

Community–Based Spiritual Life Supports for People with Developmental Disabilities

Earl Bleke
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1. Aging, Developmental Disabilities, and Spiritual Life

The convergence of three streams:

Aging

You and I are getting older – and so is everyone around us!

People with developmental disabilities are aging like the rest of us and living longer.

Developmental Disabilities

People with developmental disabilities all too often are on the outside looking in – and aging can make it worse.

Health issues increase as age advances, which leads to more isolation.

Spiritual Life

People with developmental disabilities are God’s good and beautiful creatures who have a soul and a need to nurture the soul.

The soul is the soul regardless of cognitive or physical ability.

Spiritual life supports are critical to the wellbeing of the whole of the person.

2. The story of Larry

- a. Coming to faith
- b. A life in community
- c. The blessing of a child
- d. A death in community
- e. His “family” and his wake

3. Why is such an occurrence not common?

- a. Agency, staff, community issues?
 - Too busy getting other things done
 - Can’t talk about spiritual issues
 - Don’t want to favor a particular religion or denomination
 - Staff lack spiritual life background or interest
 - The perception that people with developmental disabilities are not capable of a full spiritual life
 - Personal preferences are people supported are no known
- b. Church and community issues
 - Lack of accessibility
 - Perception that people with disabilities do not have the ability necessary to deal with spiritual issues
 - Unilateral view of spiritual supports for people with disabilities
- c. Lack of experience in spiritual issues on the part of people supported
 - Never been to church
 - Went once and it was not a happy experience
 - Lack of staff supports and encouragement

- Lack of support in expressing choices
 - Lack of desire for spiritual life supports
4. On a Journey with People with Developmental Disabilities
 - a. Privileged to be fellow travelers on the journey for as long as we travel together
 - b. Support people with developmental disabilities in being all God intends them to be
 - c. Support direct support staff in supporting people with developmental disabilities
 - to see people with developmental disabilities as whole people
 - to see people who are people with the same needs, desires, hopes and dreams, which include the need to fulfill the yearnings of the soul and to belong where we want to belong
 5. Getting from Uncommon to Common in Spiritual Life Supports
 - a. Get to know the person's choices concerning spiritual life
 - assessment tools
 - talk with family/guardian, people who know them well
 - learn about past choices and current interests
 - learn about desires to participate in fellowship and service events, as well as worship and religious educational opportunities
 - the most inclusive and least restrictive is always best – some aspects of supports may be more set aside than others (education, for example) while others will be fully inclusive)
 - b. Support the person in making choices
 - assist person to identify a denomination or particular congregation consistent with person's choices
 - assist person, as appropriate, in making contact with the congregation for desired supports
 - assist person in a pre-worship visit to get comfortable with the setting
 - invite the pastor/congregation leader to the home for a visit – good for person and pastor, as well as staff comfort level and relationships with people in the congregation
 - staff choices do not equal personal choice
 - c. Assist direct support staff in supporting person
 - help staff see that this is more than doing what we have to do
 - get mailings from the congregation so events can be calendared
 - assist staff in getting information about membership, worship, education, sacramental rites and customs
 - assist staff in recognizing the validity of person's choice, regardless of staff choices
 - help staff recognize potential situations where person may not be treated appropriately
 - assist staff in techniques for introducing person to relationships
 - help staff understand that arriving 5 minutes late and leaving 5 minutes early is not acceptable

- there may be times when we have to work our way into staying the whole time, but looking for excuses doesn't cut it
 - d. Transportation, transportation, transportation
 - look for volunteers at the church or in the community
 - consider public transportation
 - Does the church offer transportation supports?
 - e. Assist the local congregation
 - disability awareness training
 - understanding personal choices
 - understanding that staff are the professionals, in the event that staff must handle behaviors
 - f. Communicate with congregation leadership
 - troubleshoot any issues – staff, congregation, person supported
 - look for opportunities to be partners
 - advocacy opportunities
6. Recognizing Inclusion when you see it
- They know my name
- Worship in the church of choice
- Sitting with friends
- Religious education, if it is one's choice, is in the setting and format of one's choice and in a style that is effective for one's learning
- Opportunities for service and fellowship
- Seen by self as others as a contributor
- Religious leader knows my name and visits me when I am in the hospital and participates with me in milestone events in faith and life
- People visit me in my home and I in theirs
- Relationships are mutual – give and take
- People make choices about religious rites and sacraments
7. Some issues facing people with developmental disabilities during the aging process
- a. Loneliness and Isolation
 - Who are unpaid friends?
 - Where does one go besides a day services location, the doctor, etc?
 - Are family members involved?
 - b. Loss
 - Staff
 - Friends
 - Health – perhaps even more so than before
 - Mobility
 - Control
 - Sense of value to self and others
 - c. Need to
 - Be perceived as valued
 - Be missed
 - Give to others

- Receive from others who value me
- Be in community
- Express who one is
- Have hope for the future

9. Value of Spiritual Life Supports

- a. Spiritual life supports touch the soul
- b. Spiritual life supports give hope
- c. Spiritual life supports help us get beyond the present and the problems
- d. Inclusion in the faith community helps us all belong
- e. Each agency and program seeks opportunities for people to belong, be involved in the community, assist people in having social roles, serve, have friends – involvement in a faith community does this

10. Some resources

How People with Developmental Disabilities Can Access the Faith Community of their Choice, Home of Guiding Hands, San Diego, CA

Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families. A Bibliography and Address

Listing of Resources. Section of materials on grief, death, and dying. Hard copy: \$15.00. <http://rwjms.umdj.edu/boggscenter/products/index.htm>