Pastoral Care and Advocacy Beyond the Hospital Walls
Presenters

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Meggie Kobb, Staff Chaplain at the Hospital of the University of Pennsylvania who covers the Emergency Department, ED Observation Unit, and the Psychiatric Emergency Evaluation Center. She did a CPE residency at Penn, and, as the proud mother of a ten year old son on the autism spectrum, has used both her training and experience as chaplain with people with intellectual and developmental disabilities.

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Why this series?

• New national working group on Healthcare Decision Making formed by the Association of University Centers on Disabilities in response to experiences of people with intellectual and developmental disabilities and their families in acute care hospitals around the country.

• We are part of that working group, along with Trace Haythorn representing ACPE.

• Personal experiences as chaplains and as a parent.
What is “normal?”

Mom? What is...Normal?

It’s just a setting on the dryer, honey.
A Life Span Perspective

- Spiritual/faith supports at diagnosis
- Opportunity for inclusion early
- Rites of passage (baptism, confirmation, etc.) as building community
- Transitions: The power of immigrant/ethnic religious organizations as sanctuary and entry point.
- Transition from school to work
- Adult Services: A place to contribute, faith community support in health issues?
- Coping with grief and loss throughout life and at death.
Core pastoral roles

• Presence...with willingness to ask about story.
• Guidance...counsel...search for meaning
• Advocate. (Envision shepherd/shepherdess with a rod and staff, fending off danger, cutting through red tape, finding green pastures and water)
• Building community of support. Perhaps in congregation, but also in consultation with families and agencies.

Many agencies struggling with grief and loss issues. Opportunity for pastoral and community outreach.
What have you found out?

- Through pastoral visits in the hospital
- Through spiritual care assessment
- Through talking with caregivers, including agency staff, family, and/or friends.
- Through people who attend your congregation
If following up from a death...

- Who will provide support when caregivers go home, wherever that home is, e.g., agency residence, family residence, own homes.
- Do they have sources to help with funerals? People may not be connected to any congregation.
- Who needs to be told and informed?

Contacts may lead to opportunities for pastoral support, discovery of current supports, or conversations about how an agency handles grief and loss.
Anticipatory Grieving by Providers

• Moments to teach and talk about death and loss with those we support.
• Build relationships with local resources so the comforters are not strangers, e.g., a grief response team.
• Address and honor spirituality.
• Staff in-service about the pervasiveness of grief and loss.
• Loss assessments, planning ahead with family and guardians.
• Person centered planning for end of life wishes. See resource list for examples developed specifically for people with intellectual and developmental disabilities. (and really useable for anyone...next slide)
From there:

• How does an agency address and/or honor spirituality?
• What has been the spiritual journey of a family?
• Are there doors to be opened? Bridges to be built? Times to help educate agencies, congregations, advocacy groups, and others. So many are very ambivalent about faith and congregations because of:
  • Past histories and experiences
  • Stories they have heard
  • Lack of knowledge of positive models, resources, and blossoming of inclusive ministries.
  • Reluctance to ask or knock.
Other complexities

- Two worlds separated by a common language.
- Religion can/cannot be discussed in the schools
- Mis/Understandings of church/state separation
- Understandings of “professional”
- “Scientific” vs. “religious”
With agencies, walk/roll in their shoes

• Complexity of faith communities, sheer number, no central place.
• Fear of proselytizing and professional roles combined with stories of abuse, exclusion, and/or rejection
• I really don’t know if I can talk about it or how: professional role, training, policy
• Spiritual life or supports not usually included in evaluations, assessments, plans
Key Strategies for Congregational Leaders

• Professionals from agencies are also people
• Learn some of the language used in their respective profession or services and core mission statements
• How do your “faith based” supports help meet their mission as well?
• But primary, how do they help address the person (s) with disabilities and/or families you both support.
• Walk alongside the individuals and their families.
Places for Common Ground

- “Person-centered” and “family centered” supports and care
- Caring for caregivers including respite care
- Generic and natural supports
- Community inclusion and friendship
- Self determination
- Cultural sensitivity and competence
- Sense of calling and vocation
What is your congregation doing within your faith community?

• Accessibility
• Inclusive Worship
• Inclusive Religious Education
• Youth ministry
• Family Support
• Recreation and socialization
• Opportunities for service to others.
• Outreach and community ministry
• Social justice
Go to church, synagogue, or any other place of worship at least once a month
Possible areas for advocacy

- Working with agencies and advocacy groups on spiritual supports.
- Education and school
- Transition from school to work
- Community inclusion for adults
- Political advocacy
- More...
Example #1: Education

- Early intervention: how do church nursery and preschool programs include and support activities that may be crucial
- Inclusive religious education...good for everyone
- Individual plans for religious education or congregational supports
- Peers, buddies, circles of support
Key Connecting Point: IEP

- Asking family if they would like you to come, or if you can
- Showing up in Pharoah’s Court
- Assist as needed in empowering parental voice
- Presence: Desire to learn, interested in ways congregation can help individual learn chosen goals
- Your input on what is happening in your educational setting
Teachers and School Team

• May or may not be able to share information about your ministries. Ask how they get community resource information to families.
• Often willing to help church volunteers learn, especially if they see a young person surrounded by a caring circle of adults and peers.
• You can provide resources on the importance of spiritual supports.
#2: Transition to the Adult World

- From “entitlement” to “uncertainty.”
- What is God calling me to do?
- How can faith community help discover that call and places to live it out?
Putting Faith to Work

*Tapping the Power of Congregations as Pathways to Employment*

- Four state pilot project (TN, MN, KY, TX) funded by The Kessler Foundation

- Core Premises and Beliefs
  1. The capacity of congregations to care about individuals
  2. Desire to support current members in particular
  3. Capacity to take on targeted initiatives that help.
  4. The networking capacity, i.e., social capital available in any congregation.
The Dignity of Work and Call

'When you reap the harvest of your land, moreover, you shall not reap to the very corners of your field nor gather the gleaning of your harvest; you are to leave them for the needy and the alien. I am the LORD your God.'  Leviticus 33:22

4 Now there are varieties of gifts, but the same Spirit; 5 and there are varieties of services, but the same Lord; 6 and there are varieties of activities, but it is the same God who activates all of them in everyone. 7 To each is given the manifestation of the Spirit for the common good.

1 Corinthians 12:4-7
Putting Faith to Work Model

Training
Technical Assistance
Linkages to Services & Resources
Connections to Other Congregations

Congregation Members

Community Groups ➔ Businesses & Employer Networks ➔ Civic Groups ➔ Non-Profits ➔ Other Churches, Synagogues, Mosques ➔ Schools and Colleges ➔ Friends & Relatives ➔ Other Associations

Access to Meaningful Work
For People with Disabilities
Hmmmm... I should probably ask Operates a day care Is a frontline supervisor Works at the university Owns a landscaping business Is a vocational rehab counselor Works in a law firm Coordinates a non-profit network Does odd jobs around town Works at the municipal offices Owns a nursery Runs a local bank Leads her HR department Runs a temp agency Family Dental Center Forest River Dental Southeastern Dental Byron Orthodontics Castle Dental Works at a grocery store Runs a landscaping business Owns a nursing home Leads her HR department Works at a restaurant Is a construction contractor
From a prominent family in town
Volunteers with Habitat
In a book club (Jane Eyre)
Garden club member
Serves on the city council
Involved in a running club
Rotary club member
Is a Chamber member
Golfs with the VP of Big Company
Always “knows a guy” who...
Knows the mayor
Is a regular at Tim Horton’s
Is the “real” mayor
A White Paper

Putting Faith to Work:
The Call and Opportunity for Faith Communities to Transform the Lives of People with Disabilities and their Communities

Building community capacity to advance employment: Putting faith to work

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Abstract. The percentage of people with disabilities who are employed continues to be critically low. The existing services and supports infrastructure faces many constraints, including its limited capacity to reach and serve all people needing assistance. There is a present day need to find new ways to support job seekers with disabilities. Putting Faith to Work has emerged as a promising approach to build the capacity of faith-based communities to serve people with disabilities to find and keep work. This paper describes the background of the Putting Faith to Work model, as well as an overview of key features.

Keywords: Disability, employment, faith-based community, capacity building, training, technical assistance

INTERFAITH DISABILITY ADVOCACY COALITION

c/o AAPD • 2013 H Street, NW, 5th Floor • Washington, DC 20006

Statement of Solidarity by the Religious Community Around Employment of People with Disabilities

More than twenty years ago, with bipartisan support in Congress and broad endorsements from the civil rights, faith and labor communities, President George H.W. Bush signed into law the Americans with Disabilities Act (ADA), calling for the "shameful wall of exclusion" to come tumbling down. Today, our country is much more accessible and welcoming of people with a wide variety of disabilities and chronic health conditions than it was in 1990.

Nonetheless, based on all of the available data from the Census Bureau and the Bureau of Labor Statistics, it is an unfortunate fact that the law mandating equal access to employment for people with disabilities has failed to result in an increase in employment. Two-thirds of Americans with disabilities have not worked in the past year.

Connecting Individuals With Disabilities With Meaningful Employment

TIPS AND RESOURCES FOR FAITH COMMUNITIES

More people with disabilities:

• Have networking sessions or job fairs.
• Partner with nonprofit or businesses in the neighborhood that are looking for employees or volunteers. While paid employment is ideal, sometimes volunteering can lead to a paid position. It can certainly lead to a resume.
• What identified needs in the community would the person possess? Could meeting those needs turn into a small business or micro-employment related venture?
• Talk with potential employers about the benefits of hiring people with disabilities. Employers report that their employees with disabilities would characterize themselves in all of their employees. Lively, green-handed, dependable, and dedicated are among the terms used to describe their employees with disabilities.

How a Faith Community Can Support Jobseekers With Disabilities

• Help people with disabilities:
• Offer career counseling and assessment.
• Assist the person in identifying his or her strengths and challenges. Help to match interests with career options.
• Offer support groups or same-stemmiing.
• Assist in creating resumes and cover letters.
• Offer job interview classes.

www.puttingfaith-towork.org
# 3: Community Building

Is based on gifts rather than needs
Capacity rather than deficits
Friends and partners/colleagues rather than……
Is about relationships, relationships, relationships…
What’s the Third Thing?

Who, What, Where, When, How, and Why

Person considered “other”

Person/s in community
Circles of Support and Networks

• Group Action Planning. The Beach Center
• PLAN.  www.plan.ca
• Asset Based Community Development

“It’s awesome to be surrounded by people who are not sorry for what you cannot do.”
-Amy Turnbull. Song by Tom Hunter. Connections.
DISABILITY RIGHTS ARE CIVIL RIGHTS
Reach Out:

- To disability networks in your area, join in or collaborate with events being planned, e.g., Centers for Independent Living
- If none, start a conversation and help lead the way
- State Developmental Disabilities Council for key advocacy issues
- Your state’s University Center of Excellence in Developmental Disabilities. Go through www.aucd.org
- American Association for Persons with Disabilities: www.aapd.com
Moving beyond polarities to what connects us.

• “Disabled” vs. ‘normal’ or ‘typical’
  
  *We are all on the spectrum.*

• Spiritual and religious vs scientific/public/secular

• Segregation vs. Inclusion

• Victim vs. Hero

• Find a language that is not “us” and “them,” e.g. vulnerability, limits, gifts, image of God
OUR DOOR IS OPEN:
Creating Welcoming Cultures in Helping Organizations

Featuring:
BRUCE ANDERSON

COMMUNITY ACTIVATORS AUDIO
Hospitality and Welcome

Besides all the potential gifts to individual and organizational capacity, the ‘stranger’

• Helps the world to be a safer place for all of us.
• Saves us from the boredom of sameness
• Invites us to learn about ourselves, and the hidden wholeness at the heart of creation.

Parker Palmer, *Merging Two Worlds Keynote.*
http://bethesdainstitute.org/Other-Faith-and-Disability-Presentations
The great paradox of ministry, therefore, is that we minister above all with our weakness, a weakness that invites us to receive from those to whom we go. The more in touch we are with our own need for healing and salvation, the more open we are to receive in gratitude what others have to offer us. The true skill of ministry is to help fearful and often oppressed men and women become aware of their own gifts, by receiving them in gratitude. In a sense, ministry becomes the skill of active dependency: willing to be dependent on what others have to give but often do not realize they have.

Henri Nouwen, **Gracias**
And that is true for:

- Congregations and their members
- Agencies and their staff

As well as for the people and their families that we all support.
Faith communities: the largest natural support network in the United States

More Than 335,000 Congregations Nationally

Average of 186 Attendees (200 million people of faith)
Advocacy in policy making

• Our involvement in the inclusive community can also mean encouraging legislation & speaking out against policies that don’t work.
Non-partisan voices

• Be mindful of new laws in your area, and how they will affect people with disabilities.

• Listen to the concerns of families, and encourage them to tell their stories.

• Reach out to your elected officials and talk to them about what weighs on your heart.

• “Speaking truth to power”
Avonte’s Law

- Named for Avonte Oquendo, age 14, from Queens
- Eloped from his school
- Missing for months, his remains were finally found in early 2014 in the East River.
Training for first responders

• Avonte’s Law is currently receiving bi-partisan support as it makes its way through Congress.

• Would help to safeguard individuals with autism who are prone to wandering, and mobilize first responders with more effective tools for finding people with cognitive disabilities.
Issue right now:

Proposed FDA rule to ban use of electrical shock as a behavioral control.

Long campaign to stop use of electrical shock as an aversive conditioning tool at the Judge Rotenberg Center in Massachusetts.

Comments on proposed rule:

https://www.regulations.gov/#!documentDetail;D=FDA-2016-N-1111-0001
Resources

• Listing of current resources, go to:
  • Resource listing for this series.
  • Also go to The Quality Mall, www.qualitymall.org
  • Faith and Disability offices or projects within your own faith group or denomination.
  • http://faithanddisability.org for
    • Research and articles
    • Summer Institute on Theology and Disability Resource materials and videos
    • Putting Faith to Work
    • Advocacy and the ADA
  • Sign up for the Institute on Theology and Disability Facebook page.
Questions and Discussion