Building Bridges: Working with Faith Communities to Support People with I/DD

Presenters:

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Building Bridges: Working with Faith Communities to Support People with Intellectual and Developmental Disabilities

FOCUSING ON PEOPLE WITH I/DD AND THEIR FAMILIES
People with disabilities and their families have the right to live, love, work, worship, play and pursue their life aspirations just as others do in their community.
Who are we Focusing On?

All 4.9 Million people with developmental disabilities

Based on national definition of developmental disability with a prevalence rate of 1.49%
Evolution of Supports to Persons with I/DD & Their Families
What is happening to Formal Support Systems?

Expectations, Values, Culture

Federal Policy

Federal Budget

Demand for Services

Community

Family

Social Services

Person with Disability

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Where are People Supported

4.7 Million people with I/DD

- Receiving Services Out of Home 13%
- Receiving Services Living at Home 12%
- Not Receiving Services - Living at Home 75%


89% of People I/DD are Supported Outside of Formal Residential Supports

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Building Bridges: Working with Faith Communities to Support People with Intellectual and Developmental Disabilities

PROVIDING SUPPORTS
All individuals live within the context of a family

(Regardless of where a person lives)
## Recognizing the Reciprocal Roles of ALL Family Members

<table>
<thead>
<tr>
<th>Caring About</th>
<th>Caring For</th>
</tr>
</thead>
<tbody>
<tr>
<td>👏 Affection &amp; Self-Esteem</td>
<td></td>
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<tr>
<td>👏 Repository of knowledge</td>
<td></td>
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<tr>
<td>👏 Lifetime commitment</td>
<td></td>
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<tr>
<td>📦 Provider of day-to-day care</td>
<td></td>
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<tr>
<td>🧵 Material/Financial</td>
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<tr>
<td>📦 Facilitator of inclusion and membership</td>
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<tr>
<td>📦 Advocate for support</td>
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Defining Supports to Families

**GOAL**

**Individual**
Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life

**Families**
Will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal

Recognizing that individuals exist within a family system

**DISCOVERY AND NAVIGATION**
Knowledge & Skills

**CONNECTING & NETWORKING**
Mental Health & Self-Efficacy

**GOODS & SERVICES**
Day-to-Day & Caregiving/Supports

_Achieve with us._
### What Families Might Need?

<table>
<thead>
<tr>
<th>Discovery &amp; Navigation: Knowledge &amp; Skills</th>
<th>Connecting &amp; Networking Mental Health &amp; Self-efficacy</th>
<th>Day-to-Day Services Instrumental Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Information on disability</td>
<td>• Parent-to-Parent Support</td>
<td>• Self/Family-Directed services</td>
</tr>
<tr>
<td>• Knowledge about best practices and values</td>
<td>• Self-Advocacy Organizations</td>
<td>• Transportation</td>
</tr>
<tr>
<td>• Skills to navigate and access services</td>
<td>• Family Organizations</td>
<td>• Respite/Childcare</td>
</tr>
<tr>
<td>• Ability to advocate for services and policy change</td>
<td>• Sib-shops</td>
<td>• Adaptive equipment</td>
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<tr>
<td></td>
<td>• Support Groups</td>
<td>• Home modifications</td>
</tr>
<tr>
<td></td>
<td>• Professional Counseling</td>
<td>• Financial assistance</td>
</tr>
<tr>
<td></td>
<td>• Non-disability community support</td>
<td>• Cash Subsidies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Short/Long term planning</td>
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<tr>
<td></td>
<td></td>
<td>• Caregiver supports &amp; training</td>
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*Achieve with us.*
Recognition of Individual and Family Cycles

**Individual Life Cycle**
- Birth
- Early child
- School
- Transition
- Adulthood
- Aging

**Family Life Cycle**
- Single Adult
- New Couple
- Couple with Children
- Launching Children
- Family Later in Life
Trajectory towards Good Life

Friends, family, self-determination, community living, social capital and economic sufficiency

Vision of What I Don’t Want

Trajectory towards Outcomes

Trajectory towards things unwanted

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Focusing on Life Experiences

"Volunteering at church"
"Birthday parties with friends"
"Playing sports or an instrument"
"Chores and allowance"
"Making mistakes"
"Learning to say “no”"

Birth-----Early Child----School----Transition---Adulthood-------Aging

“Anticipatory Guidance for Life Experiences”
Think Across Life Stages and Generations

<table>
<thead>
<tr>
<th>Age</th>
<th>0-5</th>
<th>6-18</th>
<th>19-64</th>
<th>65</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
<td>20,572,339 (6.3%)</td>
<td>75,959,407 (23.3%)</td>
<td>178,821,105 (57.4%)</td>
<td>41,144,679 (13%)</td>
</tr>
<tr>
<td>Approx. DD (1.49%)</td>
<td>306,527</td>
<td>1,131,795</td>
<td>2,664,434</td>
<td>613,055</td>
</tr>
</tbody>
</table>

*Based on US Census Data, 2013 estimates*
Thinking Across all Life Domains

**Daily Life and Employment** (education/employment, life skills)

**Healthy Living** (medical, behavioral and mental health, wellness, nutrition)

**Community Living** (housing, transportation, community access)

**Safety and Security** (emergencies, legal, well-being, guardianship and alternatives)

**Social and Spirituality** (friends, relationships and leisure activities)

**Citizenship and Advocacy** (leadership, peer support, making choices, setting goals)

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### Long Term Services and Supports Possibilities

#### Innovative Support

New ideas; things that someone has tried, and you replicate or adapt for your own needs; things that haven’t been thought of yet or tried.

<table>
<thead>
<tr>
<th>Day Life &amp; Employment</th>
<th>Community Living</th>
<th>Social &amp; Spirituality</th>
<th>Healthy Living</th>
<th>Safety &amp; Security</th>
<th>Citizenship &amp; Advocacy</th>
<th>Supports for Family Unit</th>
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</table>

#### Traditional options

- Micro-enterprises
- Careers
- Competitive employment
- College or tech school
- Supported employment
- Work crews or enclaves
- Job coaches
- Volunteering
- Special college programs
- Co-op
- Adapted living space
- Environmental technology
- Shared living
- Public transportation
- Independent Supported Living (ISL)
- Home of Your Own (program)
- Independent Living Center
- Friendships
- Dating/relationships
- Parks and Recreation
- Inclusive faith community
- Service/social club/groups
- Special Olympics
- Special passes
- Social skills classes
- Gym membership
- Community Health Centers
- Health fairs
- Family practice providers
- In-home or community based therapies
- Family member or school staff implement therapy
- Special Olympics
- Limited/joint bank account, automatic bill pay, personal contract, agency agreement
- Personal safety devices
- Limited guardianship
- Remote monitoring
- Special Needs Trust
- Power of Attorney
- Voting
- Neighborhood group or organization
- Self-Advocacy
- Visiting your legislator
- People First/SABE
- Disability Rights Day at the Capitol
- Project STIR
- Social Media
- Technology
- Blogs
- Family & friends
- Peer Support/P2P
- Face-to-face local support groups
- Online Support Groups
- Sib-shops
- Exchange networks
- Time banks
- Human service co-ops
- General education
- Self-Directed Supports
- $$ follows the person
- Technology/remote monitoring

- Sheltered workshops
- Day habilitation
- Institutions
- Intermediate Care Facility (ICF)
- Group Homes
- Separate or special church service
- Special group outings & activities
- Center-based therapies (PT, OT, Speech, etc)
- Special or institutional medical care
- Full guardianship
- 24 hour supervision
- Paid advocate or having someone else advocate on your behalf
- Institution or center based support group
- Intensive all-day parent training
- Disability specific groups

- Center for Independent Living (CIL)
- Day Habilitation Services
- Independent Living Centers
- Supported Employment Services
- Work crews or enclaves
- Job coaches
- Volunteering
- Special college programs
- Co-op
- Adapted living space
- Environmental technology
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- Achieve with us.
Partnering Across Communities

Pediatrician, Families and Friends, Faithbased

IDEA Part C, Parents as Teachers, Health, Headstart

School, Special Education, Health, Recreation

Vocational Rehab, Health Employment, College, Military

Disability Services, Health, Housing, College, Careers

Retirement, Aging System, Health

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Building Bridges: Working with Faith Communities to Support People with Intellectual and Developmental Disabilities

FOCUSING ON FAITH COMMUNITIES
Where to Start?

• “Tell me your stories.” Conversations with individual families or groups of families.

We have to be honest:
• Stories of inclusion and support
• Stories of exclusion and pain
Some Research Findings

• Families believe spirituality is very important but also reluctant to have others inquire about it as part of assessment process (Turnbull and Poston, 2004)
• Majority of 500 families believe spirituality is very important in their homes but much fewer find those needs and interests honored in their faith community or by service providers. (Carter, 2014)
The “first church/synagogue/temple of natural supports”

- Many people prefer to turn to their faith communities for help and support.
- @335,000 congregations in this country
- Name any support: Some congregation is doing it.
- Place to contribute and use gifts. Givers as well as receivers. Some congregation is doing it.
Pastoral Care Roles

- Presence
- Counselor, guide to helping interpret meaning
- Advocate (Shepherd)
- Community Building

See
http://www.aapc.org/media/166227/gaventa_sacredspaces_last.pdf
Attention to the Long Haul

• Can be an anchoring community as well as gateway to other parts of the community

• Long term ideas adapted to congregational settings, e.g. circle of support, informal or intentional
Some Examples
Coming out this year: Guidebook for Family Support Groups in Congregations

Special Needs Parenting: From Coping to Thriving offers emotional and spiritual resources for the journey of special needs parenting. Sharing personal insights as a theologian and the parent of an adult son with special needs, Rev. Dr. Lorna Bradley offers seven encouraging and practical tools to help the reader:

- gain a deeper, grace-filled understanding of God's presence.
- process deeply held feelings of grief and guilt.
- discover strategies for patience, self-care, and healthy relationships.
- find hope and healing.

Powerful for the individual reader, the built-in reflection and discussion questions make Special Needs Parenting an ideal, real-life resource for small groups.

Special Needs Parenting is a must read for family members, pastors, and any person who works with special needs families. Dr. Bradley explores their challenges, grief, and joy with deep sensitivity, theological depth, and practical advice. A blessing to all who read it and allow their lives to be touched by wisdom born of personal experience and biblical scholarship.

Bishop Janice Riggle Huie
United Methodist Church, Texas Annual Conference

Dr. Bradley blends biblical reflection with pastoral insight, personal story, and stories from others. She earns the reader's trust by offering reflections, possibilities, and practical advice, and helps congregations ensure that every family and person is welcome and belongs.

Bill Crorentz, MDiv
Director, Summer Institute on Theology and Disability

Dr. Bradley invites the reader into a deeply honest conversation about the lived experience of parenting a child with special needs. She teaches us practical strategies for spiritual and emotional growth and helps us see that joy and hope are possible in the midst of the struggle. There is simply no other book like this.

Rev. Jaime Clark-Salvay, PhD
Associate Professor of New Testament, Perkins School of Theology

Hope & Healing

LORNA BRADLEY

from coping to thriving
Congregations at many points

• Some never have thought about inclusion or have avoided it
• Many with ministries “for” or “to” people with disabilities
• Others more collaborative, working with individuals and families
• Emerging, congregations expressing gratitude for the gifts brought.
Where to Start?

- Lots of resources for congregational ministries and faith supports (see short listing of online resources with the webinar)
- Find way to tell your faith story, i.e., the reasons why you wish to be involved as a family.
- Pastor or clergy may be place to start, may not. Many points of entry.
- Find other families where their faith communities have been supportive
Invitation

Invite someone from faith community to:

1. Your home
2. A family support meeting
3. An IEP
4. A person centered planning meeting, e.g., PATH
5. A workshop or training event
6. Explore your faith’s resources
For Service and Support Agencies

• Take spiritual wishes and needs seriously
• It is more than a right or nice thing
• A way of living out your mission of:
  • Inclusion and use of generic supports
  • Family Centered Supports
  • Self Determination
  • Culturally competent care
How to begin the conversation?

Simple questions in family centered planning:

1. F: Is spirituality or faith important to you?
2. I: How does it influence your life as a family?
3. C: What kind of communal expressions does it take or would you like it to take?
4. A: How can we assist you with that?

FICA Spiritual Assessment: [www.gwish.org](http://www.gwish.org)
Service Providers Can Assist

• Each world confusing to the other.
• Not a violation of church/state unless you proselytize.
• Nor is it a violation of “professional.”
• It may be new area for exploration, but there are resources to help. (See resource listing)
• Resources in the community who can help you with strategies and understanding.
Ways of Assisting Clergy and Congregations

Good Community Building Skills:

• Asker - open the door, ask for their help
• Consult - respect their perspective, expertise, culture and gifts
• Coach - offer to share your expertise as needed
• Collaborate - a partnership that shares responsibilities for outcomes
Build Relationships with Families at the Center

- For the long run, not just the short objective
- Build trust through respect and resources.
- Through churches, synagogues, temples, mosques, etc., you may also find other families who have not been connected to services and supports.
- Share resources with clergy for helping families plan on a long term basis, e.g. family support models and resources, faith-based resources.
For Chapters of The Arc and other Agencies for Building Partnerships

- Talk with local ecumenical or interfaith networks and, as requested, meetings where clergy and leaders are already gathered.
- Highlight stories about faith inclusion and supports in your newsletter.
- An annual awards dinner: Give one to a clergy member or congregation.
- Explore ways of having pastoral or other religious interns work with your agency and/or offer educational resources to training programs, e.g., Clinical pastoral education programs.
Systems Strategies (cont.)

• Develop policies and practices for including spiritual supports in planning and supports
• Work with other agencies and faith communities to sponsor workshops or conferences
• Many UCEDD’s and DD Councils are interested in faith based supports
• Develop inter-disciplinary, inter-faith Grief and Loss team to proactively address grief and loss, end of life issues, with individuals, families, and staff. Use clergy in training for staff.
Strategies (cont.)

• Develop an inter-agency, interfaith task force to enhance inclusive spiritual supports. An agency is a neutral base for faith organizations and vice versa.

• Build resource library, especially documentaries and films, that congregations could borrow.

• Work with men’s and women’s groups, and outreach, on creative individual initiatives, e.g. helping people with disabilities, especially congregational members, find jobs. See http://faithanddisability.org/projects/pftw/
Some Chapters of The Arc and Agencies

• Developing roles for part-time or full time coordinators of spiritual supports to work with individuals they support, families, and congregations.

• Resource to enhance person-centered, culturally competent supports, social and recreational opportunities, ongoing learning, potential friendship, places to use gifts, and much more…including the long term.
The Resources Barrier is Non-existent

• Lots of Christian, Jewish, and, more recently, Muslim resources. See website listing at http://faithanddisability.org/projects/ada-25th-anniversary/faith-and-disability-network-websites/

• Also inclusive faith based support organizations not tied to a specific denomination, e.g. Joni and Friends, Jewish Developmental Disability Awareness Month activities.

• See the two page listing of easily accessible online resources provided with this webinar.
National Initiatives

• Collaborative on Faith and Disability
  http://faithanddisability.org with
  1. Putting Faith to Work Project
  2. 2015 Webinar Series for Agencies and Congregations
  3. ADA25 Anniversary and Faith Communities: Opportunity and Challenge

• Summer Institutes on Theology and Disability
  http://bethesdainstitute.org/theology

• Autism Society of America Faith Initiative

• Jewish Disability Awareness Month (just Google)

• Gleanings Resource Newsletter: Sign up + back copies:
  http://www.aaiddreligion.org/newsletter

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This Year: The ADA25 and Faith Initiative

A time and opportunity for you to invite faith communities (your own and others) to utilize the ADA25 Anniversary to explore and strengthen inclusive spiritual and faith supports.

See: [http://faithanddisability.org](http://faithanddisability.org) for a Religious Community Pledge, Resources, Websites, and more.
Contact Information

For you: More information or questions:

bill.gaventa@gmail.com

From you: Share stories and examples of congregation and faith based supports over the long haul, including planning for the future.

bill.gaventa@gmail.com and/or

Robin Shaffert at Shaffert@thearc.org
Questions?

Please raise your hand and we will call on you OR type your question into the chat box.
Next Webinar:

The Family: Aging and Disability
Tuesday, April 7, 2015 at 2:00 – 3:00 pm Eastern

If you have any questions, please contact us at futureplanning@thearc.org