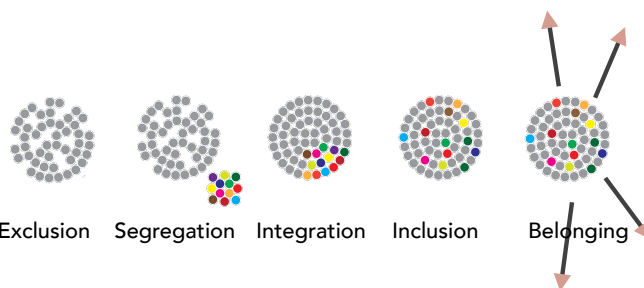


FROM BARRIERS TO BELONGING

INCLUDING PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES

ERIK CARTER | VANDERBILT UNIVERSITY

1



2



3

"FOUR SIMPLE QUESTIONS"

What are we doing **well** right now?
 What could we be doing **better** or **more of**?
 What could we be doing **differently**?
 What can we begin doing **next** to move us toward deeper community?

Reflecting on Belonging		
Are people with disabilities and their families...	What are we doing well right now in this area?	What could we do better or differently in this area?
Present		
Invited		
Unwelcomed		
Known		
Accepted		
Supported		
Cared for		
Befriended		
Needed		
Loved		
What next steps should we take to address these areas well?		

4

1. TO BE
PRESENT

5

MYTH #1
"BUT WE JUST DON'T HAVE ANYONE HERE."

6

Reflecting on Belonging

Are people with disabilities and their families...	What are we doing well right now in this area?	What could we do better or differently in this area?
Present		
Invited		
Welcomed		
Known		
Accepted		
Supported		
Cared for		
Befriended		
Needed		
Loved		

What next steps should we take to address these areas well?

"There Are No Retarded People with intellectual disability in St. Louis" Grand Rapids?



BY JEFF MCNAIR

"There are no retarded people in St. Louis," my brother Scott once told me. He'd been living in that city for six years, and neither his work life nor his church life had ever brought result, Christians like my brother don't come with mental retardation within the confines of St. Louis. At other times it appears that when we do re

OUR NEIGHBORS WITH DISABILITIES

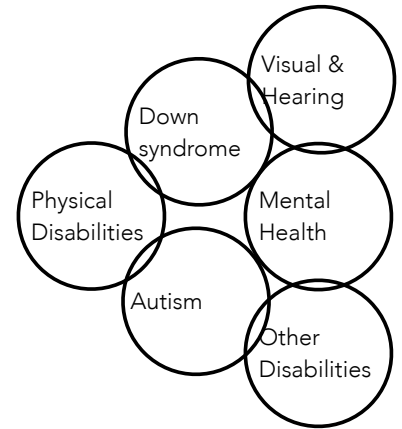
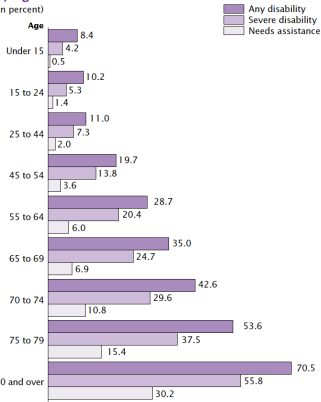


Figure 2. Disability Prevalence and the Need for Assistance by Age: 2010 (in percent)



Note: The need for assistance with activities of daily living was not asked of children under 6 years.
Source: U.S. Census Bureau, Survey of Income and Program Participation, May–August 2010.

<https://www.census.gov/people/disability/publications/sipp2010.html>

52% OF ADULTS WITH IDD DON'T ATTEND

18% OR FEWER OF CHURCHES OFFERED SUPPORTS

27% ATTEND A YOUTH OR SMALL GROUP

32% CHANGED THEIR PLACE OF WORSHIP

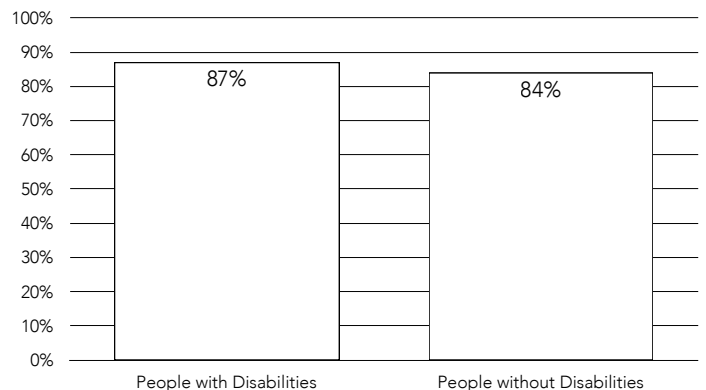
56% LACKED SUPPORT FOR THEIR CHILD

Sources: Ault et al. (2013); Carter et al. (2015); Carter et al. (2016)

MYTH #2

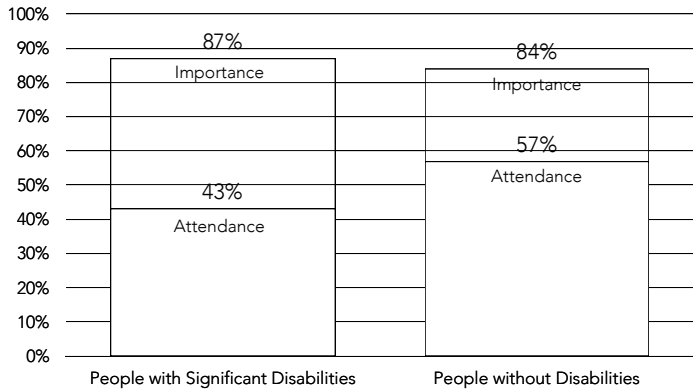
FAITH MUST BE LESS IMPORTANT TO PEOPLE WITH DISABILITIES.

MY FAITH IS SOMEWHAT TO VERY IMPORTANT



Source: National Organization on Disability

ATTENDS WORSHIP SERVICES AT LEAST ONCE PER MONTH



Source: National Organization on Disability

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“In Las Vegas last year, in five different casinos I asked five different persons in wheelchairs whether they had encountered any barriers to their entrance, the answer being always, ‘No, should there be?’ Gambling casinos, O.K.! Churches, no!”

–HAROLD WILKE

14

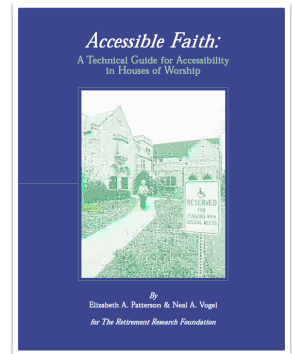
“If ‘shut-ins’ can go to Walmart, but not to your church; they are **shut out**, not **shut in!**”

–ED WOOD

15

A FEW ACCESSIBILITY CHECKLISTS

- **Congregational Assessment Survey**
www.accessibilitynetwork.net
- **Through the Roof Accessibility Checklist**
www.throughtheroof.com
- **Congregational Audit of Disability Accessibility & Inclusion**
www.phewacomcommunity.org/images/congregation-audit.pdf
- **Brief Accessibility Checklist**
www.crcna.org/disability or www.rca.org/disability
- **Signs of an Open Door Parish**
www.ncpd.org
- **Accessibility Resources for Churches**
<http://www.umdisabilityministries.org/download/audit3.pdf>



www.rrf.org/wp-content/uploads/Accessible_Faith_CF_7_19_11.pdf

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“It’s not that we deliberately excluded them. In fact, we weren’t deliberate at all. That was the problem.”

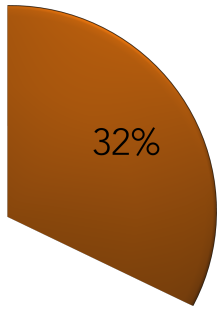
–A PASTOR

2. TO BE

INVITED

17

18



32%

Parents who changed their place of worship because their child with a disability was not included or welcomed.

Source: Ault, Collins, & Carter (2013)



Access for Individuals Who Are Blind or Have Low Vision



Symbol for Accessibility



Audio Description



Telephone Typewriter (TTY)



Volume Control Telephone



Assistive Listening Systems



Sign Language Interpretation



Accessible Print



Information Symbol



Closed Captioning

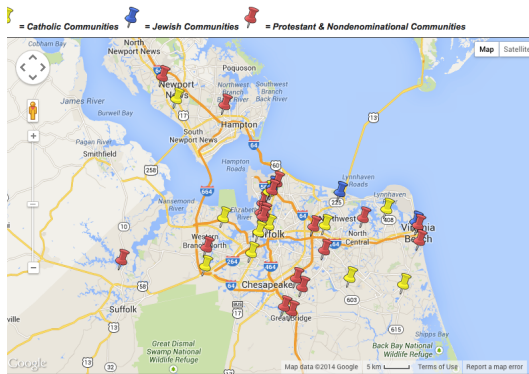


Opened Captioning



Braille Symbol

https://graphicartistsguild.org/tools_resources/downloadable-disability-access-symbols



<http://www.faithinclusionnetwork.org>

ACTIVE INVITATIONS

- Visit or share information with...
- Independent living centers and disability organizations
- Group homes
- Parent support groups
- Regional and state disability initiatives

Organization or association*	Web site
The Arc	http://www.thearc.org
American Association on Intellectual and Developmental Disabilities	http://www.aaid.org
Autism Society of America	http://www.autism-society.org
Brain Injury Association of America	http://www.biausa.org
Center for Independent Living	http://www.ilru.org
Councils on Developmental Disabilities	http://www.nacdd.org
Easter Seals	http://www.easterseals.com
Epilepsy Foundation	http://www.epilepsyfoundation.org
Federation of Families for Children's Mental Health	http://www.ffcmh.org
Goodwill Industries International	http://www.goodwill.org
Muscular Dystrophy Association	http://www.mdausa.org
National Association for the Dually Diagnosed	http://www.thenadd.org
National Disability Rights Network	http://www.napas.org
National Down Syndrome Society	http://www.ndss.org
National Muscular Sclerosis Society	http://www.nationalmssociety.org
Parents Helping Parents	http://www.php.com
People First	http://www.peoplefirst.org
Salvation Army	http://www.salvationarmyusa.org
Spina Bifida Association	http://www.sbaa.org
TASH	http://www.tash.org
United Cerebral Palsy	http://www.ucp.org
United Way	http://www.unitedway.org
County and state social service agencies	Local web search or telephone directory
Local advocacy groups	Local web search or telephone directory
Local school districts	Local web search or telephone directory
Residential service providers	Local web search or telephone directory
Respite/adult day care service providers	Local web search or telephone directory
Supported employment providers	Local web search or telephone directory
Vocational rehabilitation offices	Local web search or telephone directory
Universities with special education, rehabilitation psychology, social work, and related programs	Local web search or telephone directory

3. TO BE

WELCOMED

"Several years ago, the Bethsaida Task Force, a committee working on accessibility and inclusion issues for Episcopal congregations in the Diocese of Newark, New Jersey, brought a resolution to the annual meeting of the Diocese. The resolution proposed that any church that had a sign on its front lawn stating the name of the church and the phrase "Everyone's Welcome" should have to take the welcome phrase off by a certain date if the building was not accessible to everyone, especially people with disabilities."

-BILL GAVENTA

“We felt like we were wanted.”

–A PARENT

DISABILITY ETIQUETTE

TIPS FOR INTERACTING WITH PEOPLE WITH DISABILITIES

4. TO BE

KNOWN

Intellectual disability is “a disability characterized by **SIGNIFICANT LIMITATIONS** both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills.”

AAIDD definition (2010)

Autism is characterized by...

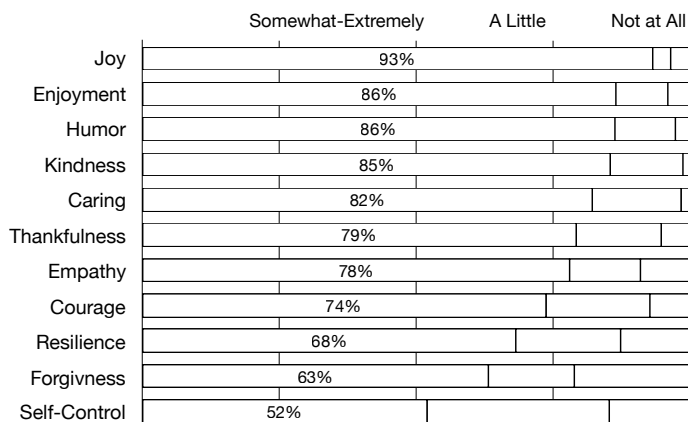
DEFICITS in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,

DEFICITS in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.

DEFICITS in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

APA definition (2012)

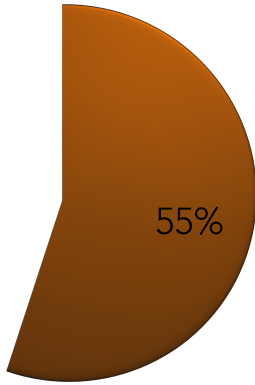
HOW MUCH IS EACH TRAIT CHARACTERISTIC OF YOUR CHILD?



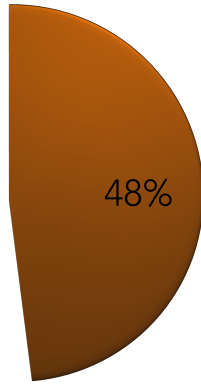
Selected Items from the Assessment Scale for Positive Character Traits-Developmental Disabilities (Woodard, 2009)

5. TO BE

ACCEPTED



Congregational leaders accept my child.



Congregation members accept my child.

Source: Carter, Boehm, Annandale, & Taylor (2016)

31

- "It seems like a lot of energy and effort when we can't really be sure that Louise will actually get anything out of being in Sunday school with the other children."
- "We have a special class for children just like your son."
- "These renovations seem a bit much. After all, we don't have any people with disabilities in our congregation."
- "I'd love to invite my neighbor to attend our church, but we just don't have a program for people with disabilities."
- "Maybe your family would feel more comfortable at Temple Beth-El—I believe they do disability ministry."
- "If Abel can't read, how will he get anything out of the class?"
- "She has autism? None of us are trained to work with those children."
- "Some members of the congregation are finding your group to be distracting. Perhaps you and your clients would be more comfortable sitting in the balcony."
- "Our church just isn't big enough to have a disability ministry."
- "Sandy really doesn't understand the meaning of communion. I'm not sure we can really allow her to participate."
- "I'm so sorry to hear about your child. You must be devastated."
- "I know he is a little old, but he would probably still best be cared for in the nursery."

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INCLUSION AWARENESS ACTIVITIES ACCESS SUNDAY CELEBRATING INCLUSION

33

A FEW INCLUSION AWARENESS RESOURCES

- **Disability Concerns (RCA)**
<https://www.rca.org/disability-awareness>
- **Methodist Church**
<http://www.umdisabilityministries.org/dasunday/>
- **Christian Reformed Church**
- <http://network.crcna.org/disability-concerns/ways-celebrate-disability-awareness-sunday>
- **Presbyterian Church (USA)**
[https://www.pcusa.org/site_media/media/uploads/phewa/pdfs/disability_access:inclusion_sunday_2013.pdf\\$\\$](https://www.pcusa.org/site_media/media/uploads/phewa/pdfs/disability_access:inclusion_sunday_2013.pdf$$)
- **Pathways**
<https://pathways.org/tools-resources/inclusion-worship/>

34

ABOUT DISABILITY AWARENESS

- Let people with disabilities lead you in this area
- Avoid simulations and other activities that inadvertently send the wrong message
- Think beyond a single Sunday
- Personal relationships are more powerful than information only

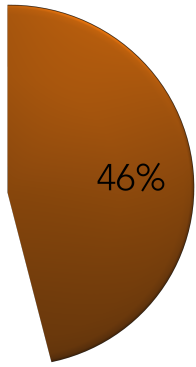


35

6. TO BE

SUPPORTED

36



Parents who say they have been asked about the best way to include their child in religious activities.

Source: Ault, Collins, & Carter (2013)

EXAMPLE QUESTIONS

- Tell us about your child.
 - What does she enjoy doing? Not enjoy doing?
 - What are her gifts and talents? What does she do well? What does she love to “show off”?
 - How does she communicate with others? Express excitement? Frustration?
- Tell us about your family.
- In what ways would you like to see your child involved in this congregation?
- What has been your child’s previous experience in other congregations?
- What should we know about supporting your child in congregational activities?
 - How can we best support her positive behavior?
 - Are there things we should definitely avoid doing or saying?
 - Are there things we should absolutely do?
 - What does she find most rewarding?
 - What is the best way to respond when your child becomes upset?
 - How can we help support your family as you raise your child? Can we _____ [offer specific examples]?

EXAMPLE QUESTIONS

- How would you describe your child’s faith? What are the best ways to communicate spiritual truths?
- Are there important goals that you have for your child as she participates in our program this year? As you look into the future?
- What could we do to make our children’s program the most exciting time of the week for your child?
- How would you like us to respond when other children or adults ask us about your child’s disability or support needs?
- What do you see as the biggest challenges to including your child in congregational activities?
- How can our congregation help support your family as you raise your child? Can we _____ [offer specific examples]?
- Is there anything else that you would like us to know about your child or family?

	Somewhat/Very Helpful	A Little Helpful	Not at All Helpful
Disability Awareness Efforts	70%	12%	18%
An Advocate for Families	68%	15%	17%
Informational Resources for Families	69%	14%	17%
Spiritual Counseling From a Leader	65%	14%	21%
A “Support Group” for Parents	62%	21%	17%
Respite Care	61%	13%	25%
Modifications to Religious Education	59%	14%	28%
A Spiritual/Religious Education Plan	59%	14%	27%
Support in Religious Education	56%	13%	32%
Support During Worship Services	48%	12%	41%
“Special” Worship Services	46%	12%	42%
Financial Support	43%	18%	39%
Transportation to Congregation Events	34%	13%	54%
A More Accessible Congregation	32%	13%	55%

Source: Carter, Boehm, Annandale, & Taylor (2016)

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 address 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 or are and have been from those who have been in similar situations. Each community might reflect on the need for a support group and possible formats. Would the focus be on a particular diagnosis (e.g., parents of children with autism) or range of the full spectrum of disabilities (e.g., parents of children with autism)?

In many cases, it's not just the group, and how often would it meet? Additionally, each community should think about what types of support groups it may want to offer. There are many ways to connect parents with one another and needed support, and there are many ways to help with learning, connections, empowerment, and support. Sharing may also benefit from getting to know others who have similar or even with a disability.

71% of parents of children with disabilities are in support groups.

12% of the congregations provide a support group.

Practical Strategies

- Contact local agencies and disability organizations (e.g., see the Family Matters, Down and Disabled) to ask what needs they see in the community for connecting and supporting parents. Ask how they can help them. Request referrals.
- Consider a list of support groups for parents and siblings in your area. They may be surprised by what already exists in your area.
- Make sure key people in your congregation are familiar with these services of support so they can be shared with interested families.
- Talk with families to assess congregation and ask how you might design a group that best meets their needs.
- Find out if there are people who are passionate and interested in disability. Invite them to the group. This can mean that you would have guest speakers or leaders - not every one has to lead the group.
- Review that 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. Meeting there could meet an important local need.

Online Resources

- Down Syndrome Resource Center (www.downsociety.org)
- Family Matters (www.familymatters.org)
- Down Syndrome Resource Center (www.downsociety.org)
- Family Matters (www.familymatters.org)

For Further Reading

- Carter, C. (2016). *Empowering Parents: Creating Congregational Support for Families of Children with Disabilities*. Grand Rapids, MI: Faith Alive.
- DeWitt, S. (2015). *Parent support group: A new model for faith communities*. *Journal of Pastoral Care and Christian Education*, 76(4), 30-35.
- Wiersma, J. L., & Jolley, P. (2015). *Disability: Resources for congregations*. Grand Rapids, MI: Faith Alive.
- Wiersma, J. L., & Jolley, P. (2015). *Disability: Resources for congregations*. Grand Rapids, MI: Faith Alive.

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 Alissa K. Logeman

<http://vkc.mc.vanderbilt.edu/assets/files/resources/CongregationPracticeGuide.pdf>

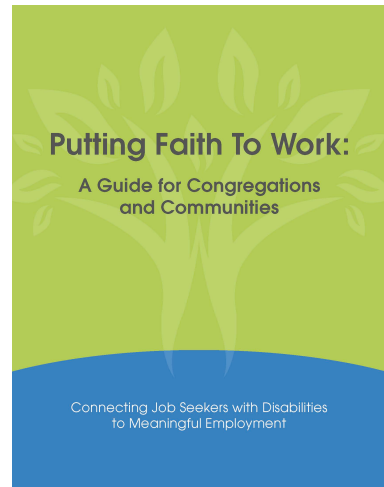
Mentally-Disabled Boy In Italy Denied Communion For "Not Understanding" Rite

'I feel really let down by the Catholic faith... what they are doing is so cruel': Mother accuses church of discrimination over priest's Communion ban on Down's boy, 7

Family claims discrimination because child was denied first communion

7. TO BE
CARED FOR

43



www.puttingfaithtowork.org

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www.friendshiphousepartners.org

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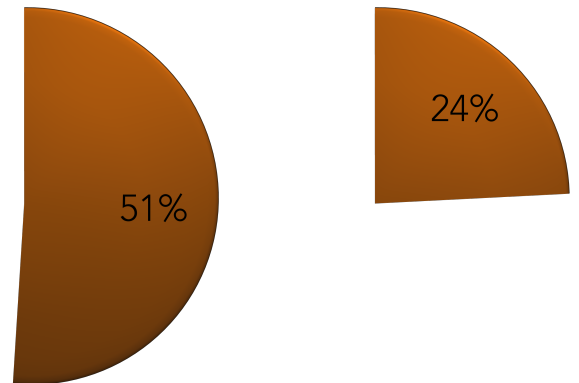
8. TO BE
BEFRIENDED

46

"... alone we are poor,
together we are rich."

-SUE MOSTELLER

47



Never invited to a social activity with peers

Have **no** friends outside of staff and family

Source: www.nlts2.org and www.nationalcoreindicators.org

48

Disability Category	Never Visits With Friends	Rarely Or Never	Not Invited To Other Youth's
Autism	44%	84%	51%
Deaf-Blindness	27%	64%	35%
Emotional Disturbance	11%	26%	17%
Hearing Impairment	8%	41%	12%
Intellectual Disability	16%	42%	25%
Learning Disabilities	7%	19%	11%
Multiple Disabilities	30%	63%	44%
Orthopedic Impairment	20%	47%	30%
Other Health	6%	24%	12%
Speech/Language	9%	22%	11%
Traumatic Brain Injury	8%	34%	20%
Visual Impairment	15%	33%	22%

Source: Wagner, Cadwallader, Garza, & Cameto (2004)

“...being loved and befriended does something for you that rights and choice cannot possibly do. It brings you the invaluable experience of being chosen by someone else. Whatever it is that rights and choice can do—and we do not have to prove that they can do a lot of very important things—**but whatever rights and choice can do, they are not going to make me your friend.**”

– HANS REINDERS
THE POWER OF INCLUSION AND FRIENDSHIPS

9. TO BE
NEEDED

“And then there is the Lord’s Prayer. When it declares, “Thine is the Kingdom, the Power, and the Glory,” JT places special emphasis on “the Power.” He stiffens his back and fills his chest with air, and then enunciates “Power” with more vigor than he speaks any other word in any other sentence at any other time. He pushes out the “P” as though it were a sour lemon. In nearby pews, parishioners cannot fail to hear; they nod in agreement, or, when the service is over, they tilt their heads in respectful silent greeting to JT—their acknowledgement that he is singularly different and perhaps singularly blessed. Nearly 30 pews away and across the aisle in front of the altar, our minister looks up, spots JT, fails to control a satisfied grin, and knows that, whatever efficacy he had in reaching others in the congregation that day, he—as God’s minister—has touched JT.”

–RUD AND ANN TURNBULL



The way God designed our bodies is a model for understanding our lives together as a church:

every part dependent on every other part,
the parts we mention and the parts we don’t,
the parts we see and the parts we don’t.

If one part hurts,
every other part is involved in the hurt,
and in the healing.

If one part flourishes,
every other part enters into exuberance.

1 Corinthians 12: 12, 25-26

10. TO BE
LOVED

55

MYTH #3

**PEOPLE WITH INTELLECTUAL
DISABILITY PRIMARILY HAVE
"SPECIAL NEEDS"**

56

MYTH #4

**PEOPLE NEED PROGRAMS
MORE THAN RELATIONSHIPS**

57

MYTH #5

**FOSTERING BELONGING IS
BEST LEFT TO THE EXPERTS**

58

MYTH #6

**SOMEONE ELSE SHOULD
DEFINITELY ADDRESS THIS**

59

<http://faithanddisability.org/resources/position-statements-from-denominations-faith-groups-and-other-organizations/>

American Baptist Churches, USA
Resolution on the Church and Persons with Disabilities (1978, 1994, 1998)
Resolution on Employment of Persons with Disabilities (1983, 1994, 1998)
Resolution on Mental Illness (1991)
Resolution on Ministry to the Handicapped (1959)

Assemblies of God
Ministry to People with Disabilities: A Biblical Perspective (2000)

Baha'i
Human Rights and Disability (1988)

Catholic Church
Conclusions of a Vatican Conference on the Family and Integration of the Disabled
60