



Welcoming People with Developmental Disabilities and Their Families: **A Practical Guide for Congregations**

By Courtney E. Taylor, Erik W. Carter, Naomi H. Annandale, Thomas L. Boehm, and Aimee K. Logeman



Table of Contents

| | |
|-----------------------------------------------------------------------------------|----|
| An Introduction to this Guide | 3 |
| Undertaking Congregation-wide Disability Awareness Efforts | 4 |
| Connecting Families to Resources | 5 |
| Facilitating or Connecting Parents to a Support Group | 6 |
| Identifying a Congregational Advocate for Families | 7 |
| Offering Respite Care | 8 |
| Providing Spiritual Counseling | 9 |
| Making Modifications in Religious Education Programs | 10 |
| Crafting a Spiritual or Religious Education Plan | 11 |
| Creating Personal Supports for Religious Education | 12 |
| Designing Special Worship Services that Include People with Disabilities | 13 |
| Arranging for Support During Worship Services..... | 14 |
| Assisting Families With Financial Support..... | 15 |
| Assisting With Transportation to Congregational Activities..... | 16 |
| Making the Congregation More Physically Accessible | 17 |
| Endnotes | 18 |

Full reports of our project findings will be posted at:
vkc.mc.vanderbilt.edu/vkc/religionandspirituality/

An Introduction to this Guide

Faith matters in the lives of many young people with developmental disabilities and their families.¹ Yet far too many children and adults with labels like Down syndrome, autism, or intellectual disability struggle to find a congregation that will welcome and weave them into the life of their faith community. What a missed opportunity! Young people with disabilities miss out on the chance to be part of a community where they can worship, learn, fellowship, and serve with others. And congregations miss out on the chance to receive the wonderful gifts, friendship, and faith of a vital part of their community. Faith communities are *incomplete* without the presence and participation of people with disabilities and their families.

We have written this guide to equip congregations with ideas and practical steps to strengthen the invitation, supports, and hospitality offered to people with disabilities and their families. This guide draws from a two-year project focused on faith and flourishing in the lives of adolescents and young adults with developmental disabilities and their families in Tennessee. As part of this project, we asked almost 500 parents across the state to answer two simple questions:

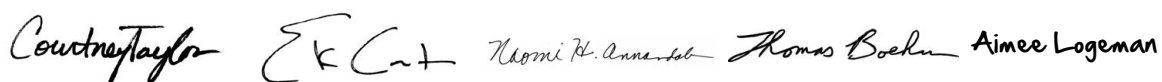
- How helpful would each of 14 potential congregation-provided supports be to you in raising your child with an intellectual disability or autism?
- Is this particular support now available in your congregation?

In each of the sections of this guide, you will learn what these parents had to say in response to both questions. For congregations wondering how best to support families impacted by disability, answers to the first question suggest some promising starting points. Responses to the second question, however, are quite striking. For congregations committed to reaching and serving all of their community, an important opportunity lies in the large gap between the two sets of numbers.

The sections of this guide are arranged around the fourteen supports upon which we asked families to reflect. We included a brief description of each support and outlined several steps congregations could take to put the support into practice. Online resources and additional readings are offered for congregations wanting to learn more. We offer these ideas not as an exhaustive list of the supports that would benefit families impacted by disabilities. Indeed, the supports these families need most of all are the ordinary supports congregations strive to provide to all families—a warm welcome, a lavish love, an assurance of belonging, a commitment to walk alongside one another no matter what, and a place to share one's gifts.

We hope this guide will encourage and equip your congregation to be one in which people with and without disabilities have rich opportunities to worship, learn, fellowship, and serve alongside one another in community.

Warmly,



Disabilities, Religion, and Spirituality Program, Vanderbilt Kennedy Center, January 2014

Undertaking Congregation-wide Disability Awareness Efforts

Parents considered congregation-wide disability awareness to be among the most helpful efforts faith communities could undertake.

Why is it so important to foster awareness and understanding of disability? Often, the biggest barrier people with disabilities and their families encounter are not inaccessible *stairs*, but unwelcoming *stares*. Some congregation members have had few opportunities to get to know the young people in their community with autism, Down syndrome, or a variety of other developmental disabilities. They may be uncertain about how to welcome and converse with someone who has a disability. And they may be unaware of the supports that would enable active participation in congregational life. Thoughtfully sharing information about disability and the importance of welcoming everyone can have a powerful impact. At the same time, many people are simply unaware of the presence of people with disabilities already in their congregation or living in the neighborhoods surrounding their buildings. Almost one in five Americans has a disability and nearly one in three families has a relative with a disability.² Helping congregation members extend new invitations and hospitality to a segment of their community is just as important as providing information about various disabilities.



70% of parents reported this support would be helpful.

10% said their congregations provided this support.

Practical Strategies

- Assemble a small team of ministry leaders, family members, people with disabilities, and others to collectively reflect on the extent to which programs and activities convey a clear recognition that people with disabilities are present and participating in congregational life.
- Emphasize themes of welcome, inclusion, and accessibility within congregational brochures, websites, bulletins, and other materials.
- Educate religious leaders and staff about how to talk respectfully about disabilities and to communicate effectively with people with disabilities and their families.
- Reflect on how many members with disabilities are only loosely involved because supports are unavailable or they anticipate they might not be welcomed.
- Find out what resources related to welcoming people with disabilities are available within your own denomination or faith tradition. Let leaders and others in your congregation know about these resources.
- Some congregations set a regular time each year to hold an inclusion awareness service or other disability awareness events. It is important to remember that awareness grows over time and should be emphasized throughout the entire year, rather than just at a one-time event.
- Host a panel discussion on disability-related topics and

invite people with disabilities and their families to share.

- Periodically offer training in disability etiquette. Promote people-first language and positive views of disability in all of your communications.
- Initiate a congregation-wide survey to find out who in your community is impacted by disability and how you might best support them.



Online Resources

"All are Welcome": A Faith Community Inclusion Guide
(www.opwdd.ny.gov/node/445)

Pathways Awareness (<http://pathways.org/inclusion/worship>)



For Further Reading

DeYoung, T. A., & Stephenson, M. (Eds.) (2013). *Inclusion handbook: Everybody belongs, everybody serves* (2nd ed.). Grand Rapids, MI: Disability Concerns.

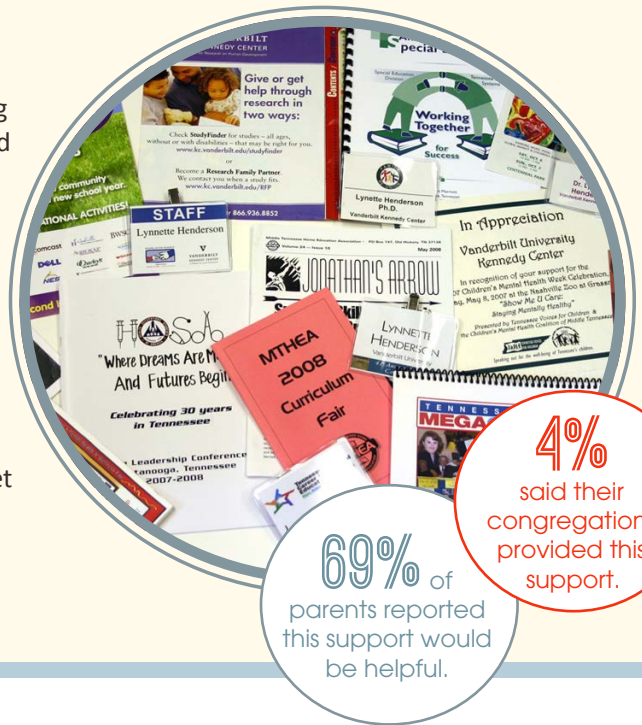
Newman, B. J. (2011). *Autism and your church: Nurturing the spiritual growth of people with autism spectrum disorder* (2nd ed.). Grand Rapids, MI: Zondervan.

Newman, B. J. (2012). *Helping kids include kids with disabilities* (Revised edition). Grand Rapids, MI: Faith Alive.

Connecting Families to Resources

Many families turn first to their faith community for needed information and guidance on raising their children.

Faith communities can play a helpful role in providing resources and connections to people with disabilities and their families who are seeking needed supports or services. Creating a resource center for families could be as simple as compiling a collection of books, pamphlets, and Internet resources relevant to families impacted by disability. For example, a congregation might gather information about local agencies serving people with disabilities and their families, or identify congregation members who are themselves connected to these community resources. For example, most congregations already include members who are special educators, therapists, community service providers, or advocates. While a faith community certainly does not need to develop expertise on disability resources, knowing who else in the community does have this expertise and facilitating connections for families can meet a real need.



Practical Strategies

- Identify individuals in your congregation who themselves have expertise related to local disability services and supports. For example, you might learn that members of your congregation are employed as special educators, counselors, paraprofessionals, or in other areas of the disability field.
- Compile a list of disability-related support groups in your area. If you discover few (if any) are available, consider hosting one.
- Prepare a packet of practical information and resources that religious educators, ministry leaders, and others could share with family members impacted by disability.
- Connect with the your state's University Center for Excellence in Developmental Disabilities (www.aucd.org). Request resources and information (e.g., program flyers, fact sheets) that could be shared with families in your congregation.



Online Resources

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (www.kc.vanderbilt.edu)

University of Tennessee Boling Center for Developmental Disabilities (www.uthsc.edu/bcdd)

Tennessee Disability Pathfinder (kc.vanderbilt.edu/pathfinder)

Parent Technical Assistance Centers (www.parentcenternetwork.org)



For Further Reading

Exceptional Parent Magazine (www.eparent.com)

Durand, V. M. (2011). *Optimistic parenting: Hope and help for your challenging child*. Baltimore, MD: Paul H. Brookes.

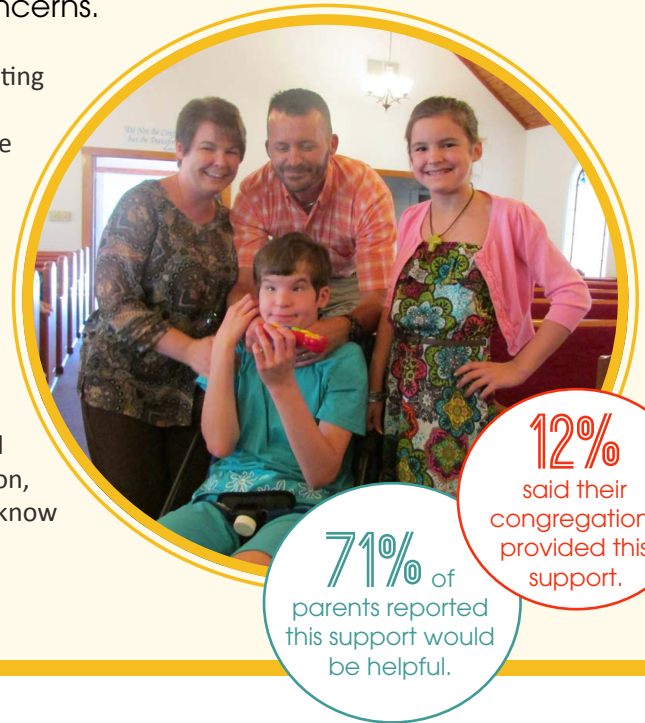
Naseef, R. A. (2013). *Autism in the family: Caring and coping together*. Baltimore, MD: Paul H. Brookes.

Pelligrino, L. (2012). *The common sense guide to your child's special needs: When to worry, when to wait, and what to do*. Baltimore, MD: Paul H. Brookes.

Facilitating or Connecting Parents to a Support Group

Families raising children and youth with intellectual and developmental disabilities sometimes face unique challenges and concerns.

Support groups can help families process concerns, learn helpful parenting strategies, and share the strengths and gifts of their children with disabilities. These groups also offer an opportunity for people who have recently received a diagnosis to meet and learn from those who have been in similar situations. Faith communities might reflect on the need for a support group and possible formats. Would it be focused on a particular diagnosis (e.g., parents of children with autism) or stage of life (e.g., parents of transition-age students)? Or would it be more general? Who would lead the group, and how often would it meet? Additionally, faith communities should find out what types of support groups (if any) local disability organizations already offer. There are many ways to connect parents with one another and needed support, and these efforts can increase feelings of belonging, connection, empowerment, and support. Siblings may also benefit from getting to know others who have a brother or sister with a disability.



71% of parents reported this support would be helpful.

12% said their congregations provided this support.

Practical Strategies

- Contact local agencies and disability organizations (e.g., the Arc, Autism Society, Down Syndrome Association) to ask what needs they see in the community for connecting and supporting parents. Ask how you can help them support families.
- Compile a list of support groups for parents and siblings in your area. You may be surprised by what already exists in your region.
- Make sure key people in your congregation are familiar with these avenues of support so they can be shared with interested families.
- Talk with families in your congregation and ask how you might design a group that best meets their needs.
- Find two or three people who are passionate and interested in disability to facilitate the group. This can mean that they schedule guest speakers or leaders – not everyone has to lead on their own.
- Perhaps there are only a few families in your congregation impacted by disability. Talk with other congregations about how you might collaborate to meet broader needs within your community.
- Provide space for an existing or newly formed support group to meet in your facilities. Hosting them could meet an important local need.



Online Resources

- Tennessee Disability Pathfinder* (kc.vanderbilt.edu/pathfinder) compiles a list of parent support groups statewide.
- Sibling Support Project* (www.siblingsupport.org)
- Parent-to-Parent* (www.p2pusa.org)



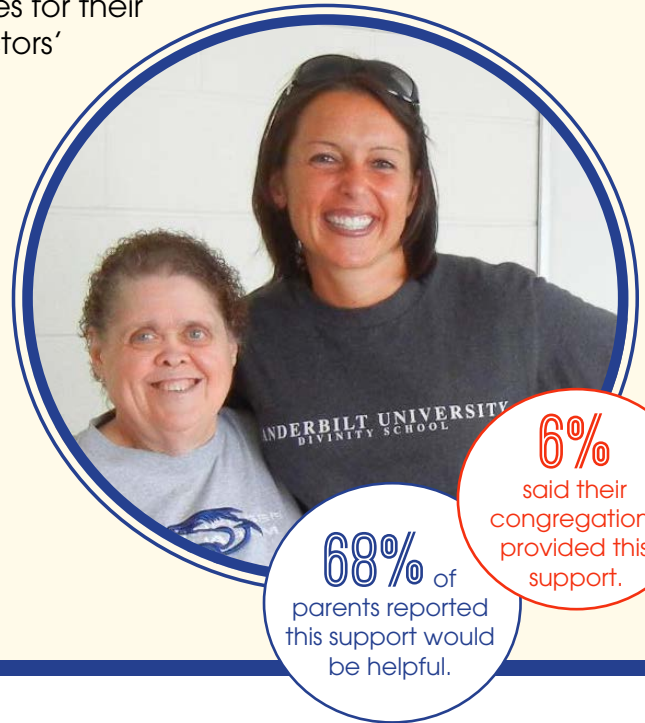
For Further Reading

- Cook, J. G. (2008). *A compassionate journey: Coming alongside people with disabilities or chronic illnesses*. Grand Rapids, MI: Faith Alive.
- DeBonis, J. (2005). *Parent support group technical manual*. Sante Fe, NM: New Mexico Developmental Disabilities Planning Council.
- Meyer, D. J., & Vadasy, P. F. (2007). *Sibshops: Workshops for siblings of children with special needs*. Baltimore, MD. Paul H. Brookes.
- Santelli, B., Poyadue, F. S., & Young J. L. (2001). *The parent to parent handbook: Connecting families of children with special needs*. Baltimore, MD. Paul H. Brookes.

Identifying a Congregational Advocate for Families

So many parents of children and youth with intellectual and developmental disabilities serve as constant advocates for their children—in the schools, within service systems, at doctors' offices, and elsewhere.

Having someone else who can “be the asker” on their behalf within their congregation can be a wonderful support for both families and faith communities. By getting to know the family—perhaps over a cup of coffee or a meal—the “congregational advocate” can ask what supports and opportunities would make the young person with a disability and his or her family feel most welcomed and included in the life of the faith community. The advocate would share this information with leaders to help identify ways to support presence and participation within the congregation.



68% of parents reported this support would be helpful.

6% said their congregations provided this support.

Practical Strategies

- Consider who in your congregation might be especially effective in this role of family advocate. For example, people who are well connected socially, can think outside the box, and want their congregation to be a supportive community may be worth approaching.
- Make sure advocates understand the breadth of opportunities and potential supports available throughout the congregation and know who to talk with to make things happen.
- Anchor this effort within an existing hospitality ministry or new membership process. This will help the congregation deepen its ability to create a culture of welcome to anyone new to your community.
- Develop a list of responsibilities for the advocate, such as identifying the needs of people with disabilities and their families, thoughtfully sharing those needs with others, finding meaningful ways to include people with disabilities in congregational life, and identifying barriers to meaningful participation.
- Encourage advocates to be proactive in identifying and addressing needs arising within the growing relationship between family and congregation.
- Follow up regularly with families to communicate care for them. Avoid waiting until problems arise before an advocate gets more deeply involved.



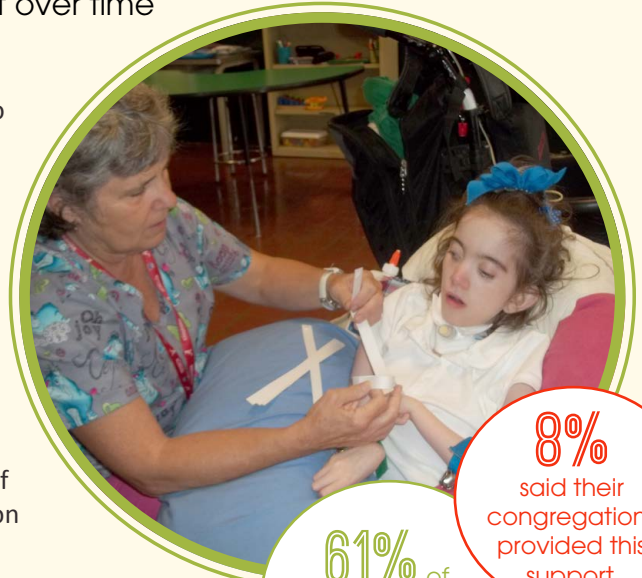
For Further Reading

- Gaventa, B. (2012). Faith and spirituality: Supporting caregivers of individuals with disabilities. In R. C. Talley & J. E. Crews (Eds.), *Multiple dimensions of caregiving and disability: Research, practice, policy* (pp. 117-134). New York, NY: Springer.
- Gaventa, B. (2012). Lessons in community building from including the “other”: Caring for one another. *Journal of Religion, Disability and Health*, 16, 231-247.
- Preheim-Bartel, D., & Neufeldt, A. H. (2011). *Supportive care in the congregation: Providing a congregational network of care for persons with significant disabilities*. Goshen, IN: Mennonite Publishing Network.

Offering Respite Care

Although life can be challenging for anyone, families impacted by disability sometimes encounter additional stressors that over time can impact their well-being.

At the same time, parents of children with disabilities may be unable to take time for themselves due to financial costs, difficulties finding a trustworthy “sitter,” or even feelings of guilt. Providing respite care means coming alongside a family to offer a brief break from the routine demands of everyday life. This respite could be as short as an hour or two, or as long as a week or more. It can involve going into a family’s home or providing space at your facility where family members with developmental disabilities can be cared for and/or participate in enjoyable activities. Either way, parents and/or siblings can get a much-needed break and time to focus on themselves, their marriage, or other family needs. Some parents may be reluctant to ask for or to receive this help. Encouraging parents to take advantage of opportunities for respite and renewal offered through your congregation can have a substantial positive impact on these families.



61% of parents reported this support would be helpful.

8% said their congregations provided this support.

Practical Strategies

- Coordinate a small network of people to provide occasional respite to families in the home. People could sign up for 2-hour blocks of time so that parents can run errands, have a date night, or take care of other needs.
- Host a weekly, monthly, or quarterly event at your congregation for children with disabilities and their siblings to play or learn without their parents.
- If your congregation offers a summer day camp or VBS program, make sure invitations and supports are in place for children with disabilities to also attend.
- Invite youth and young adults to serve within your respite program. Those who volunteer often report being transformed by having the opportunity to spend time with and get to know their neighbors with disabilities.
- A formal respite program is not the only way to address the respite needs of families. When children and youth with disabilities are fully included in congregational activities and develop friendships, parents have additional opportunities to rest and recharge.
- Avoid presuming whether and how particular families might prefer to access respite care. You learn from families what works best by asking them. In addition, find out what types of activities their children would most enjoy.
- Help coordinate a “respite co-op” effort. This involves creating a network of parents who provide respite for each other, trading hours of care.
- Many guidelines already exist for establishing formal respite programs for families. Talk with leaders of these programs about how they address any safety, liability, and cost issues associated with these efforts.



Online Resources

ARCH National Respite Network and Resource Center
(www.archrespite.org)

South Carolina Respite Coalition (www.screstitecoalition.org)



For Further Reading

ARCH National Respite Network and Resource Center. (2013). *Bringing respite to your community: A start-up manual*. Chapel Hill, NC: Author.

ARCH National Respite Network and Resource Center. (2013). *ABCs of respite: A consumer guide for family caregivers*. Chapel Hill, NC: Author.

Edgar, M., & Kagan, J. (2010). Respite in the faith community. *ARCH Fact Sheet, 53*, 1-7. Available at www.archrespite.org

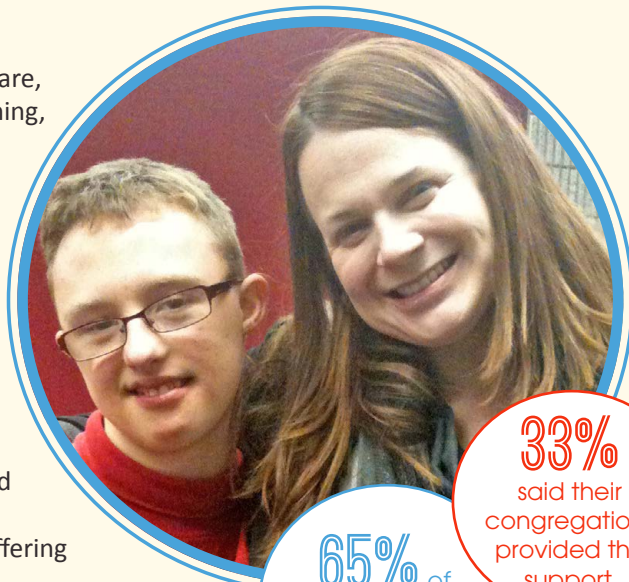
Family Connection of South Carolina. (2013). *Families giving families a break*. Available at www.screstitecoalition.org

Tipler, K. (2010). Volunteer respite: Valuable resources. *ARCH Fact Sheet, 18*, 1-15. Available at www.archrespite.org

Providing Spiritual Counseling

Parents of children with disabilities may have both ordinary and unique spiritual counseling needs.

These needs—which sometimes surround issues related to diagnosis, care, and relationships with others—often approach deep questions of meaning, purpose, and ultimate concerns. For example, parents who recently learned of their child’s disability diagnosis may wonder why this has happened or what the future holds. A parent of an adolescent with severe autism may be exhausted by providing daily care or being the constant advocate. Or an aging parent may worry about who will care for his son or daughter in the years ahead. At the same time, many parents find great joy and personal growth in raising children with disabilities. Amid many swirling questions, parents often report that spiritual support is not readily available from others in their congregation, including clergy. Nourishing the spiritual lives of these parents can help them navigate the challenges and joys of raising a child with disabilities. Clergy can support parents by asking them about their lives and their children, inviting them into deeper conversations, and offering needed spiritual supports.



65% of parents reported this support would be helpful.

33% said their congregations provided this support.

Practical Strategies

- Make sure the spiritual counseling you offer to any family in your congregation is also available to members who have children with developmental disabilities.
- Encourage parents who have children with disabilities to inform congregational leaders about parenting issues and challenges they are navigating.
- Avoid simplistic answers to the “why?” and “what does this mean?” questions parents might pose, especially in crisis situations and around diagnoses. Instead, create a culture in which deep exploration of meaning and purpose is the norm, and recognize that some questions may not be easy to answer. Sometimes, simply honoring the question can be more powerful than trying to provide an answer.
- Connect clergy and ministry leaders with resources and training on providing counseling and other supports to family members impacted by disability.
- Walk alongside families during critical transitions. Times such as the birth of a child, a new diagnosis, entry into school, and transition to adulthood are often when support is most needed.
- Invite local professionals who work closely with or counsel families impacted by disability to meet and share with you the needs they see and how best to address them.



For Further Reading

- Carter, E. W. (2007). Supporting individuals with disabilities and their families: The other six days. In *Including people with disabilities in faith communities: A guide for service providers, families, and congregations*. Baltimore, MD: Paul H. Brookes.
- Gaventa, W. C. (2003). Pastoral counseling with individuals with disabilities and their families (pp. 120-145). In R. J. Wicks, R. D. Parsons, & D. Capps (Eds.), *Clinical handbook of pastoral counseling* (Vol. 3). Mahwah, NJ: Paulist Press.
- Gaventa, W. (2008). Families and faith communities: The promise and power of the pastoral role. *Frontline*, 73, 20-22.
- Kornfeld, M. Z. (2000). *Cultivating wholeness: A guide to care and counseling in faith communities*. New York, NY: Bloomsbury Academic.
- Thompson, C. (2009). Ableism: The face of oppression as experienced by people with disabilities. In S. A. Kujawa-Holbrook & K. B. Montagno (Eds.), *Injustice and the care of souls: Taking oppression seriously in pastoral care* (pp. 211-226). Minneapolis, MN: Fortress.

Making Modifications in Religious Education Programs

Across the country, students with intellectual and developmental disabilities are spending a greater proportion of their school day in the same classes, clubs, and other school activities as their peers without disabilities.

With the right modifications, adaptations, and other supports, students with and without disabilities benefit greatly from learning alongside and from one another. This movement toward full inclusion is still just beginning in religious education programs. Religious education classes provide opportunities for young people to learn about their religious traditions and scriptures, to grow in their beliefs and practices, and to develop friendships and supportive relationships. Sometimes, changes related to how a person participates or the supports they are given are needed to ensure students with disabilities can also benefit fully from these rich and important learning opportunities.



59% of parents reported this support would be helpful.

12% said their congregations provided this support.

Practical Strategies

- Remember that every person is unique, including people who share a common disability label. The modifications that will help one person participate more actively may be quite different than the supports another person will need.
- Always keep the goals you have for all young people in your program front and center. There are often multiple ways to support a particular person to meet those goals. Modifications to the way things are usually done can still enable that person to be fully involved, even if that involvement looks somewhat different from another's.
- Work closely with families and be sensitive to their goals and expectations. Every family is different and their ideas about what is most important and beneficial for their particular child may vary widely.
- When choosing religious education curricula, select options that already include various ideas for modifications for students with diverse learning needs.
- Peers can be an especially effective source of support within youth and young adult programs.
- Modifications that have worked in school may also be helpful within religious education programs. Ask families to share ideas or connect with a special educator from their children's schools to ask for input.
- Ask for help from educators, special educators, para-professionals, and others who already are part of your congregation, but are perhaps not involved in your reli-

gious education program.

- Modifications can take many different forms. Some ideas include involving the child in part of the activity rather than the entire lesson, finding alternative ways to participate, providing periodic breaks, and/or rearranging the order of an activity.



Online Resources

The IRIS Center (<http://iris.peabody.vanderbilt.edu>)
CAST: Universal Design for Learning (www.cast.org/udl)
Searchable Online Accommodation Resource (<http://askjan.org/soar>)



For Further Reading

Carter, E. W. (2007). Designing inclusive religious education programs. In *Including people with disabilities in faith communities: A guide for service providers, families, and congregations* (pp. 89-120). Baltimore, MD: Paul H. Brookes.

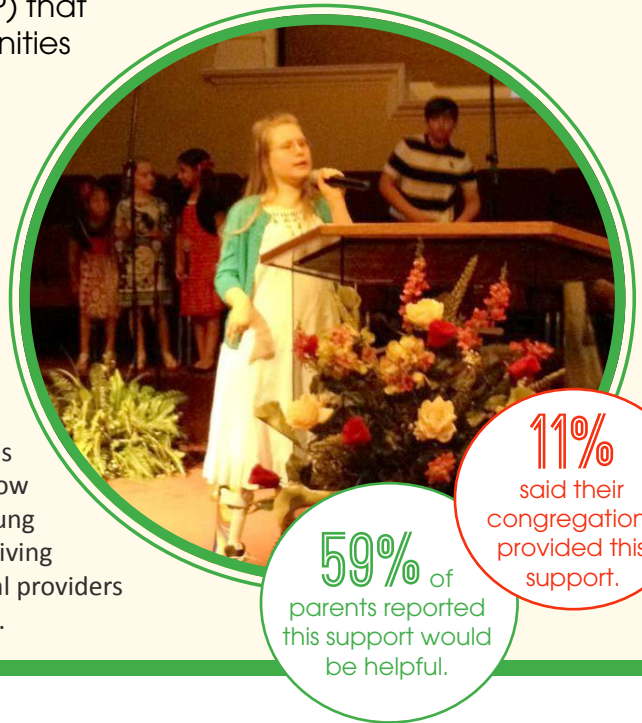
Kane, L. W. (2010). *Including adults with disabilities in religious life and education*. Nashville, TN: Vanderbilt Kennedy Center. [Available online]

Lee, A. F. (2013). *Leading a special needs ministry: A practical guide to including children and loving families*. Cummins, GA: Rethink Group.

Crafting a Spiritual or Religious Education Plan

In schools, students with disabilities who receive special education services are provided an Individualized Education Program (IEP) that outlines the personalized goals, supports, and opportunities that will provide a rich educational experience.

Similarly, a religious education “support plan” could be developed to outline those experiences and supports that might help someone grow spiritually and participate fully within their faith community. Such a plan seeks to meet the unique needs of a particular person alongside the common needs of everyone who is part of that faith community. This support plan could be a more formal document developed in collaboration with a religious education director, class teacher, family member, clergy, and others. Or it could be as simple as a short summary of a young person’s strengths, gifts, needs, dreams, and preferred supports shared with the adults with whom their child spends time. Program leaders and others benefit by having this roadmap for how best to support the inclusion, contributions, and spiritual growth of young people with disabilities. For adults with developmental disabilities receiving agency supports, a spiritual support plan could focus on how residential providers or individual staff could best address the spiritual needs of their clients.



59% of parents reported this support would be helpful.

11% said their congregations provided this support.

Practical Strategies

- Talk with parents about their goals and dreams for their child’s congregational involvement and faith development and ask youth and young adults similar questions.
- Set aside time to meet with families to brainstorm the answer to this question: What would make coming to worship services, our youth program, religious education programs, or other congregational activities the very best part of the week for your child? Use this information to help craft an individualized support plan.
- Develop a brief questionnaire to gather information on each child’s strengths, interests, and gifts; support needs and challenges; spiritual and participation goals for the upcoming year; ideas for how to best communicate with the person; and helpful supports in worship, classroom, and other congregational settings (see resources to the right).
- Ask parents if they are willing to share their child’s current school IEP (or relevant sections). This document could provide insights into supports and accommodations that could be transferred from school to congregational settings.
- Consider whether a “spiritual support plan” might be a good idea for all children and youth involved in your

programs. You may discover that efforts to understand and address the unique needs and goals of each child might enhance your ministries.



Online Resources

Spiritual Inclusion Plans (www.opwdd.ny.gov/node/443)
One-Page Profiles (www.personalisingeducation.org/one-page-profiles)



For Further Reading

Carter, E. W. (2007). Designing inclusive religious education programs. In *Including people with disabilities in faith communities: A guide for service providers, families, and congregations* (pp. 89-120). Baltimore, MD: Paul H. Brookes.

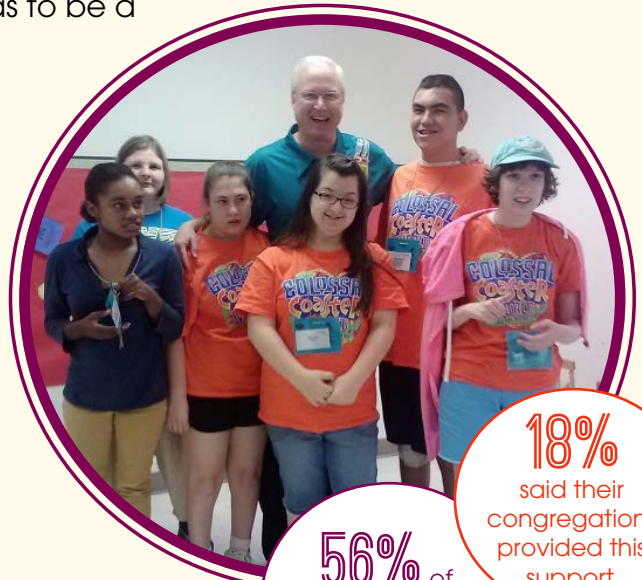
Hatton, C., Turner, S., Shah, R., Rahim, N., & Stansfield, J. (2004). *What about faith? A good practice guide for services on meeting the religious needs of people with learning disabilities*. London, UK: Foundation for People with Learning Disabilities.

Newman, B. J. (2011). *Autism and your church: Nurturing the spiritual growth of people with autism*. Grand Rapids, MI: Friendship Ministries

Creating Personal Supports for Religious Education

Everyone needs a little support to be part of a community. Support for young people with developmental disabilities often has to be a bit more intentional, intensive, or lasting.

This is especially true within religious education programs. According to a recent study, more than half of parents said their child could not participate in a religious activity because support was not provided.³ Religious education classes are important places where young people learn about their faith and develop relationships within community. Arranging for others to help provide some supports for young people can be good for everyone involved. The person offering support could be a same-age peer, an older mentor, or an adult. While having a consistent person to provide this support is often preferred, rotating systems can also be successful.



56% of parents reported this support would be helpful.

18% said their congregations provided this support.

Practical Strategies

- A recurring lesson of inclusive education in schools is that it enhances the learning of *all* students, not just students with disabilities. Cast this same vision throughout your congregation.
- Look for opportunities for peers to support one another before turning to adults. Many children and youth are used to working together in school and are quite effective at providing supports.
- Offer training and guidance to ensure volunteers understand how to best support the young person and feel confident in their roles.
- Emphasize to adults the importance of providing “just enough” support so that the student is able to participate, but independence and social connections are not hindered.
- Create a “circle of support” by finding two or more people who work in tandem to provide the breadth of supports that would enable a person’s active participation.



Online Resources

The Inclusive Church (<http://theinclusivechurch.wordpress.com>)



For Further Reading

- Carter, E. W., Cushing, L. S., & Kennedy, C. H. (2009). *Peer support strategies: Improving all students' social lives and learning*. Baltimore, MD: Paul H. Brookes.
- Kane, L. W. (2010). *Including adults with disabilities in religious life and education*. Nashville, TN: Vanderbilt Kennedy Center. [Available online]
- McNair, J., & Carter, E. W. (2010). Special issue: Inclusive Christian religious education (Part 1 and 2), *Journal of Religion, Disability & Health*, 14.
- Newman, B. J. (2012). *Helping kids include kids with disabilities* (Revised edition). Grand Rapids, MI: Faith Alive.

Designing Special Worship Services that Include People with Disabilities

In some communities, efforts to make changes to existing worship services so they are more inclusive of people with developmental and other disabilities are met with initial hesitation.

In response, some congregations have planned additional worship services specifically with the needs of individuals with developmental disabilities in mind. For example, the service might include more visuals and illustrations, allow for more movement, encourage more active participation, or incorporate other modifications. For families wondering whether their child will be truly welcomed in a faith community—as well as for residential staff serving adults with disabilities—these services may feel like a safe initial entry point into the congregation. Rather than replacing existing services within a faith community, these services should be designed as an additional venue in which people with and without disabilities can worship, serve, and fellowship together. However, it is important to remember that such venues for worship should not be the only place where people with and without disabilities encounter one another. Strong efforts should be made to ensure every aspect of congregational life is open to and supportive of people with developmental disabilities. Everyone in a community should have the opportunity to receive the gifts, friendship, and faith of people with disabilities.



47% of parents reported this support would be helpful.

7% said their congregations provided this support.

Practical Strategies

- Consider first how additional supports would make it possible for people with disabilities to be part of existing congregational activities before deciding to start something new.
- Talk with people with disabilities, their families, and others in your community to understand their views about the benefits and drawbacks of launching new worship activities.
- Avoid designing any worship services *for* people with disabilities and instead think about efforts to design accessible worship services for *anyone* in your congregation or community.
- Make sure people without disabilities are also invited and encouraged to be part of these services.
- Involve people with disabilities in leadership roles throughout all aspects of the planning and carrying out of these new activities.



Online Resources

Rejoicing Spirits (www.rejoicingspirits.org)

Friendship Ministries (www.friendship.org)

Young Life Capernaum (www.younglife.org/ForEveryKid/Capernaum)



For Further Reading

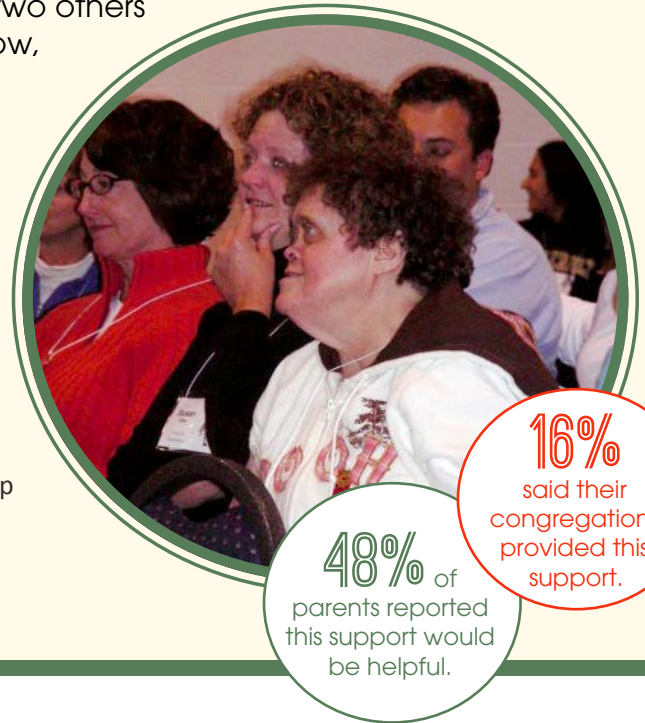
Rejoicing Spirits Ministry. (2004). *How to start a Rejoicing Spirits ministry*. Exton, PA: Author.

Scanlan, A., & Snyder, L. (2010). *Rhythms of grace: Worship and faith formation for children and families with special needs*. Nashville, TN: Morehouse Education Resources

Arranging for Support During Worship Services

One personal way of supporting young people with developmental disabilities during worship services is to identify one or two others within the congregation who commit to getting to know, sitting with, and supporting them.

Arranging for such “faith partners” or “companions” can provide an avenue for someone new to a congregation to learn the rhythms and practices of the worship service, participate in the rituals and singing, and meet others. As these relationships develop, everyone involved grows in friendship and faith. Another avenue is to talk with families about how best to support children who are unable to remain in the sanctuary during worship services. When children engage in challenging or disruptive behaviors, couples sometimes alternate which parent will stay home and which will attend worship services. Eventually, many stop coming altogether. Arranging for someone to care for their child during worship services can allow parents to worship together and take time to focus on their own spiritual formation.



48% of parents reported this support would be helpful.

16% said their congregations provided this support.

Practical Strategies

- Consider who might enjoy—and benefit from—serving as a faith partner. By connecting people with shared interests, or who live close to one another or are of similar ages, new relationships may be more likely to extend to the other six days of the week.
- A faith partner can support a person in many ways, including sitting together, sharing a hymnal, helping with a responsive reading, whispering explanation of certain aspects of the services, or reading passages of scripture together.
- Be creative in finding ways to help people with and without disabilities get to know each other so the support they exchange comes out of that relational knowledge base and a shared sense of trust and mutual understanding.
- Encourage clergy to affirm the importance of the presence of all congregational members in worship services. Members should hear the message that everyone belongs.
- Sometimes our assumptions about acceptable behavior in worship lead us to exclude people with developmental disabilities. Prayerfully consider which of your expectations are truly *essential* to how your congregation worships, and which could be more *flexible*.
- Allow flexibility in how people participate in worship services. Some members may need to move around a bit, leave during times when sounds become overwhelming, or participate in adapted ways in order to be part of the communal worship.



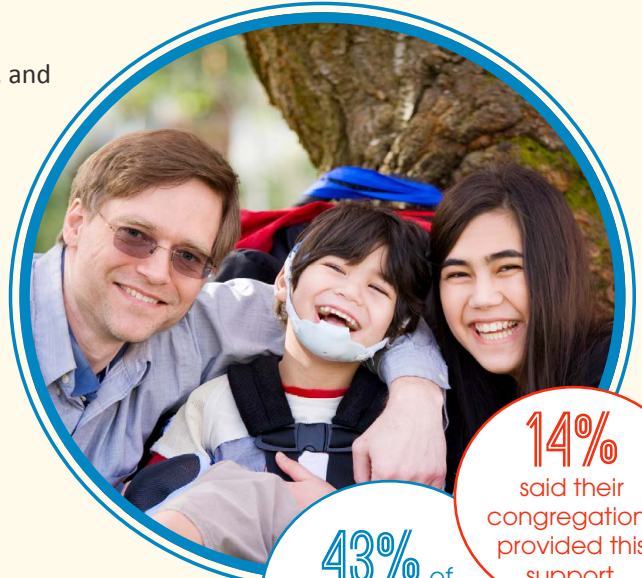
For Further Reading

- Carter, E. W. (2007). Welcoming, including, and connecting: Becoming a responsive congregation. In *Including people with disabilities in faith communities: A guide for service providers, families, and congregations* (pp. 53-88). Baltimore, MD: Paul H. Brookes.
- Kohler, T., & Earl, S. (2005). *Waddie Welcome & the beloved community*. Toronto, CA: Inclusion Press.
- O'Brien, J., & O'Brien, C. L. (1997). *Members of each other: Building community in company with people with disabilities*. Toronto, CA: Inclusion Press.
- Perske, R. (1988). *Circle of friends: People with disabilities and their friends enrich the lives of one another*. Nashville, TN: Abingdon Press.
- Preheim-Bartel, D., & Neufeldt, A. H. (2011). Supportive care in the congregation: *Providing a congregational network of care for persons with significant disabilities*. Goshen, IN: Mennonite Publishing Network.

Assisting Families With Financial Support

Like any family, parents of children with developmental disabilities sometimes face financial challenges.

But the added costs of disability-related medical treatments, therapies, and other needed supports can introduce additional challenges for these families and impact their overall well-being. Although financial waiver programs are sometimes available through state- and federally-funded programs for families impacted by developmental disabilities, the waiting lists are often years long and eligibility requirements are often very narrow. As a result, one of every four children with disabilities lives in a family with earnings below the poverty level.⁴ Faith communities have a long history of providing financial support to members of their congregation and the broader community who are in need. Consider how you might share resources with families with children with disabilities to meet pressing needs in their lives.



43% of parents reported this support would be helpful.

14% said their congregations provided this support.

Practical Strategies

- Many congregations offer workshops on financial planning. Make sure families impacted by disabilities are invited. Providing respite care might enable them to attend.
- Consider launching a scholarship fund to assist families in need within your congregation.
- Help raise money for specific equipment, supplies, therapies, or other services needed by families, but not covered by insurance or other funding sources.
- Research local and national groups that may be able to award small grants.
- Consider starting a resource exchange board, which connects needs among members of the congregation to available resources provided by other members.
- Ask families directly about needs that others can directly meet, such as cleaning, cooking, or respite for parents.
- Surprise parents by offering a night of respite at a nice hotel, periodic cleaning services, or a sitter so they can go out on a much-needed date.



Online Resources

- Possibilities: A Financial Resource for Parents of Children with Disabilities* (www.pacer.org/publications/possibilities)
- Military OneSource* (www.militaryonesource.mil/efmp)
- Children with Disabilities: Facing Financial Challenges* (www.financialworkshopkits.org/workshops/category/children-with-disabilities.aspx#)



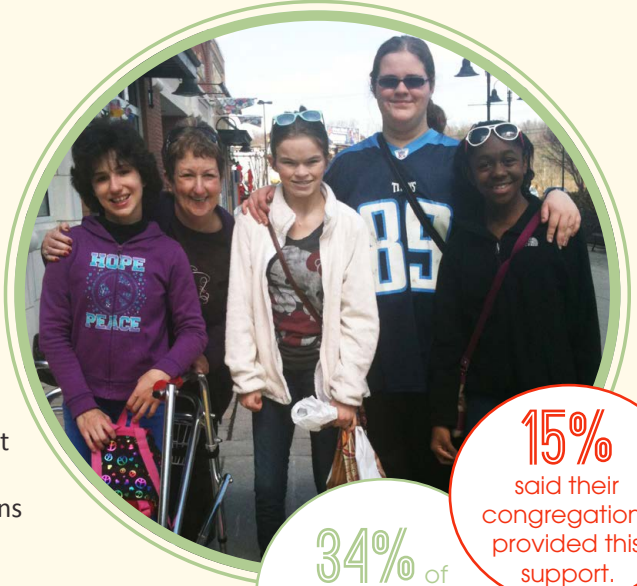
For Further Reading

- Carter, E. W. (2011). After the benediction: Walking alongside people with significant disabilities and their families in faith and life. *Journal of Religion, Disability, and Health*, 15, 395-413.
- Copen, L. J. (2005). *Beyond casseroles: 505 ways to encourage a chronically ill friend* (2nd ed.). Rest Ministries Publishers.
- Easter Seals. (2002). *With open arms: Embracing a bright financial future for you and your child*. Chicago, IL: Author.

Assisting With Transportation to Congregational Activities

Access to affordable and reliable transportation continues to remain elusive for many people with disabilities.

In fact, a national survey found that more than two fifths of adults with significant disabilities said inadequate transportation was a problem.⁵ Without transportation, people can become isolated in their own community. Access to a good job, medical appointments, and other community activities may not be possible. This includes participation in a faith community. In addition to worship services, a host of other congregational activities often take place throughout the week (e.g., potlucks, choir practice, Bible studies, community ministries). Although the Americans with Disabilities Act mandates all public transportation be physically accessible, most public options are still limited, unpredictable, and inaccessible for people with physical disabilities. Moreover, adults with developmental disabilities living apart from their families may be dependent on residential staff's availability and willingness to take them to faith community activities. Congregations can meet a real need by helping with some of the transportation needs experienced by adults with developmental disabilities.



34% of parents reported this support would be helpful.

15% said their congregations provided this support.

Practical Strategies

- Ask young people and their families about support needs in this area. Inadequate transportation may be a barrier for some, but certainly not all individuals with disabilities.
- Organize congregation members who are willing to offer rides to fellow members with disabilities to and from activities throughout the week.
- Transportation to other community activities is also greatly needed, including to medical appointments, the grocery store, or to recreation and leisure activities.
- Does your congregation have a bus or van? If so, consider organizing a transportation ministry that anyone in your congregation—with or without disabilities—can request. If your congregation does not have a vehicle, perhaps another congregation in the area does and it could be a shared outreach activity.
- Consider fundraising or applying for a grant to purchase an accessible van.
- Organize a carpooling co-op in which anyone needing transportation can connect with someone going in the same general direction.

Online Resources

- AbleData Transportation Resources* (www.abledata.com)
- Community Transportation Association* (www.ctaa.org)
- Easter Seals Project Action: Accessible Community Transportation in Our Nation* (www.projectaction.org)
- Access Nashville* (www.accessnashville.net)
- U.S. Department of Transportation Disability Resource Center* (www.dot.gov/drc)

For Further Reading

- National Highway Traffic Safety Administration (no date). *Adapting motor vehicles for people with disabilities*. Washington, DC: Author. [Available online]

Making the Congregation More Physically Accessible

From curb cuts and accessible bathrooms to assistive listening devices and large print hymnals, making your congregation more physically accessible for everyone often is a first step committed congregations take toward welcoming a broader segment of their community.

If someone has difficulty getting into your congregation or navigating the various spaces where life takes place together, they are unlikely to return for long. An inaccessible building can push people away from your congregation instead of communicating a message of hospitality. However, physical accessibility was ranked the lowest in terms of needs by parents in our project. Why? It may be that some of their faith communities have already taken steps to ensure basic accessibility features are in place. It may also be because the parents in our project had children with intellectual disability or autism, rather than physical disabilities. While physical accessibility is essential, it is important to remember that extending a warm welcome requires much more than a ramp.



32% of parents reported this support would be helpful.

23% said their congregations provided this support.

Practical Strategies

- Complete a congregational accessibility survey in which you reflect on the different spaces in which congregational life takes place to ensure they can be accessed by people with disabilities, seniors, parents of small children, and anyone else in your community.
- Form an accessibility team to regularly reflect on the accessibility of your facilities and programs.
- When considering physical accessibility, do not focus only on your sanctuary. Also consider the classrooms, fellowship halls, gymnasiums, restrooms, and community locations in which people gather on a regular basis.
- Think beyond your property. If your congregation has home-based activities such as Bible studies, hosts events such as retreats, or participates in camping ministries, consider accessibility in these locations.
- Needed changes can sometimes outstrip financial resources. Prioritize improvements and start with those that will have the most immediate impact.
- Most accessibility efforts can be made at little or no cost and with the help of willing congregation members. When needed efforts are more expensive, creatively explore funding possibilities within and beyond the congregation. Some denominations offer support in this area.



Online Resources

ADA National Network (www.adata.org)
Congregational Accessibility Network
(www.accessibilitynetwork.net)



For Further Reading

Bowen, I. (2010). *Renewing the commitment: An ADA compliance guide for nonprofits*. Chicago, IL: The Chicago Community Trust. [Available online]

Evison, I. (2001). *Money and ideas: Creative approaches to congregational access*. Herndon, VA: Alban Institute.

North Carolina Office on Disability and Health. (2005). *Planning meetings that are accessible to all participants*. Chapel Hill, NC: Author. [Available online]

Patterson, E., & Vogel, N. (2004). *Accessible faith: A technical guide for accessibility in houses of worship*. Chicago, IL: Retirement Research Foundation. [Available online]

Shepard, C. H., & Greenstein, D. (2010). *Accessibility manual*. Boston, MA: UUA.



Endnotes

- ¹Carter, E. W. (2013). Supporting inclusion and flourishing in the religious and spiritual lives of people with intellectual and developmental disabilities. *Inclusion, 1*, 64-75.
- ²Visit www.disabilitystatistics.org or <http://www.census.gov/people/disability>
- ³Ault, M. J., Collins, B. C., & Carter, E. W. (2013). Congregational participation and supports for children and adults with disabilities: Parent perceptions. *Intellectual and Developmental Disabilities, 51*, 48-61.
- ⁴Parish, S. L., Rose, R. A., & Andrews, M. E. (2010). TANF's impact on low-income mothers raising children with disabilities. *Exceptional Children, 76*, 234-253.
- ⁵Kessler Foundation and National Organization on Disability. (2010). *2010 survey of Americans with disabilities*. Washington, DC: Author.

This guide was edited, designed, and produced by the Communications and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. The preparation of this guide was supported in part by a generous grant from the Martin McCoy-Jespersion Discovery Grants in Positive Psychology. We are grateful for their investment in efforts to help people with disabilities and their families to flourish in all aspects of life. Full reports of our project findings will be posted at kc.vanderbilt.edu. For questions about the project or associated research, contact Erik Carter, Associate Professor of Special Education, at erik.carter@vanderbilt.edu.

The Vanderbilt Kennedy Center works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. Visit us online at: kc.vanderbilt.edu

03/2014

COVER ART ©PHILIPP G • ISTOCKPHOTO.COM