

# FROM EXCLUSION TO EMBRACE

## SUPPORTING INCLUSION AND BELONGING FROM BOTH SIDES OF THE DOORS

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"I am a Christian myself. I go to church every Sunday. So, that's what I do .... I believe that first and foremost, God is the most important thing in my life.."

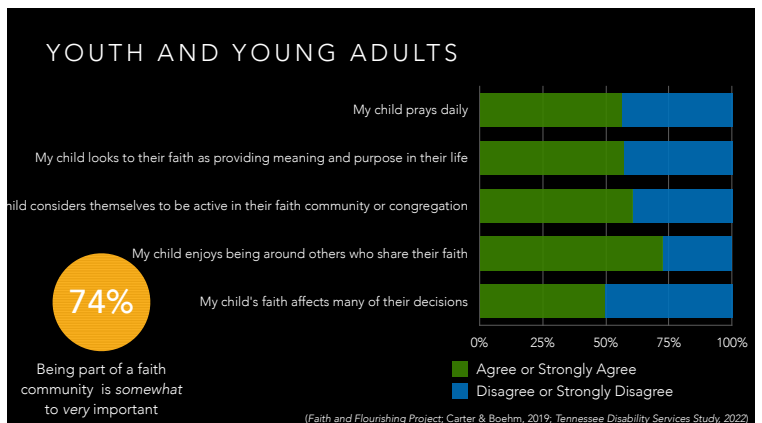
-JAMES, 15-YEAR-OLD WITH AUTISM

"It is a good church. People good to me. My youth group's good ... they love me and they cheer me up."

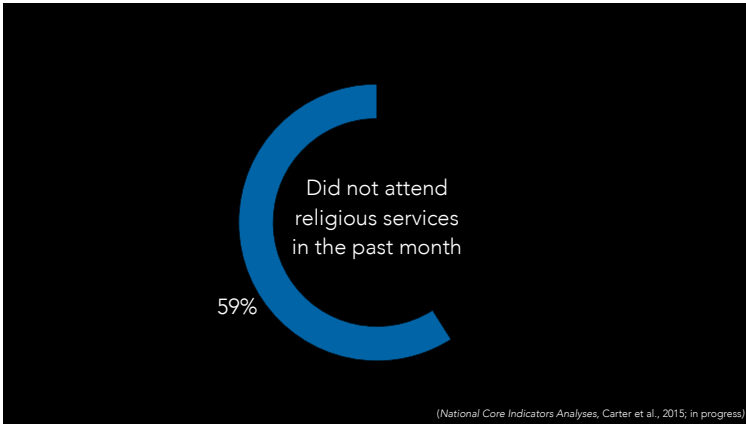
-MAURICE, 15-YEAR-OLD WITH INTELLECTUAL DISABILITY

(Faith and Flourishing Project; Liu et al., 2014; Accessible Worship Project, Carter et al., in press)

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“There’s a place for everybody here [at my church]. You belong to something that’s greater than the whole.”

–AUDREY, PARENT OF A DAUGHTER WITH INTELLECTUAL DISABILITY

“The small group that we’re in often prays for our family and we talk about the issues we are dealing with. We feel very connected to them and, of course, the same things go for the other members.”

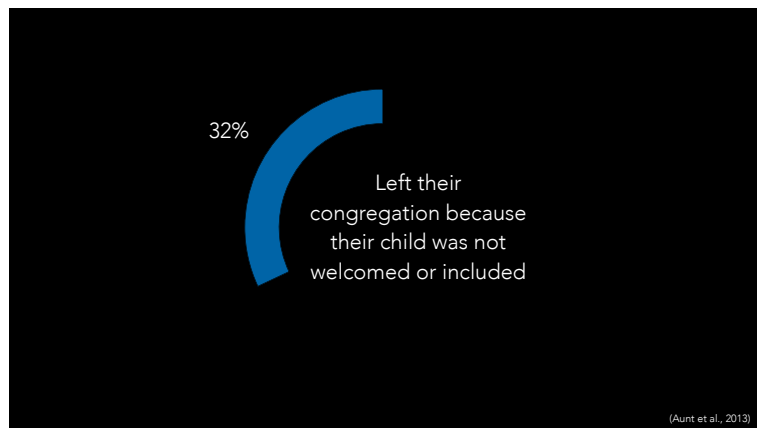
–LINDA, PARENT OF A SON WITH INTELLECTUAL DISABILITY

(Faith and Flourishing Project, Carter et al., 2016; Systematic Reviews, Carter, 2021, in press)

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### KEY THEMES OF RESEARCH & PRACTICE

1. Spirituality **has relevance** to the lives of individuals with IDD and their families.
2. Spirituality can have **considerable importance**.
3. Spirituality is experienced and expressed in very **diverse ways**.
4. Spirituality is **rarely static**.
5. Spirituality can be **highly influential**.
6. Spirituality can require **planning and support**.

(Carter et al., 2021)

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## Communities

Exclusion

Ministry  
Apart

## Congregations

14



15

29%

Prepared to integrate individuals with disabilities into worship

(Annandale & Carter, 2014)

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“When I first started going to the Orthodox church and found out that we had a healing service, I was like: ‘Aw, crap! Here we go. Someone’s going to try to heal me or something again.’”  
 —LIZ, 34-YEAR-OLD WITH PHYSICAL DISABILITIES

“You have people who get so stuck in their ways—or think that this is how it needs to be—that it’s like you forget that we’re all here for a reason. We’re all here for one purpose, and that’s unity. Christ meant for the whole—for everybody—to be together.”  
 —SIERRA, 35-YEAR-OLD WITH AUTISM

(Accessible Worship Project, Carter et al., 2022; Ault et al., 2013)

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## Communities

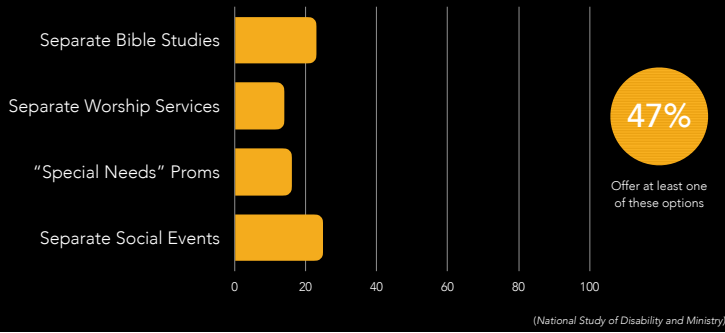
Exclusion    Segregation

Ministry  
Apart    Ministry  
To

## Congregations

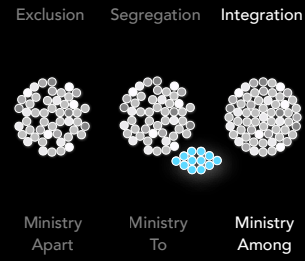
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## SEPARATE PROGRAMS AND EVENTS



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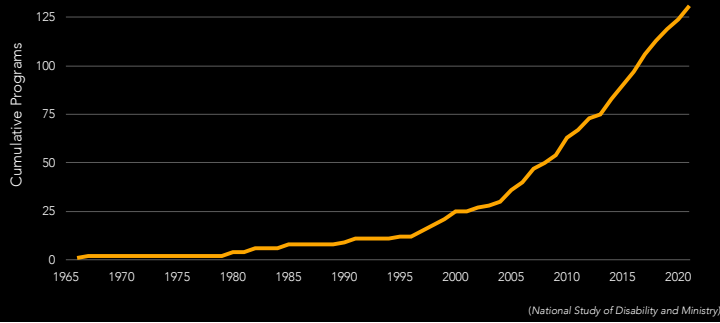
## Communities



## Congregations

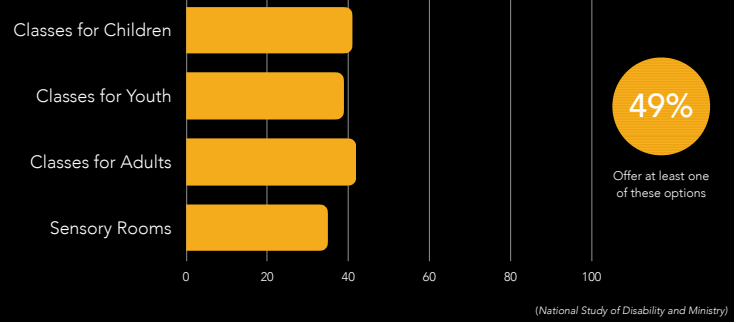
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## TRENDS IN FORMAL MINISTRIES



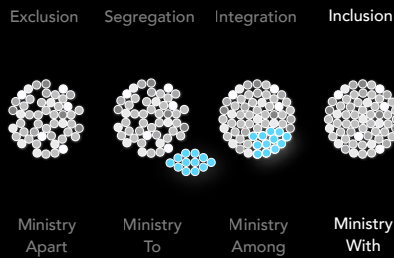
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## SPECIALIZED CLASSES AND SPACES



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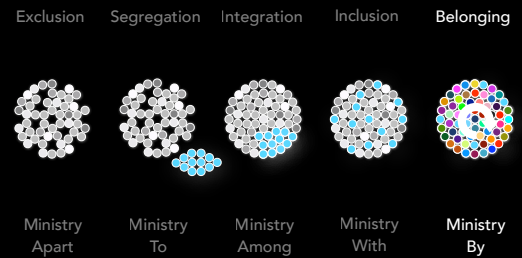
## Communities



## Congregations

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## Communities



## Congregations

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## Service Systems

- I do not know how to address it.
- I feel uncomfortable addressing it.
- I never really thought about it.
- I do not have time to address it.
- It is not my responsibility to address it.
- I am not permitted to address it.
- We lack staff to address it
- Someone else is addressing it.
- It is not relevant to this segment of the community.

## Congregations

- Awareness
- Attitudes
- Architecture
- Activities
- Communication
- Expectations
- Resources
- Training
- Theology
- And many others...

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## CHANGING THIS LANDSCAPE

1. Responding
2. Reflection
3. Planning
4. Inviting
5. Supporting
6. Befriending
7. Partnering
8. Celebrating



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## RESPONDING

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## SERVICE SYSTEMS

- Personal aspirations
- Self-determination
- Choice
- Community inclusion
- Supportive relationships
- Cultural competence
- Natural supports
- Quality of life



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### RATIONALE

Faith and spirituality may offer positive support for others in our communities. Spiritual beliefs could be recognized as expressions, and faith communities could be supported. The rights, needs, and preferences of people with disabilities, especially acutely disabled people, should be explored in settings where they can participate in spiritual expression and organized religion as they so choose and promotes the provision of any and all supports needed by people with disabilities to so participate.

### STATEMENT

The rights, needs, and preferences of people with disabilities, especially acutely disabled people, should be explored in settings where they can participate in spiritual expression and organized religion as they so choose and promotes the provision of any and all supports needed by people with disabilities to so participate.

"...the right of individuals with disabilities to participate in spiritual expression or organized religion as they so choose and promotes the provision of any and all supports needed by people with disabilities to so participate."

### POSITION STATEMENT

People with mental retardation and related disabilities have the right to choose their own expressions of faith, and to participate in spiritual activities. The person's history, tradition, and current preferences are rights that must be honored by services systems and faith-based communities, as should the choice not to participate.

### ISSUES

While many agencies provide religious freedom, they seldom often help people participate in their choice and/or traditions.

Individuals and their families, even though many congregations and strategies are available, often do not adapt beyond the practice of faith and develop relationships and social and serve others.

"Spirituality, spiritual growth, and religious expression that respect a person's history, tradition, and current preferences are rights that must be honored by services systems and faith-based communities, as should the choice not to participate."

- Agencies should provide education regarding spiritual expression and related developmental disabilities.

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## CONGREGATIONS

- Love our neighbors
- Welcome the stranger
- Upend societal hierarchies
- See everyone as indispensable
- Move the margins to the middle
- Widen our welcome
- Pursue the unpursued
- Recognize the imago Dei in everyone

American Baptist Churches, USA

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## REFLECTING

## SERVICE SYSTEMS

- How does your **organization support** the spiritual expressions of those you serve?
- How are you addressing spirituality within **person-focused planning**?
- What are **your own views** regarding spirituality and supports?
- How are you **seeking input** from local faith communities on your community supports?



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- ✓ Our mission statement reflects a commitment to support the choices of people with disabilities, including those related to spiritual exploration and religious expression.
- ✓ Our written policies explain the importance of supporting people's religious preferences, as well as point to practical strategies for doing this well.
- ✓ Our staff and the people with disabilities whom we serve are aware of and familiar with these policies.
- ✓ We can identify someone (e.g., staff person, board member, advocate) who is responsible for ensuring that spiritual supports are addressed and that our policies are evidenced in practice.
- ✓ We understand the different ways we should be addressing the spiritual and religious needs of the people whom we serve.
- ✓ We discuss with new staff the importance of listening for, seeking out, and supporting people's choices and preferences, including their religious preferences.
- ✓ We provide staff with the training they need to do this effectively and with confidence.
- ✓ We ask about the spiritual needs, strengths, and connections of people with disabilities when they first begin receiving our services and supports.

- ✓ We revisit these conversations periodically to make sure we are continuing to meet their needs.
- ✓ We orient people with disabilities and their families/advocates to the types of supports we make available for individuals interested in being involved in a faith community.
- ✓ We provide the opportunities, space, and support people need to explore and express their spirituality at home, within a congregation, or elsewhere, if they so choose.
- ✓ We periodically assess and seek to remove potential barriers that hinder us from addressing the spiritual and religious needs of people with disabilities.
- ✓ It is clear the people whom we serve are involved in the faith community of their choice.
- ✓ Participation in community activities, including attending congregational activities, is not used to reinforce good behavior or punish inappropriate behavior.
- ✓ We have established relationships with local congregations and faith-based organizations as partners in this work.
- ✓ We recognize and affirm the sense of calling and vocation held by our staff providing direct support to people with disabilities.

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**Reflection Tool for Agencies**

It can be valuable to reflect on the extent to which your agency views spirituality and religion as being important to people with disabilities and takes intentional steps to support this aspect of people's lives. The following indicators can help prompt discussion among staff about this area of your services and supports.

Indicators	How well does this describe our agency?	What steps can we take to improve in this area?
Our mission statement reflects a commitment to support the choices of people with disabilities, including those related to spiritual expressions and religious expressions.	Not at all   Somewhat   Fully	
Our mission policies explain the importance of supporting people's religious preferences, as well as point to practical strategies for doing this well.	Not at all   Somewhat   Fully	
Our staff and the people with disabilities whom we serve are aware of and familiar with these policies.	Not at all   Somewhat   Fully	
We can identify someone (e.g., staff person, board member, advocate) who is responsible for ensuring that spiritual supports are addressed and that our policies are evidenced in practice.	Not at all   Somewhat   Fully	
We understand the different ways that we should be addressing the spiritual and religious needs of the people whom we serve.	Not at all   Somewhat   Fully	
We discuss with our staff the importance of listening for, seeking out, and supporting people's choices and preferences, including their religious preferences.	Not at all   Somewhat   Fully	
We provide staff with the training they need to do this effectively and with confidence.	Not at all   Somewhat   Fully	
We talk about the spiritual needs, strengths, and connections of people with disabilities when they first begin receiving our services and supports.	Not at all   Somewhat   Fully	

Indicators	How well does this describe our agency?	What steps can we take to improve in this area?
We assess those conversations periodically to make sure we are continuing to meet their needs.	Not at all   Somewhat   Fully	
We create people with disabilities and their families/advocates to the types of supports we make available for individuals interested in being included in a faith community.	Not at all   Somewhat   Fully	
We provide the opportunities, spaces, and support people need to explore and express their spirituality at home, within a congregation, or elsewhere, if they so choose.	Not at all   Somewhat   Fully	
We periodically assess and seek to remove potential barriers that hinder us from addressing the spiritual and religious needs of people with disabilities.	Not at all   Somewhat   Fully	
It is clear that the people whom we serve are involved in the faith community of their choice.	Not at all   Somewhat   Fully	
Participation in community activities, including attending congregational activities, is not used to reinforce good behavior or punish inappropriate behaviors in this work.	Not at all   Somewhat   Fully	
We have established relationships with local congregations and faith-based organizations as partners in this work.	Not at all   Somewhat   Fully	
We recognize and affirm the sense of calling and vocation held by our staff providing direct support to people with disabilities.	Not at all   Somewhat   Fully	
We respect the religious values of our staff and strive to define support roles and responsibilities that align with those values.	Not at all   Somewhat   Fully	
Other:		
Other:		

Adapted from Carter, E. V. (2007). *Nothing about us without us: A disability self-advocacy guide*. Portland, OR: Pacific Northwest Institute on Disability Studies, Paul D. Brinker.



## CONGREGATIONS

- What are the prevailing **postures and practices** of your congregation?
- What **opportunities and supports** should be expanded or developed?
- What needs are you **hearing** from members or **seeing** in your community?
- How are you **seeking input** from local service providers on your widening your welcome?



**EXAMPLE REFLECTION APPROACHES**

TOOL	DESCRIPTION
Accessibility Checklists	Addresses the physical, programmatic, and communication accessibility of the areas (e.g., sanctuaries, classrooms, bathrooms, offices) and activities in which congregation members gather
The Five Stages	Addresses behaviors and perspectives that suggest a progressing posture of ignorance about, pity toward, care for, friendship with, and co-laboring alongside individuals with disabilities
Indicators of Welcome	Addresses specific ways in which congregations can demonstrate hospitality and inclusion in the areas of worship services, religious education, service, outreach, fellowship, family supports, general awareness, community partnerships, and accessibility
Journey of a Congregation	Addresses 14 aspects of a congregation's response related to: awareness, internal advocacy, discussions, plans, accommodations, welcoming environment, hurdles, inclusion, local outreach, leadership, new consciousness, transformation, external advocacy, and outreach
Dimensions of Belonging	Addresses the extent to which individuals with disabilities and their families are invited, present, welcomed, known, accepted, supported, cared for, befriended, needed, and loved within their faith community in ways that lead to belonging
Community Conversations	Reflection events involving a cross-section of congregational and community members to collaboratively respond to key questions: <i>What could we do to include people with disabilities and their families well in the life of their faith community? What could we do to come alongside them in other areas of their lives? How might we partner with others in these areas?</i>

**EXAMPLE REFLECTION APPROACHES**

- Individual conversations
- Group-based discussions
- Congregational surveys
- And many others

**Congregational Outreach Survey**

Our congregation is called to be an integral part of our community. We desire to be an inviting congregation that is intentional about finding ways to working among, mutually respect, and serve congregational people with disabilities and their families. We invite you to reflect on our mission. How do we help welcome people with disabilities who might want to attend our congregation? Are there needs we can help meet or support we could provide? Thank you for helping welcome people with disabilities and their families into our faith community. Your answers to this survey will determine and help us identify areas we can take to become a congregation open for our hospitality.

1. How would you describe yourself? (Check all that apply.)

- I have a disability.
- I have a child with a disability.
- I have a sibling or relative with a disability.
- I have a friend or neighbor with a disability.
- I interact with people with disabilities in my workplace.
- I do not have anyone with a disability.
- Other: \_\_\_\_\_

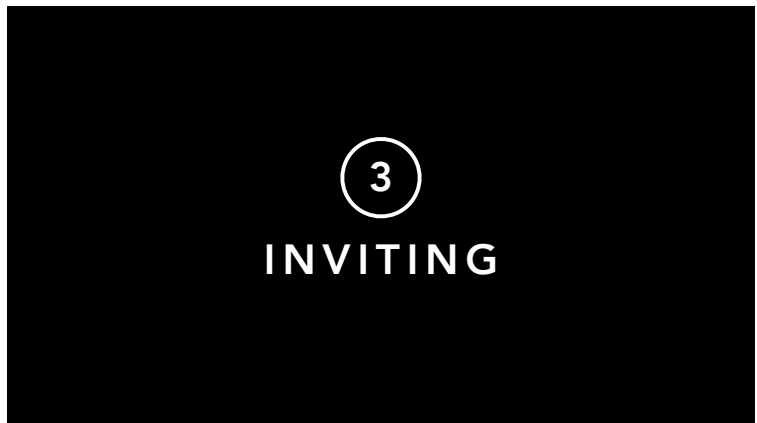
2. If you or a family member has a disability which of the following suggests help you participate more fully in congregational life or meet a personal need? (Check all that apply.)

- Transportation
- To worship services
- To other congregational activities throughout the week
- To other events in the community
- Additional support to participate in
- Worship services
- Religious programs
- Faith programs
- Adult programs
- Support care (e.g., offering a periodic break to parents of children with disabilities)
- To attend worship services
- Participation in other congregational activities
- To other services throughout the week
- Support groups for parents, siblings, and other caregivers of people with disabilities
- Pastoral counseling
- Pastoral or other pastoral assistance
- Supportive individual or other adult resources
- Support of volunteering for your needs among agencies, organizations, and groups
- Information about faith-based services and programs within our community and area

3. In the space below, we encourage you to share with us other needs not already listed.

Name: \_\_\_\_\_

Phone: \_\_\_\_\_





## SERVICE SYSTEMS

- In what ways are you inviting local faith communities to **learn about** your organization's mission and work?
- In what ways are you inviting them to **share about** the opportunities and supports they provide?



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<https://www.thearda.com/us-religion/maps/us-county-maps>



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## CONGREGATIONS

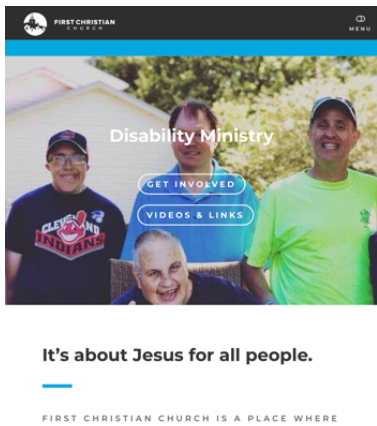
- How does your **website** and **social media** communicate your commitment to welcoming people with disabilities and their families?
- What are the avenues through which you **announce** your welcome throughout your city and disability communities?
- What are the avenues through which you are **inviting** throughout your city and disability communities?



<https://data.census.gov/cedsci>

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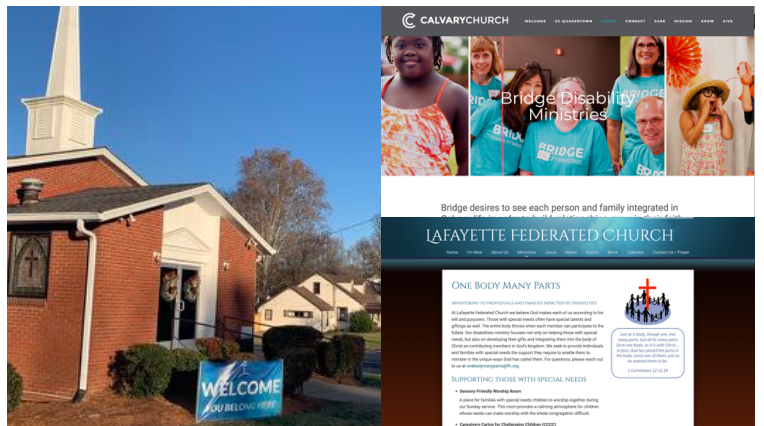
It's about Jesus for all people.

FIRST CHRISTIAN CHURCH IS A PLACE WHERE



Special Needs

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Bridge Disability Ministries

Bridge desires to see each person and family integrated in  
LAFAYETTE FEDERATED CHURCH

ONE BODY MANY PARTS

SUPPORTING THOSE WITH SPECIAL NEEDS

• Supportive Ministry Team

A group of families who special needs children is working together during our Sunday services. These are providing a caring atmosphere for children who may have special needs with the whole congregation effort.

• Changing Family Relationships (2002)

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# 4

## PLANNING

### SERVICE SYSTEMS

- What **questions** are you asking of the individuals and families you serve?
- How do your **planning tools** address and capture this information?
- Is your planning always **individualized** and **contextualized**?
- Are you **inviting insights** from congregation members who already know the individuals and families well?



### SPIRITUAL PRACTICES

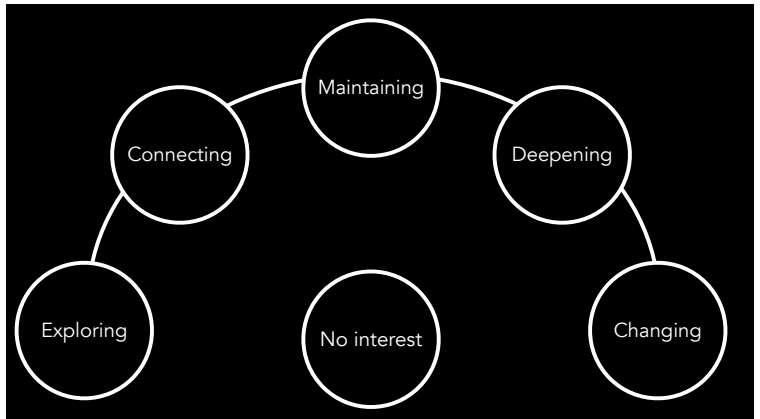
- What are some things that give you joy or happiness? What brings meaning to your life?
- Do you have religious or spiritual beliefs that are important to you? What are those beliefs?
- What are some of the ways that you express your faith or spirituality?
- What traditions, rituals, or practices are especially important to you?
- Are there holy days, festivals, or other special events that you observe?
- What gives you strength?
- How do you cope when going through difficult times? To whom do you turn?
- What would you say are your gifts? What do people compliment you on?
- Have you experienced a sense of calling in your life?
- What else is important for us know about your religious and spiritual beliefs?

### CONGREGATIONAL PARTICIPATION

- Do you currently attend a congregation (e.g., church, mosque, synagogue, temple)?
- Tell me about it.
- Who do you go with?
- What do you do there? How do you participate in services and activities?
- How often do you go?
- What do you like most about it? What do you wish was different?
- How is being part of this congregation important in your life?
- In what ways would you like to be more involved? Less involved?
- If you could try out any new class, program, or activity, what would it be?
- Is your congregation supportive for you? How so?
- Are there particular people who are especially friendly or helpful?
- What keeps you from being involved in the ways that you would like?
- Were you involved in a congregation when you were younger? Was this an important part of family life?

### SUPPORT NEEDS

- What supports will you need to be involved in your congregation in the ways you would like?
- Which of these supports can we provide? Which would you prefer to come from someone else?
- Would you like help finding a congregational home?
- Do you have the spiritual supports, relationships, and connections that you would like?
- Are there religious practices or restrictions we should keep in mind as we support you?
- Would you like us to help you address your spiritual needs? If so, how?
- Would you like help learning more about your faith?
- How well are we doing at helping you meet your spiritual needs?
- Do you have any needs that are not being addressed?







## CONGREGATIONS

- What questions are you asking of the **individuals** and **families** who attend your congregation?
- How are you intentional about planning for each person's **presence** and **participation**?
- Is your support always **individualized** and **contextualized**?
- How are you involving clergy, ministry leaders, and other members in **congregation-wide planning**?
- Are you inviting insights from **outside professionals** who know these individuals and families well?

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## INDIVIDUALIZED SUPPORT PLANS

Activities	What did involvement look like?	What supports and adaptations were needed for participation?	Who carried out this part of the plan?	Are there changes to be made?
Small group activities				
Large group activities				
• Worship services				
• Meals, sacraments, or other community traditions				
• Services, outreach, social opportunities				
Faith partner				
Other				

**INDIVIDUALIZED EDUCATION PLAN FOR CHILDREN AND YOUTH**

1. How often will your child be involved in our program this month? We will do our best to provide any learning activities that will help your child reach the goals of your plan.

2. How often will your child be involved in our program this month? We will do our best to provide any learning activities that will help your child reach the goals of your plan.

3. How often will your child be involved in our program this month? We will do our best to provide any learning activities that will help your child reach the goals of your plan.

4. How often will your child be involved in our program this month? We will do our best to provide any learning activities that will help your child reach the goals of your plan.

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7. How often will your child be involved in our program this month? We will do our best to provide any learning activities that will help your child reach the goals of your plan.

8. How often will your child be involved in our program this month? We will do our best to provide any learning activities that will help your child reach the goals of your plan.

9. How often will your child be involved in our program this month? We will do our best to provide any learning activities that will help your child reach the goals of your plan.

10. How often will your child be involved in our program this month? We will do our best to provide any learning activities that will help your child reach the goals of your plan.

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## SUPPORTING

## SERVICE SYSTEMS

- Are we **informing** individuals and families about available options?
- Is **transportation** provided to the congregation individuals actually want to attend?
- Are we **accompanying** individuals who need our assistance?
- What personalized **guidance** or **support strategies** are shared with the congregation?
- How often are these supports **revisited**?



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For each of the following congregational and other religious activities, indicate the desired level of involvement, need for support, and provider of support.

	What involvement would he or she like? If none, indicate this.	What supports are needed to make this happen meaningfully?	How will these supports be provided? Who will take primary responsibility?
Worship services			
Sunday/Sabbath school or other religious education programs			
Small groups or Bible studies			
Fellowship, recreational, and other social activities			

For each of the following congregational and other religious activities, indicate the desired level of involvement, need for support, and provider of support.

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Worship services			
Sunday/Sabbath school or other religious education programs			
Small groups or Bible studies			
Fellowship, recreational, and other social activities			

Will transportation need to be arranged or provided?  No  Yes

Back Up: \_\_\_\_\_

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For each of the following congregational and other religious activities, indicate the desired level of involvement, need for support, and provider of support.

	What involvement would he or she like?	What supports are needed to make it happen meaningfully?	How will these supports be provided? Who will take primary responsibility?
Worship services			
Sunday/Sabbath school or other religious education programs			
Small groups or Bible studies			
Fellowship, recreational, and other social activities			

Will direct support from staff need to be provided?  No  Yes  
Back Up: \_\_\_\_\_

Will a behavior support plan need to be developed?  No  Yes  
Back Up: \_\_\_\_\_

Who has been a part of this conversation? (Name/Relationship) \_\_\_\_\_ Who else should we invite to be part of this conversation? \_\_\_\_\_

When will this plan be revisited to determine whether it is working or needs to be strengthened? We will update this plan in \_\_\_\_\_ months. Due Date: \_\_\_\_\_

What future needs should be considered or might be anticipated when this plan is updated? \_\_\_\_\_

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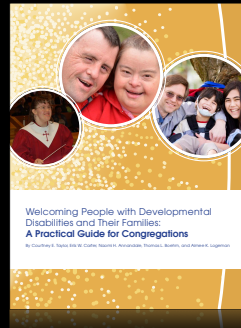
## CONGREGATIONS

- Are the supports **already available** to anyone in the congregation also offered to individuals and their families?
- How well are people's support needs **anticipated and solicited**?
- Are we **aware** of potential ways of supporting individuals and their families?

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## EXAMPLE SUPPORTS VALUED BY PARENTS

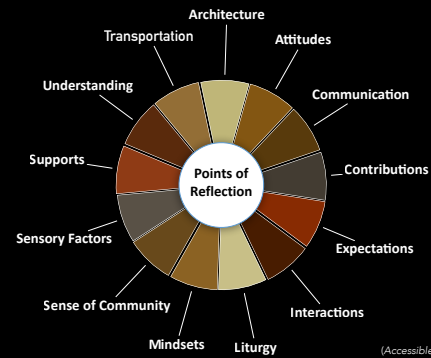
- Disability awareness initiatives
- Resources for families regarding disability and services
- Support groups for parents
- Congregational advocates
- Spiritual counseling from a congregation leader
- Respite
- A spiritual or religious education support plan
- Additional support from someone during religious education
- Additional support from someone during worship services
- Adapted worship services for people with disabilities
- Financial support from the congregation
- Transportation to congregational activities
- Additional investments toward physical accessibility.



<https://vkc.vumc.org/assets/files/resources/CongregationPracticeGuide.pdf>

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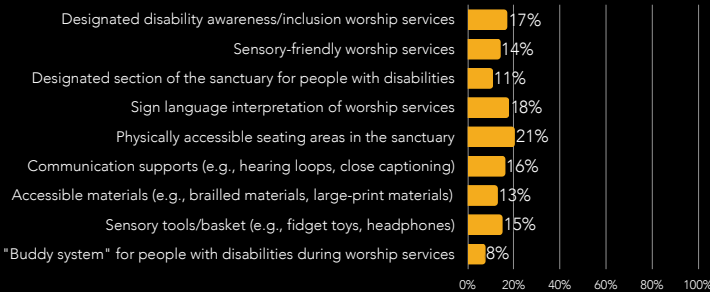
## ASPECTS OF ACCESSIBLE WORSHIP



(Accessible Worship Project, Carter et al., 2022)

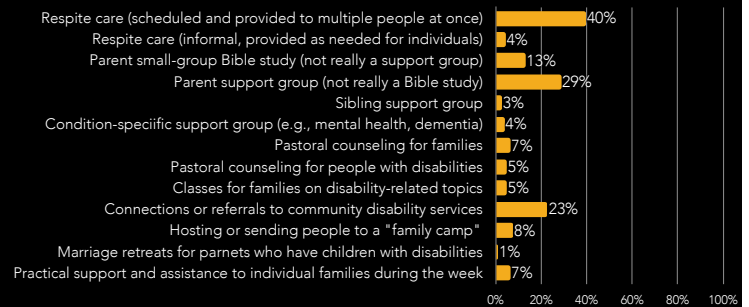
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## WORSHIP



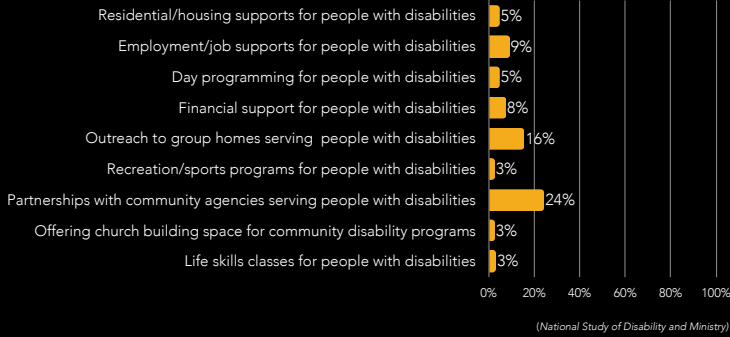
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## FAMILY SUPPORTS



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## THE OTHER SIX DAYS



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6

## BEFRIENDING

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## SERVICE SYSTEMS

- What kinds of **introductions** are being made to others who attend or lead within the congregation?
- How are people **connected to others** who share interests or experiences in common?
- How do you support opportunities for people to **get together** between Sundays?



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## CONGREGATIONS

- How well do we support meaningful participation in **all aspects** of congregational life—worship, education, service, and outreach?
- How are we intentionally designing **fellowship opportunities** where people can meet one another?
- How are we encouraging **shared activities** around **common interests** over time?



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## PARTNERING

## SERVICE SYSTEMS

- How might congregation members help with **employment**?
- How might congregation members help with **housing**?
- How might congregation members help with **transportation**?
- How might congregation members help with **relationship building**?
- How might congregation members help with **ordinary experiences**?



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**Putting Faith To Work:**  
A Guide for Congregations and Communities

Connecting Job Seekers with Disabilities to Meaningful Employment

[www.puttingfaithtowork.org](http://www.puttingfaithtowork.org)

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**CONGREGATIONS**

- How might we support people with disabilities with **employment**?
- How might we support people with disabilities with **housing**?
- How might we support people with disabilities with **transportation**?
- How might we support people with disabilities with **relationship building**?
- How might we support people with disabilities with **ordinary experiences**?
- How might we **advocate** for local change in these areas?

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**CELEBRATING**

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Which most closely resembles the congregations in your midst?  
Which most closely describes the experiences of people you support?

Exclusion	Segregation	Integration	Inclusion	Belonging
Ministry Apart	Ministry To	Ministry Among	Ministry With	Ministry By

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**FROM EXCLUSION TO EMBRACE**  
SUPPORTING INCLUSION AND BELONGING  
FROM BOTH SIDES OF THE DOORS

ERIK CARTER  
VANDERBILT UNIVERSITY  
[WWW.ERIKWCARTER.COM/STONEBELT](http://WWW.ERIKWCARTER.COM/STONEBELT)

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- Advocating** Speaking up regarding accessibility needs and calling the congregation to respond
- Reflecting** Regularly examining all aspects of congregational life to identify areas of strength and need
- Asking** Inviting the perspectives and preferences of people with disabilities regarding accessibility
- Researching** Seeking out the expertise and experiences of others from outside of the church
- Equipping** Increasing the capacity and commitment of church members to support inclusion
- Embracing** Adopting a posture or culture that values people with disabilities and their gifts
- Proacting** Taking active and advance steps to welcome and include people with disabilities
- Including** Weaving and welcoming people with disabilities within all aspects of congregational life
- Praying** Seeking guidance and support from God in all of these endeavors

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## SERVICE AND LEADERSHIP BY PEOPLE WITH DISABILITIES

