

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

Presenters:

Bill Gaventa, M.Div.

Director, Summer Institute on Theology and Disability and the Collaborative on Faith and Disability

Michelle “Sheli” Reynolds, SIB, Ph.D.

Director of Individual Advocacy and Family Support, UMKC UCEDD



*For people with intellectual
and developmental disabilities*

Achieve with us.®

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

FOCUSING ON PEOPLE WITH I/DD AND THEIR FAMILIES

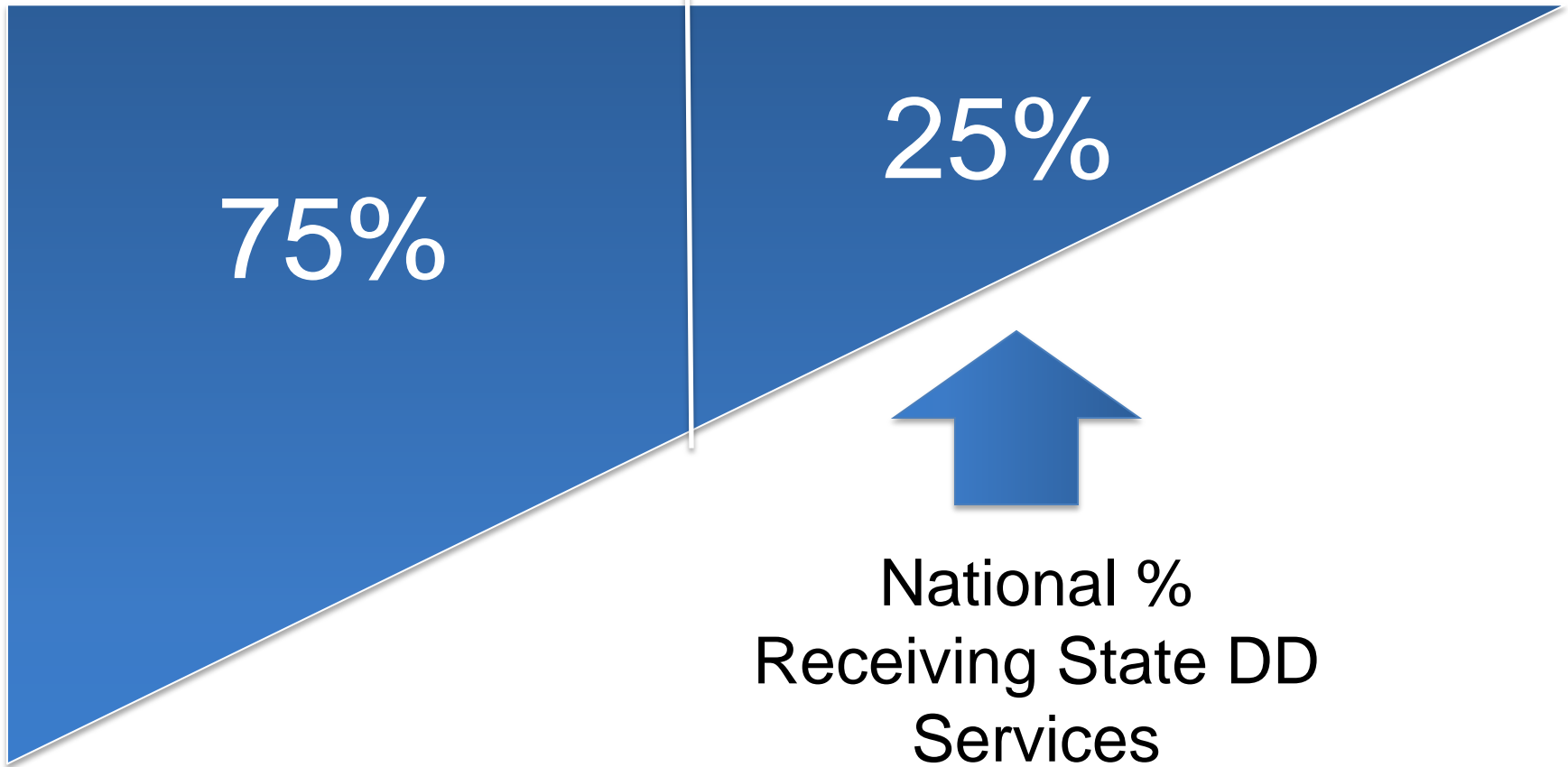


**People with disabilities
and their families have the
right to live, love, work,
worship, play and pursue
their life aspirations
just as others do in their
community.**



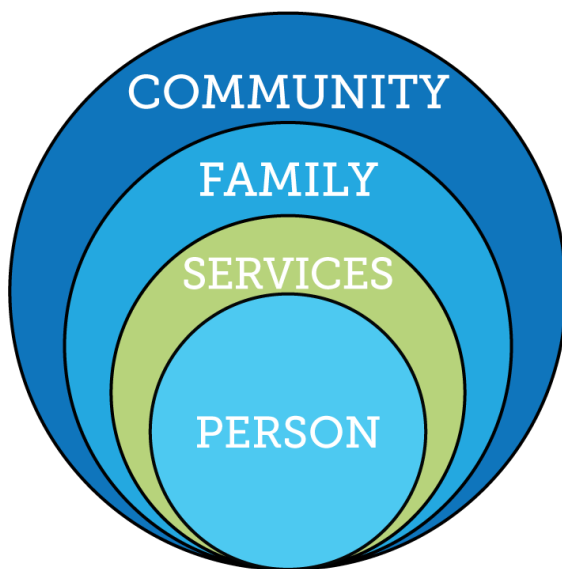
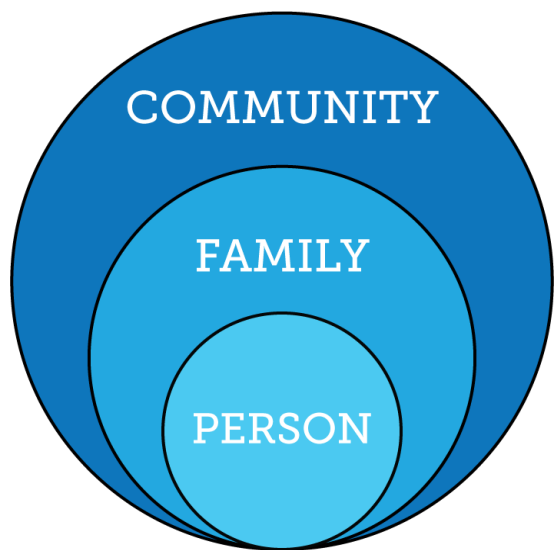
Who are we Focusing On?

All 4.9 Million people with developmental disabilities

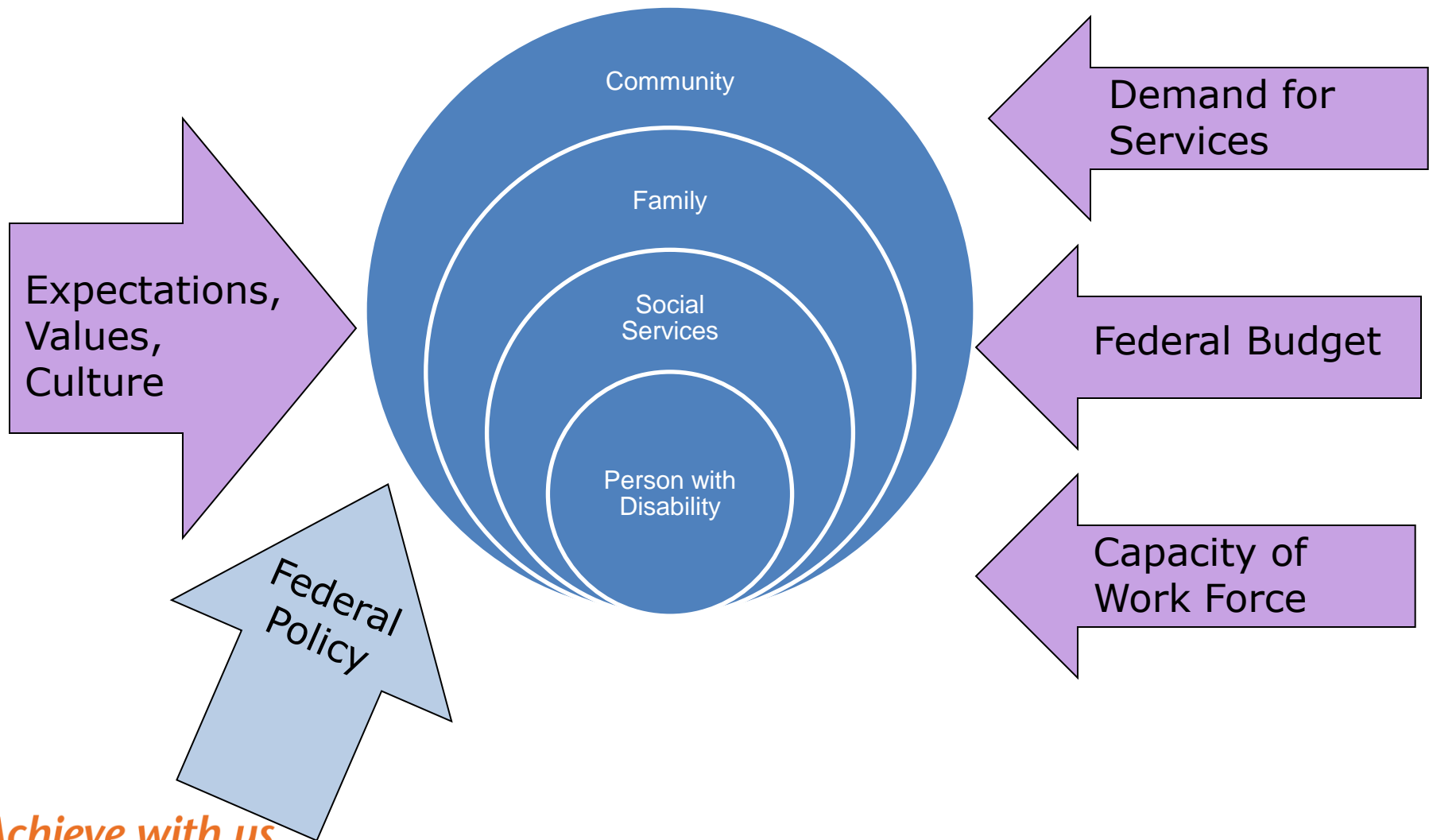


Based on national definition of developmental disability with a prevalence rate of 1.49%

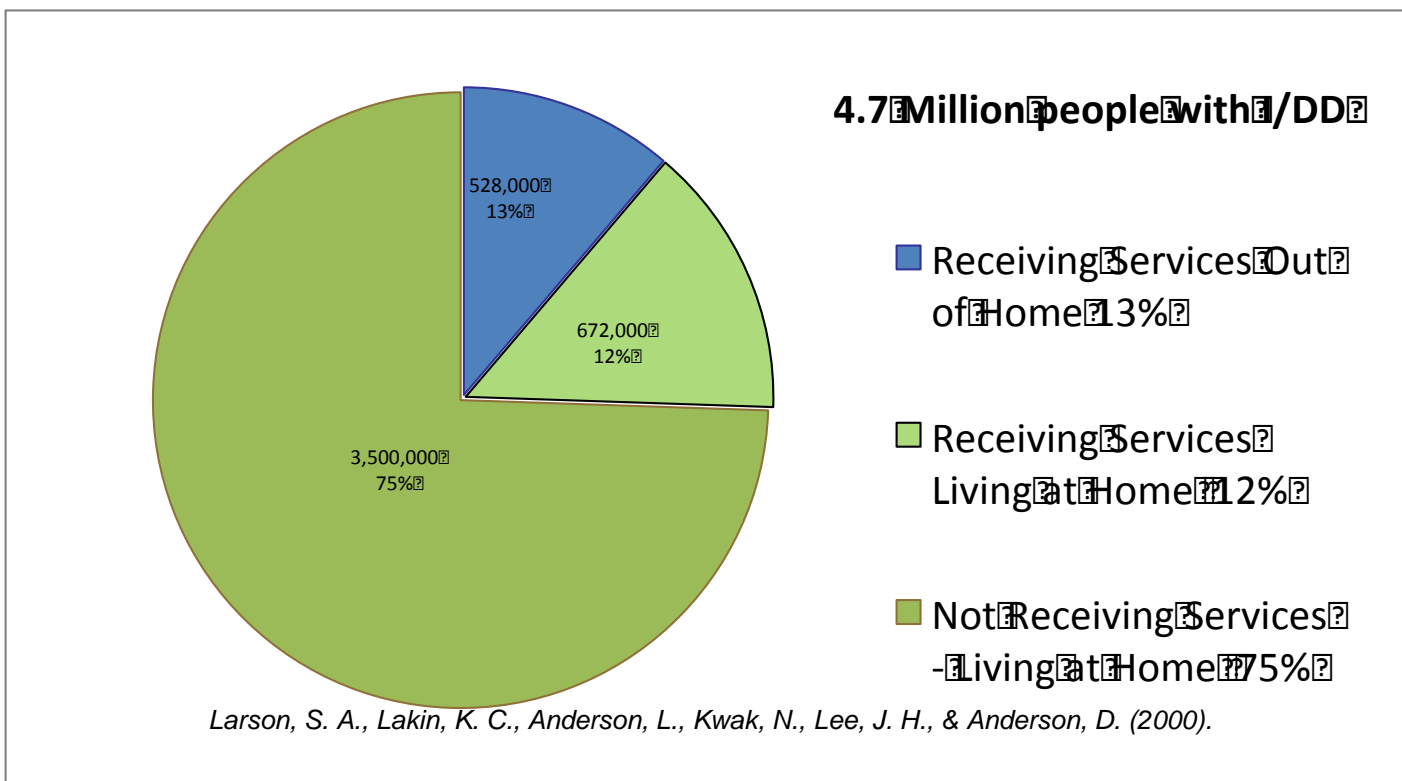
Evolution of Supports to Persons with I/DD & Their Families



What is happening to Formal Support Systems?



Where are People Supported



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

**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

 <p>Caring About</p>	Affection & Self-Esteem
	Repository of knowledge
	Lifetime commitment
 <p>Caring For</p>	Provider of day-to-day care
	Material/Financial
	Facilitator of inclusion and membership
	Advocate for support

**Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et al (2011)*



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

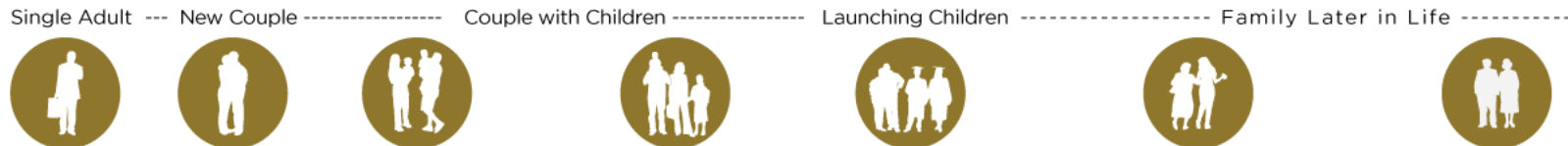
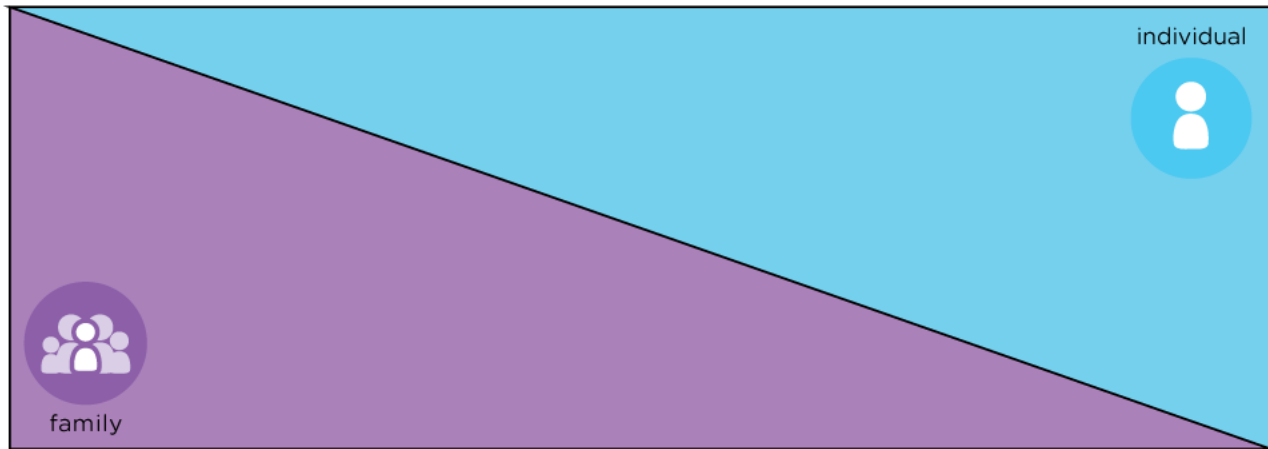


What Families Might Need?

Discovery & Navigation: Knowledge & Skills	Connecting & Networking Mental Health & Self-efficacy	Day-to-Day Services Instrumental Supports
<ul style="list-style-type: none">• Information on disability• Knowledge about best practices and values• Skills to navigate and access services• Ability to advocate for services and policy change	<ul style="list-style-type: none">• Parent-to-Parent Support• Self-Advocacy Organizations• Family Organizations• Sib-shops• Support Groups• Professional Counseling• Non-disability community support	<ul style="list-style-type: none">• Self/Family-Directed services• Transportation• Respite/Childcare• Adaptive equipment• Home modifications• Financial assistance• Cash Subsidies• Short/Long term planning• Caregiver supports & training

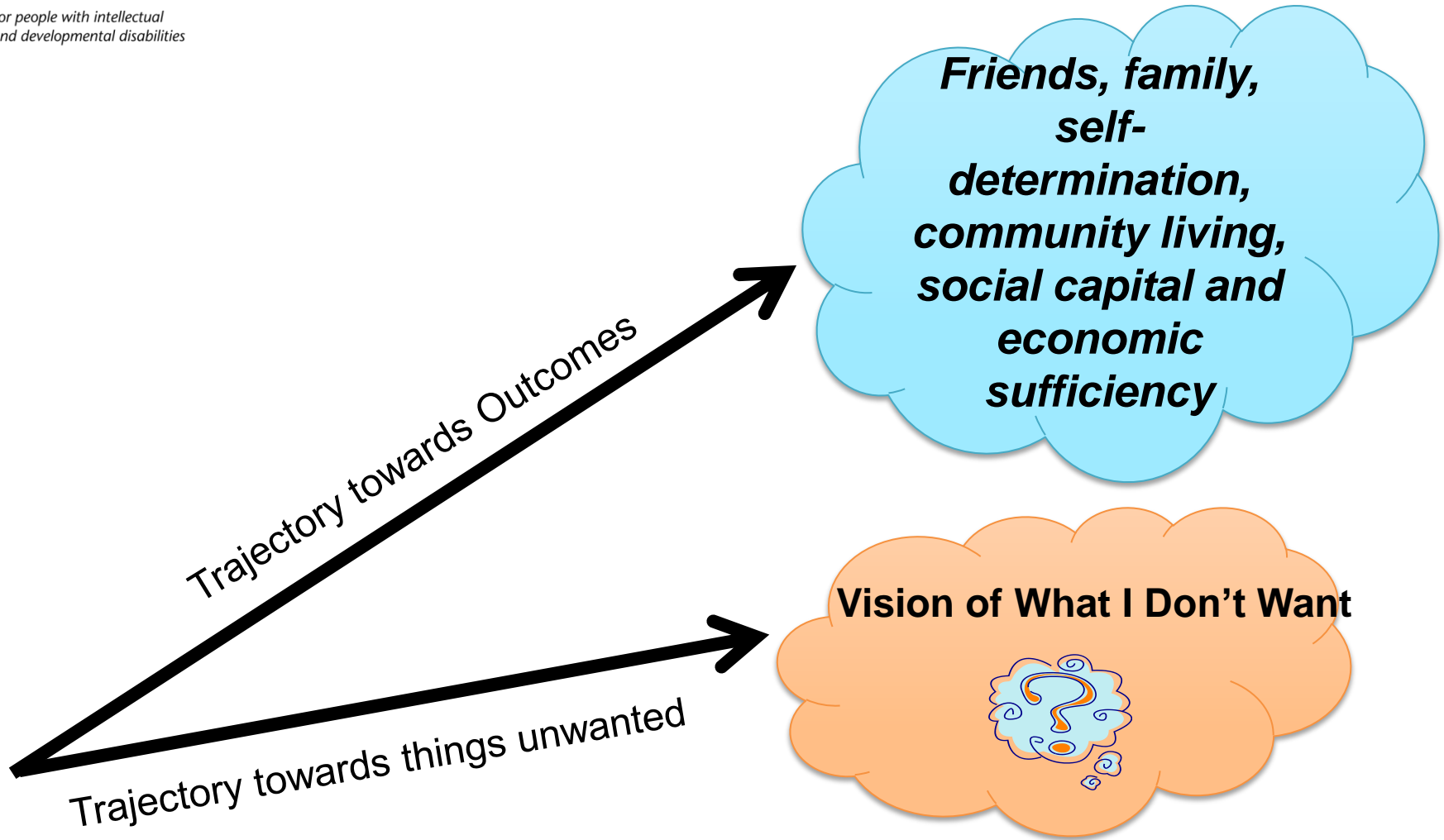
Recognition of Individual and Family Cycles

Individual Life Cycle

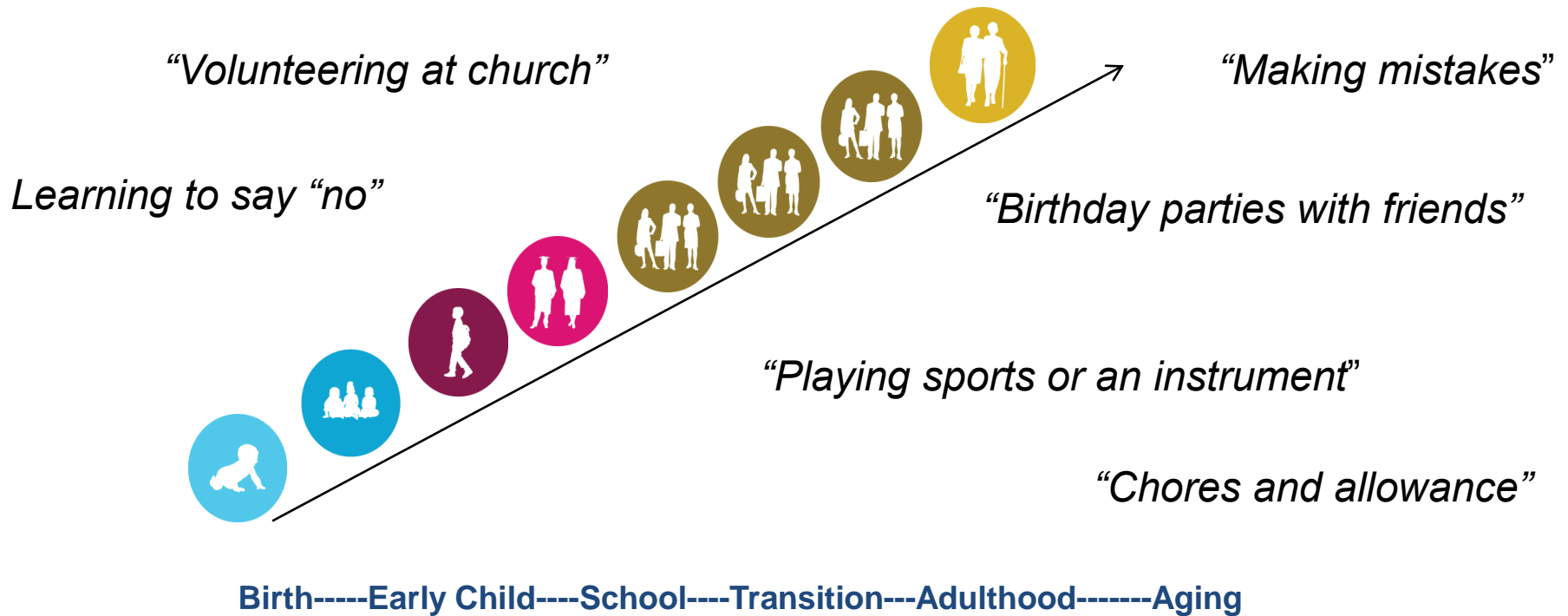


Family Life Cycle

Trajectory towards Good Life



Focusing on Life Experiences



“Anticipatory Guidance for Life Experiences”

Think Across Life Stages and Generations

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

*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)

Long Term Services and Supports Possibilities

	 Daily Life & Employment	 Community Living	 Social & Spirituality	 Healthy Living	 Safety & Security	 Citizenship & Advocacy	 Supports for Family Unit	 Supports & Services
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.							
	<ul style="list-style-type: none"> • Micro-enterprises • Careers • Competitive employment • College or tech school • Supported employment • Work crews or enclaves • Job coaches • Volunteering • Special college programs 	<ul style="list-style-type: none"> • Co-op • Adapted living space • Environmental technology • Shared living • Public transportation • Independent Supported Living (ISL) • Home of Your Own (program) • Independent Living Center 	<ul style="list-style-type: none"> • Friendships • Dating/relationships • Parks and Recreation • Inclusive faith community • Service/social club/groups • Special Olympics • Special passes • Social skills classes 	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • Limited/ joint bank account, automatic bill pay, personal contract, agency agreement • Personal safety devices • Limited guardianship • Remote monitoring • Special Needs Trust • Power of Attorney 	<ul style="list-style-type: none"> • Voting • Neighborhood group or organization • Self-Advocacy • Visiting your legislator • People First/SABE • Disability Rights Day at the Capitol • Project STIR 	<ul style="list-style-type: none"> • Social Media • Technology • Blogs • Family & friends • Peer Support/P2P • Face-to-face local support groups • Online Support Groups • Sib-shops 	<ul style="list-style-type: none"> • Exchange networks • Time banks • Human service co-ops • General education • Self-Directed Supports • \$\$ follows the person • Technology/ remote monitoring
Traditional options	<ul style="list-style-type: none"> • Sheltered workshops • Day habilitation 	<ul style="list-style-type: none"> • Institutions • Intermediate Care Facility (ICF) • Group Homes 	<ul style="list-style-type: none"> • Separate or special church service • Special group outings & activities 	<ul style="list-style-type: none"> • Center-based therapies (PT, OT, Speech, etc) • Special or institutional medical care 	<ul style="list-style-type: none"> • Full guardianship • 24 hour supervision 	<ul style="list-style-type: none"> • Paid advocate or having someone else advocate on your behalf 	<ul style="list-style-type: none"> • Institution or center based support group • Intensive all-day parent training • Disability specific groups 	<ul style="list-style-type: none"> • Systems supports • Provider and agency staff

Partnering Across Communities

Pediatrician, Families and Friends,
Faithbased

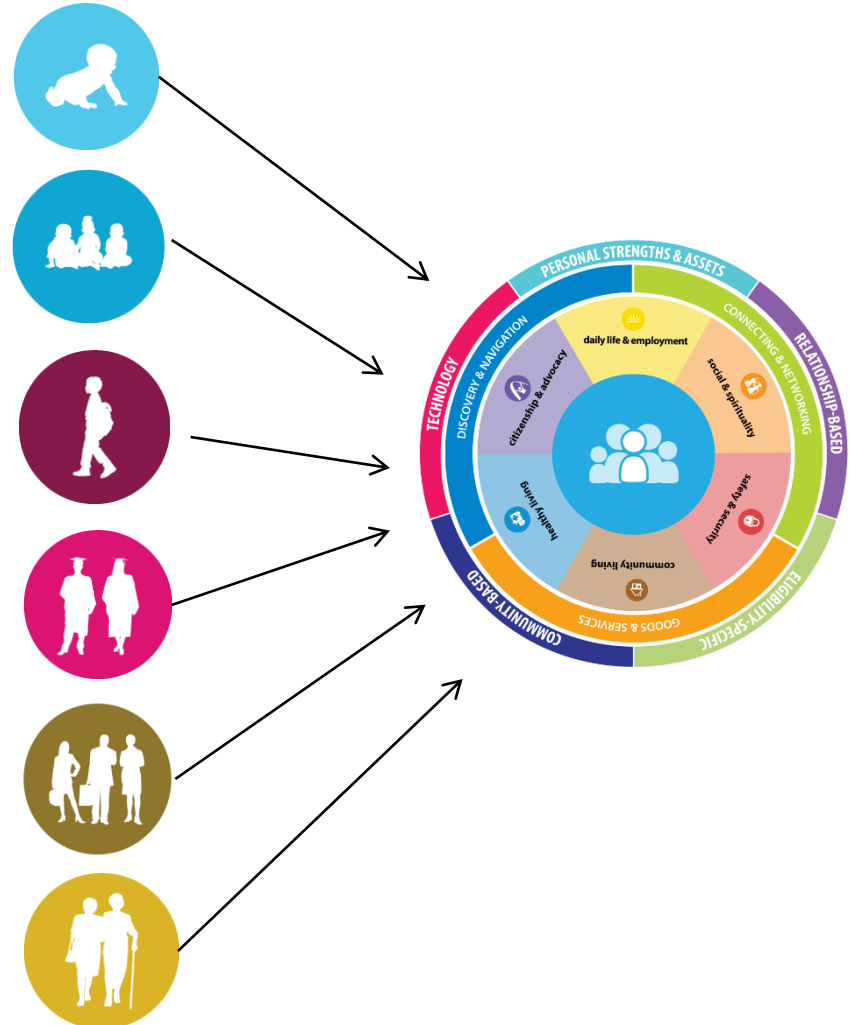
IDEA Part C, Parents as
Teachers, Health, Headstart

School, Special Education, Health,
Recreation

Vocational Rehab, Health
Employment, College, Military

Disability Services, Health,
Housing, College, Careers

Retirement, Aging System,
Health



**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

Kintsugi, a Japanese style of art, means "beautifully broken."
Repaired with seams of gold, each piece is more interesting due to its unique journey.



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 readers' trust by offering reflections, possibilities, and guidance, and helps congregations ensure that every family and person is welcome and belongs.

Bill Gaventa, 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-Soules, PhD
Associate Professor of New Testament, Perkins School of Theology



BRADLEY

SPECIAL NEEDS PARENTING

special needs PARENTING



from coping to thriving

LORNA BRADLEY

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

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



*For people with intellectual
and developmental disabilities*

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 people with intellectual
and developmental disabilities*

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://bethesda institute.org/theology>
- Autism Society of America Faith Initiative
<http://www.autism-society.org/living-with-autism/community-inclusion/autism-and-faith/>
- Jewish Disability Awareness Month (just Google)
- Gleanings Resource Newsletter: Sign up + back copies:
<http://www.aaidreligion.org/newsletter>



*For people with intellectual
and developmental disabilities*

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> for a Religious Community Pledge, Resources, Websites, and more.

Contact Information

For you: More information or questions:

bill.gaventa@gmail.com

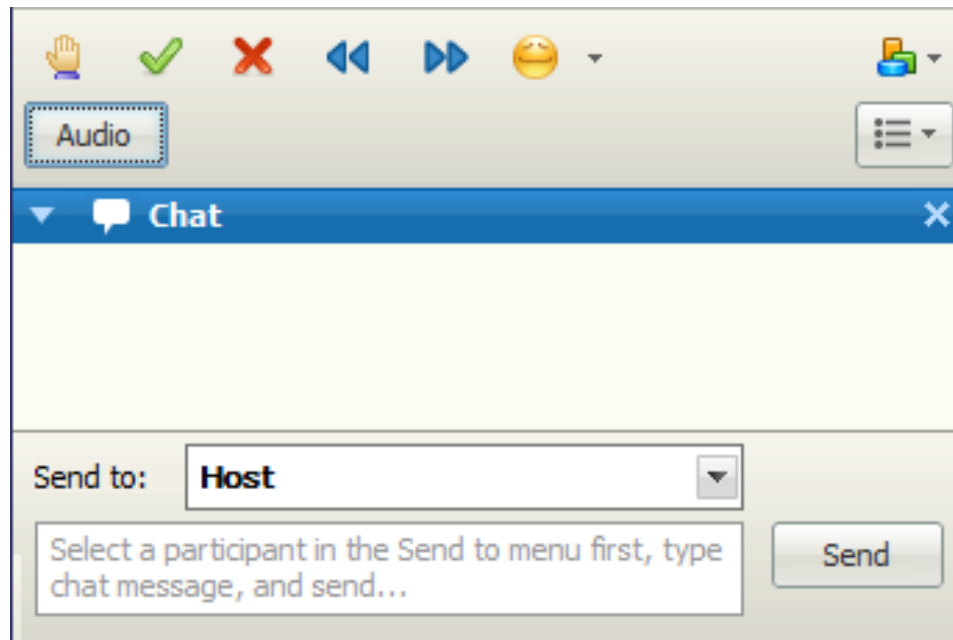
From you: Share stories and examples of congregation and faith based supports over the long haul, including planning for the future.

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