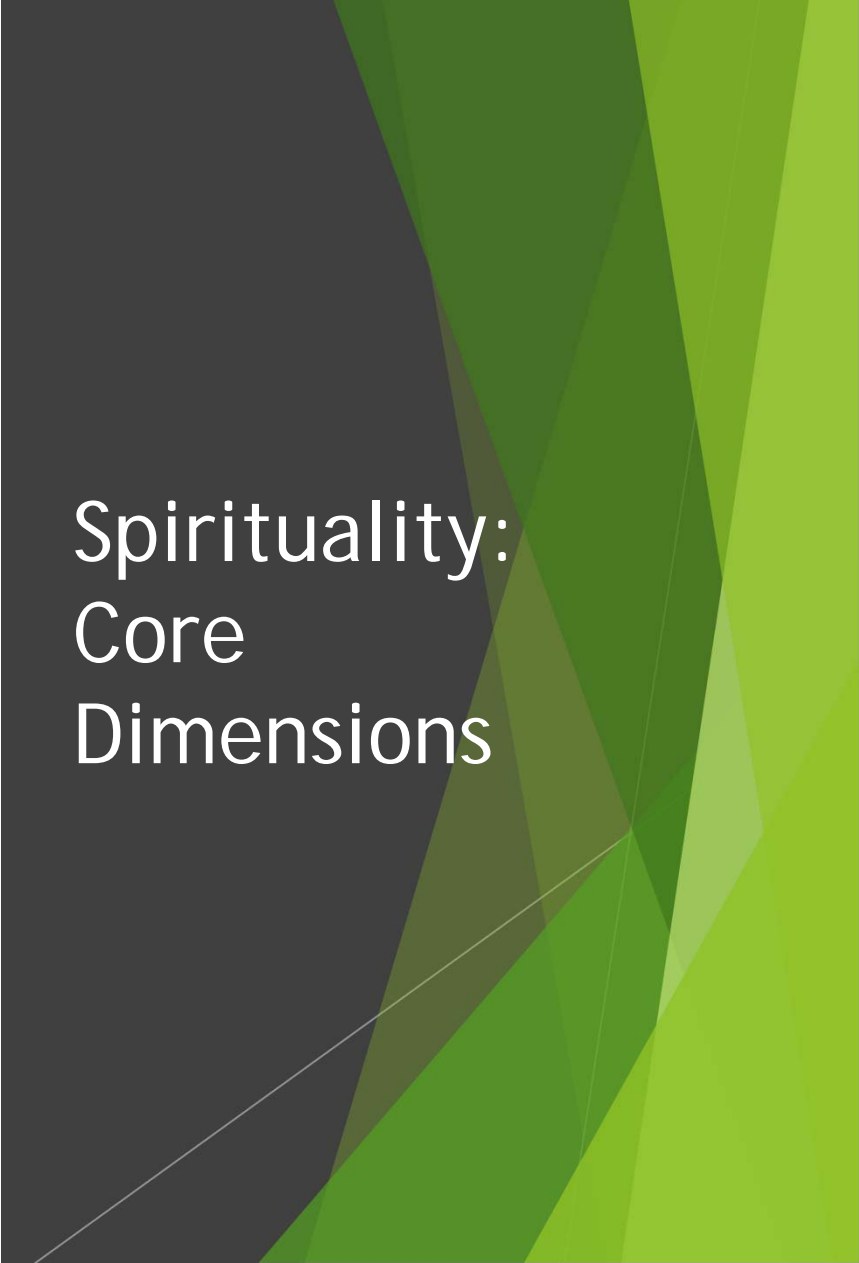
# Spirituality

*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.*

- ▶ Dr. Christina Puchalski,  
George Washington  
University Institute on  
Spirituality and Health

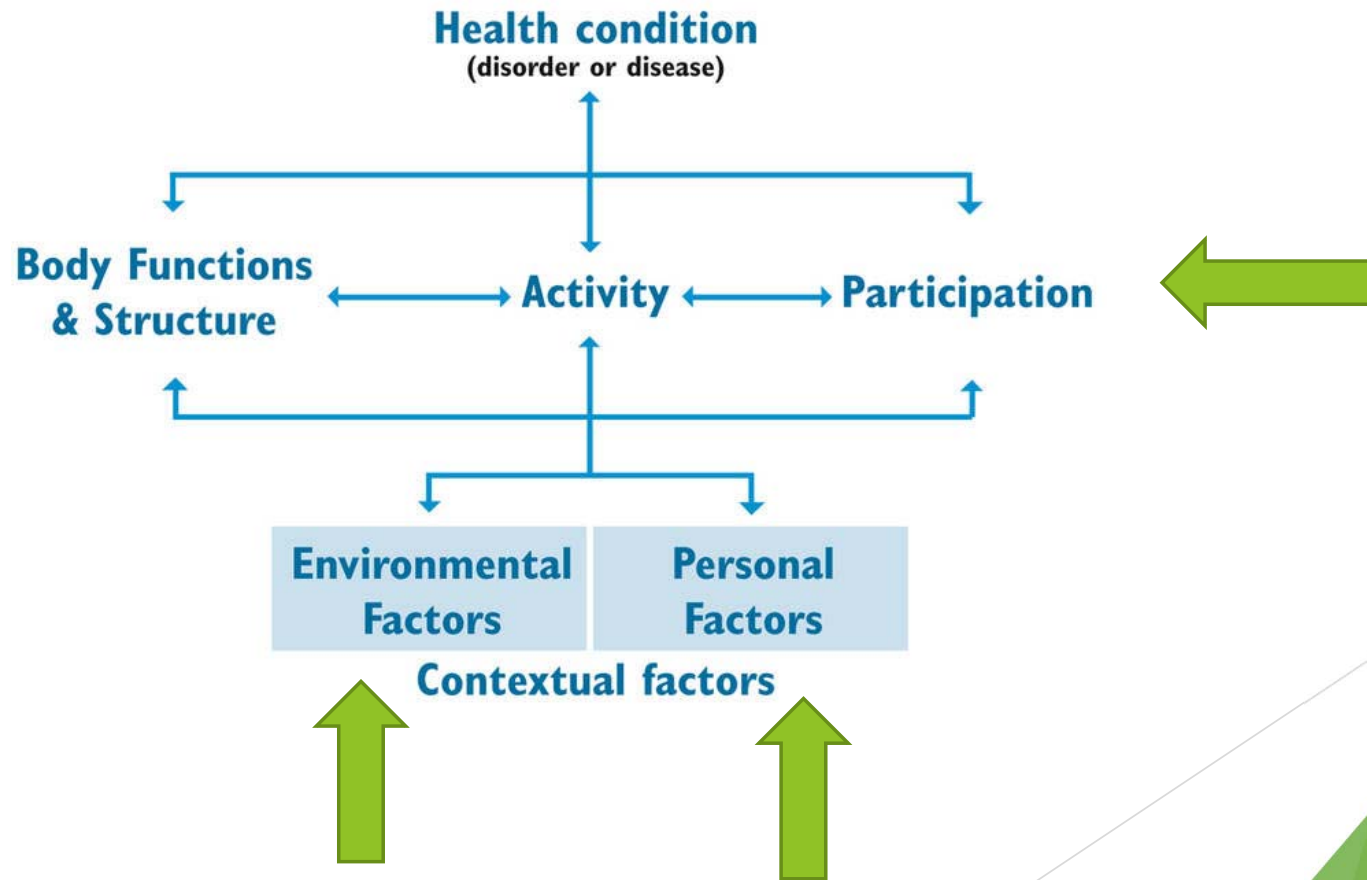
- ▶ Identity: Who am I?
  - ▶ Meaning, passions, values, what one considers to be sacred, my story
- ▶ Purpose: Why am I?
  - ▶ From passions, interests, and gifts, what am I to do, make a difference to others, vocation, employment, calling, “social role valorization”
- ▶ Connection and culture: Whose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

*“I am Jewish, I like going to this Catholic Church. It helps me know who I am, and shapes my identity.”* Young man with ASD, Reinventing Quality Conference panel.  
8/3/2016



## Spirituality: Core Dimensions

# World Health Organization: Where does spirituality fit in?



# Spirituality, Core Values, and Policy in Western Services and Supports

- ▶ **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.
  - ▶ William Gaventa. "Defining and Assessing Spirituality and Spiritual Supports: Moving from Benediction to Invocation. In H. Switzky & S. Greenspan (Eds.), *What Is Mental Retardation: Ideas for an Evolving Disability in The 21st Century* (Washington, DC: American Association on Intellectual and Developmental Disabilities, 2006), 151-166.

# Values, Spirituality, and Practice

Fundamental Human/Spiritual Question	Core Spiritual Theme	Policy Value	Practices
Who am I?	Identity/Meaning	Independence	Person-centered language and planning. Including spirituality
Why am I?	Purpose, Calling, Vocation	Productivity	Employment, volunteering, making a difference, serving
Whose am I? Who do I belong to?  (Also closely related to culture, below)	Community Connection	Integration/Inclusion	Community inclusion, participation, least restrictive environment. Citizenship, Friendships
Where have I come from? Who are my people?	Cultural traditions, preferences, ways of understanding	Cultural Competence	Person centered planning, connections, honoring choice and uniqueness
How do I shape my own destiny? Why do bad things happen?	Choice, Control, Power	Self Determination	Advocacy Rights Empowerment

# Rationales for Invoking and Including Spirituality

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



# Spirituality at/in Life Span Transitions

Spiritual supports at diagnosis

Opportunities for early and ongoing inclusion

Rites of passage as building community

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

# Quality of Life Models: World Health Organization

- ▶ “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment. (WHO 1997, p.1)....
- ▶ An essential feature of the construct of Quality of Life is the acknowledgment of both subjective and objective criteria for evaluation..... Objective norms can be found in legal and professional standards. Subjective norms can be obtained by simply asking the person about his or life experiences or by using satisfaction inventory methods.”
  - ▶ Will Buntix. “Understanding Disability: A Strengths-Based Approach.” In Michael Wehmeyer (Ed.) *The Oxford Handbook Of Positive Psychology And Disability*. (New York: Oxford Press, 2013) 11.

# Three models of quality of life

“Domains of Quality of Life According to Three Major Authors: Schalock et.al, (2007), the World Health Organization (WHO 1997) and the Quality of Life (QOL) Research Unit, Toronto.” Will Buntix, 12.

World Health Organization	Quality of Life Research Unit, University of Toronto	Robert Schalock, et. al., in definitions used by the American Association on Intellectual and Developmental Disabilities
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	

# Participation is more than Attending or Being Present!!

In English, think of the word:

- ❖ 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...
- ❖ Not apart from...

# It is Belonging: Erik Carter



# For Professionals in the Worlds of Services and Supports

Re-interpreting the Role of Professional to Include honoring and fostering community relationships

Recognize spirituality as dimension of life for people they support and themselves.

From "value free" to "value clear."

Honesty about the mutuality of the relationships.

New forms of "professional" vows: steadfastness, loyalty, and commitment to others.

# For both worlds of disability and spirituality ...a uniting center

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

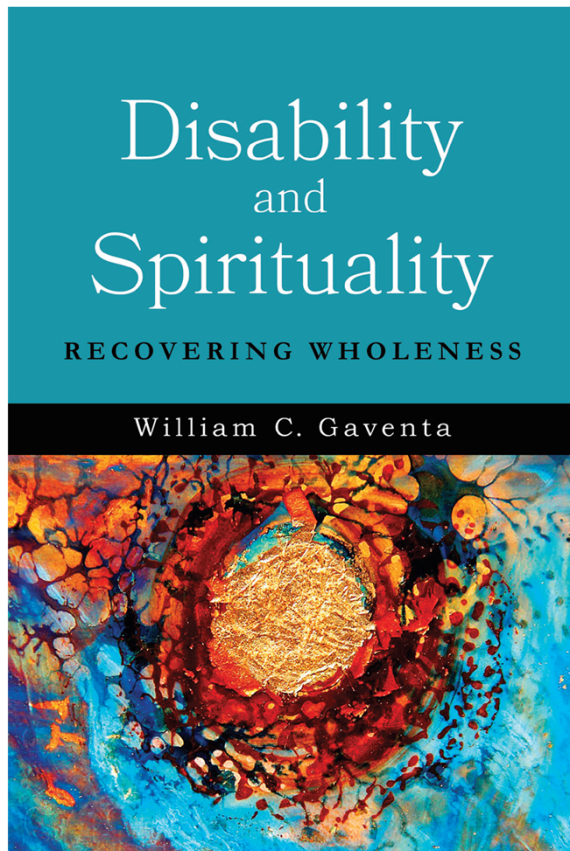
In other words, quality of life, living fully, thriving, flourishing. Full of meaning and connections.

**DEEP and WIDE**

# Related Writing

- ▶ Carter, E. Spirituality, Disability, and Quality of Life. *Journal of Policy and Practice in Intellectual Disabilities*. (in press)
- ▶ Sango, P and Forrester-Jones, R. 2022. Spirituality and the Quality of Life of Individuals with Intellectual Disability. *Journal of Long-Term Care*, (2022), pp. 193–204. DOI: <https://doi.org/10.31389/jltc.139>
- ▶ Gaventa, W. Whose am I? Spiritual pathways into the heart of belonging. (forthcoming) In A. W. Harris & S. M. Wilson (Series Eds.), J. L. Jones & K. L. Gallus (Vol. Eds.), *Belonging and Resilience in Individuals with Intellectual and Developmental Disabilities - Community and Family Engagement*. Springer International.
- ▶ Gaventa, W. and Dell, M., (2018) Spirituality, ethics, and people with intellectual disabilities, in *Ethical Considerations at the Intersection of Psychiatry and Religion*. London: Oxford University Press.





## Presenter:

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