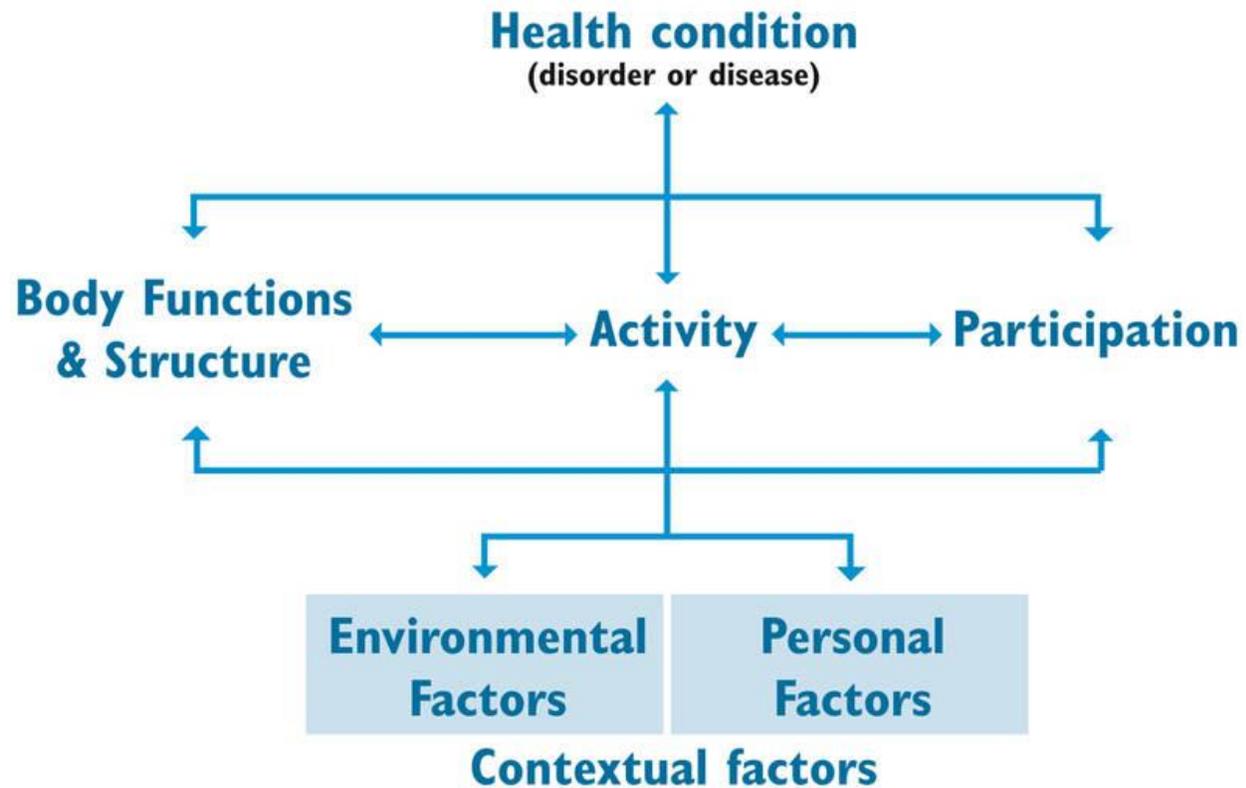
The background features abstract, overlapping green geometric shapes in various shades, including light lime green, medium green, and dark forest green, creating a dynamic, layered effect. The shapes are primarily located on the left and right sides of the slide, framing the central white space.

*Spirituality and Quality of Life and
Pathways to Community Connections*

Bill Gaventa, M.Div.

World Health Organization: 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

Spirituality at the Core of Values 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.

Spirituality: Three Core Dimensions

- ▶ Identity: Who am I?
 - ▶ Meaning, passions, values, what one considers to be sacred
- ▶ 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: Whose am I?
 - ▶ Connections with others, place, sacred, past or future, nature, 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

Samples of theological research

Many others at Summer Institute on Theology and Disability
website: <http://faithanddisability.org/projects/summer-institute/>

Rabbi Julia Watts Belser names four primary themes in Jewish tradition and texts that undergird the rights of persons with disabilities.

1. “b’tselem Elohim,” the equality and infinite value of the individual coming from God’s creation of humankind “in his own image.”
2. “areyvut:” the belief in communal responsibility for one another and its inclusiveness.
3. the principle of “kavod:” freedom means the respect of the agency and dignity of every person.
4. the Jewish commitment to social justice, based on the principles of “tsedek” (righteousness and justice) and “tikkun olam,” the obligation to work for repair of the world.

Julia Watts Belser. *Guide to Jewish Values and Disability Rights*. (New York: Jewish Funders, 2016)

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	

Most dynamic model: Toronto Quality Unit



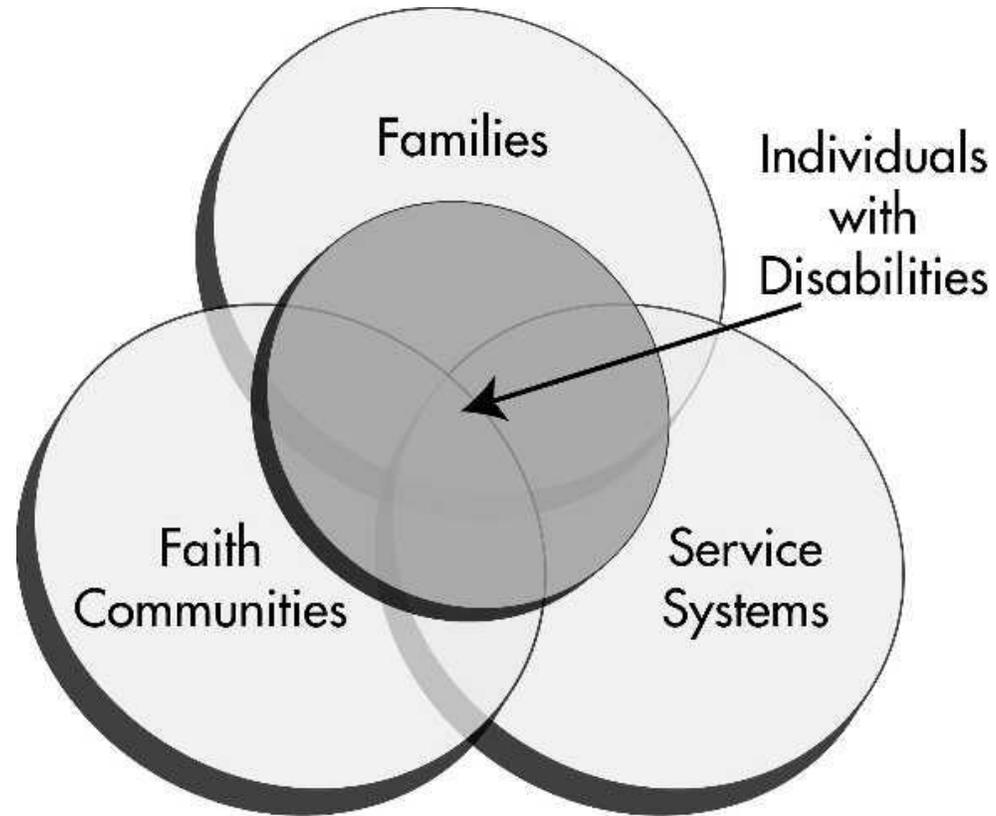
Self Determination and Person Centered Planning and Supports

As is true within many families of children not identified, spirituality and involvement in a faith community hold a prominent place in the lives of parents of children with IDD (e.g., Coulthard & Fitzgerald, 1999; Ekas, Whitman, & Shivers, 2009; Haworth, Hill, & Glidden, 1996; Marshall et al., 2003; Michie & Skinner, 2010; Poston & Turnbull, 2004; Skinner, Correa, Skinner, & Bailey, 2001; Vogel & Reiter, 2004).

Indeed, descriptive studies suggest that faith and family flourishing have been intimately linked for many of these parents (e.g., Mirsaleh, Rezai, Khabaz, Ardekani, & Abdi, 2011; Poston & Turnbull, 2004; Rogers-Dulan, 1998; Tarakeshwar & Pargament, 2001).

But significant percentage families find that that interest is not honored by either the service community or the religious community. (Erik Carter)

Modeling Collaboration



The Promise

- ▶ Collaborative efforts to address spiritual supports are and can be developed between faith communities, service systems, and advocacy groups along the life-span. Addressing architectural and attitudinal barriers collaboratively.
 - ▶ William Gaventa, “The Challenge and Power of Location and Role: Pastoral Counseling in the Lives of Children with Disabilities and their Families.” (American Association of Pastoral Counselors, *Sacred Spaces*, 2014) Vol. 6. 53-86. Online Journal at <http://www.aapc.org/news-events/sacred-spaces/>

Service Providers: The Heritage Christian Story

Tools for Holistic Person-Centered Living and Planning

- Supportive culture
- Spiritual Life Plans
- ISP Process
- Quest for natural supports
- Personal Outcome Measure (POM) interview and written summary
- My Action Plan
- Individual Satisfaction Questionnaire

Supportive Culture

Our mission statement references each “individual’s gifts, strengths and needs.”

- Annual conversation with each department about how the words of the mission statement ‘become alive’ at their site
- “Champion” - Champion of a cause... The cause? A person achieving what really matters in their life. - Identify employees who seem to naturally serve in a whole-person honoring manner. - Empower these employees to lead and model this style of serving.
- Spiritual Life team
- Bridge Builders: Connectors, Listeners, Networkers
- Story-tellers
 - Fosters inspiration and possibility thinking.
 - Creates a supportive community.
 - Carries traditions into the future

Spiritual Life Plan

- Individualized plan created with each person who receives residential services; updated as needed
- Incorporated into new employee training
- Questionnaire format with input from individual, family and staff
- Identifying information
- Faith-community attendance and participation
- Spiritual gifts and strengths
- Personal practice
- Spiritual companionship
- Spiritual encouragement
- End of life planning (optional)

ISP Process & Natural Supports

- Annually agency Medicaid Service Coordinators and brokers attend an in-service regarding our agency mission statement; incorporated into this conversation is the role of local faith-communities as places of welcome and for the development of natural supports.
- During ISP development faith-communities are considered for natural supports and possible employment networking.
- At the initial intake meeting the discussion includes faith community background and involvement.
- The ISP is linked to the Personal Outcome Measure written summary.

Personal Outcome Measures

- Personal Outcome Measure (POM) interview incorporates several questions related to spirituality and faith.
- The written summary includes a Spirituality Section.
- The person who was interviewed, the program manager and the person's service coordinator receive a copy of the POM summary for discussion and valued outcome development.

My Action Plan

- The personal valued outcomes that the person wants to accomplish in the next few months and the actions he/she will take to achieve them
- The 'actions' belong to the person, not to her/his support team: My Action Plan is about my actions not someone else's actions
- Focuses on questions raised in the POM and ISP process that relate to “What will make my life better”?
- The person owns the plan and the supports that will be required.

Individual Satisfaction Survey

- Annual survey of each person who receives residential or day habilitation services.
- Purpose of survey is to measure levels of satisfaction, not development of individualized plans.
- Includes a question regarding satisfaction with present spiritual supports.

Gene's Story: He speaks and people listen

- Had no current faith-community but a strong childhood history of church attendance; he requested assistance to find a church. Friends invited Gene to attend their church; he did and felt welcomed.
- After a year of regular attendance he advocated for himself to become a deacon at the church; he was unanimously elected. No one told him he could not become a deacon.
- He has the ability to see through distracting arguments and get right to the point- a valued gift that had been missing from the vestry before he joined them.
- He is highly valued by his faith-community.

Suzy's Story: She serves and people embrace her

- Joined a church near her group home.
- She annually leads the church effort to provide Christmas food and presents for single-mothers in the congregation.
- Suzy desired to move to her own home, a non-certified home with her sister.
- Before she moved Suzy independently made plans with her church for a ride to church each Sunday.
- The natural supports of her church empower her independence.

For Professionals in the Worlds of Services and Supports

- ▶ Re-interpreting the Role of Professional
- ▶ 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 Faith Communities and Clergy

- ▶ Recognize they are single largest resource for social capital and natural supports, in fact or in potential.
- ▶ Recognizing that faith does not equate with reason.
- ▶ Healing of memories of past abuse and neglect at the hands of clergy and churches
- ▶ Moving past an interpretation of disability through the singular lenses of poverty and/or suffering, even though both experiences are sometimes the case.
- ▶ Moving past the theistic question of “Why the disability?” to Jesus’s answer in John 9: “so that the grace of God may be revealed,” i.e., here is an opportunity to embody that grace and love, along with the more important “Why?” question--enabling people with disabilities to explore and define their own sense of purpose and calling, starting first within the church.

For both worlds...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

Resources

- ▶ The National Collaborative on Faith and Disability 2015 Webinar Series: Honoring Spiritual Needs and Gifts: From Inertia to Collaborative Action by Providers and Congregations. <http://faithanddisability.org/webinar/>
- ▶ Erik Carter's book and Collaborative's listing of research studies.

