

Everybody Belongs. Everybody Serves.

A Handbook for Disability Advocates

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Disability Concerns
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Preface

You are looking at this booklet because you love God, his people, and especially people with disabilities. Thank you! We developed this booklet to help you

- understand the importance of your role,
- carry out your role more effectively.

As a volunteer with Christian Reformed Disability Concerns, you are part of a network of about 550 people who serve as Church Advocates, Regional Advocates, and Agency Advocates in Christian Reformed churches, classes, and agencies respectively. The Disability Concerns Advisory Committee as well as two part-time administrative assistants and a full-time director support this network of volunteers.

We present this booklet to help you, not to overwhelm you.

It has many practical ideas. But all these ideas could seem like too much for a church, certainly too much for one person. Please use this booklet with prayerful discernment. Ask the Lord to guide you and your congregation in the steps you need to take to enfold individuals with disabilities into the life of your church.

We present this booklet to you recognizing that it is a mile wide and an inch deep.

Inclusion happens one person at a time. Please get to know the individuals in your church to learn best how they may be included. Many disabling conditions are not mentioned here, and many excellent resources could be added. Please let us know if you have expertise in some area. Or let us know about a great website or book.

Special thanks to Curt Gesch, people at Telkwa CRC, and many Regional Advocates and others who contributed their efforts to this booklet. All Scripture quotations are from the NIV.

Please let us know if you would like us to send you a copy in large print.

God's blessings in your work!
Rev. Mark Stephenson, Director

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Introduction—Mission, Vision, and Outcome

Disability Concerns seeks to bring about
the full participation
of all the people with disabilities
in the life of the church

and the full participation of the church
in the lives of people with disabilities.

We present this booklet in the hope that churches more and more become hospitable, inclusive, and healthy communities that intentionally seek

- ⇒ to end the isolation and disconnectedness of persons with disabilities and their families,
- ⇒ to nurture the spiritual lives of people with disabilities so that they become professing and active members of their churches, and
- ⇒ to encourage the gifts of people with disabilities so that they can serve God fully in their churches.

The desired outcome for the work of Disability Concerns is this: in every congregation, everybody belongs and everybody serves.

Further information:

The website of Christian Reformed Disability Concerns, **www.crcdisabilityconcerns.org**, has many resources for worship, caring, and accessibility as well as more than 20 issues of our newsletter, *Breaking Barriers*, which contain personal stories and descriptions about various disabilities.

Groundings —A Biblical Perspective

Jesus' first recorded sermon proclaimed that God's kingdom was at hand. Then he spent the rest of his public ministry on earth bringing in the kingdom. Our calling as advocates for people with disabilities is to carry on Jesus' work so that all people, especially people with disabilities, will be welcomed to the body of Christ and encouraged to use their gifts in ministry. The Scriptures provide us with a basic foundation for this work:

⇒ All people are created in the image of God; therefore, each person has intrinsic value not based on what she can do but on who she is.

"Then God said, 'Let us make humankind in our image . . . '"
(Genesis 1:26)

⇒ Jesus' body, the church, has many parts but is ONE; therefore, each member of Christ's body (each person) is essential for a healthy church.

"The body is a unit, though it is made up of many parts; and though all its parts are many, they form one body. So it is with Christ. . . . those parts of the body that seem to be weaker are indispensable." (1 Corinthians 12:12, 22)

⇒ All believers are called by God; therefore, each believer has a mission given by God to fulfill while here on earth.

"For we are what [God] has made us, created in Jesus Christ for good works, which God prepared beforehand to be our way of life." (Ephesians 2:10)

⇒ All believers have spiritual gifts; therefore, each believer receives from God the gifts he needs to accomplish this mission.

"Now there are varieties of gifts but the same Spirit . . . " (1 Corinthians 12:4)

⇒ All believers are invited to participate in God's work; therefore, every member of Christ's body fulfills an essential and unique function in the body.

"To each is given the manifestation of the Spirit for the common good . . . " (1 Corinthians 12:7)

⇒ In healthy churches, everybody belongs.

“Above all, love each other deeply, because love covers over a multitude of sins. Offer hospitality to one another without grumbling.” (1 Peter 4:8-9)

⇒ In healthy churches, everybody serves.

“Each one should use whatever gift he has received to serve others, faithfully administering God's grace in its various forms.” (1 Peter 4:10)

The Commitment of the Christian Reformed Church

We who are part of the Christian Reformed Church in North America have committed ourselves to the inclusion of people with disabilities in the life and ministry of the churches:

Resolution on Disabilities, adopted by Synod 1985:

Whereas the Bible calls us to be a caring community as the covenant people of God,

Whereas we recognize that our Lord Jesus Christ requires the involvement of all his people in the ministry of his church,

Whereas we have not always made it possible for people with disabilities to participate fully in the community and have often isolated them and their families,

We pledge ourselves to be the caring community according to I Corinthians 12, paying special attention to the needs and gifts of people with physical, sensory, mental, and emotional impairments.

We pledge ourselves, to make public these needs and capabilities through our various communication and educational materials.

We pledge ourselves to overcome three barriers:

1. the attitudinal barriers which make persons with disabilities feel unwelcome;
2. the communication barriers in sight, sound, and understanding which may impede participation; and
3. the physical and architectural barriers which make it difficult for persons with some disabilities to enter.

We commend those within the denomination who have made efforts to eliminate these barriers in order to use the gifts of all people in our life together as God's family.

Later, the Synod of 1993 adopted the following: "That synod heartily recommend full compliance with the provisions of the Americans with Disabilities Act . . . and its accompanying regulations in all portions of the CRC located in the U.S. and Canada"

Description of Disability

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

(Article 1: Purpose, *UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, December 2006)

This description recognizes two basic aspects of disability:

1. A disability is an impairment which may be noticeable to other or may be “invisible” to those who do not know the person well:

- ⇒ physical—such as paralysis or multiple sclerosis
- ⇒ mental—such as schizophrenia or bi-polar disorder
- ⇒ intellectual—such as Down syndrome
- ⇒ sensory—such as blindness or hard of hearing

2. A disability results, in part, from various barriers which hinder full and effective participation in society. These barriers include

- ⇒ **Physical barriers** such as curbs without cutouts and non-accessible restrooms,
- ⇒ **Communication barriers** such as lack of availability of large print materials or of closed captioning of videos,
- ⇒ **Attitudinal barriers** which impose a wide variety of stereotypes on people with disabilities resulting in, for example, an unemployment rate of 70% for people who are deaf and for people who are blind.

Relationship —The Main Thing

The medical, educational, and social service communities give labels to people such as “autism,” “cerebral palsy,” “dementia,” and “macular degeneration.” These labels can be useful for understanding and helping people, but a person is not his or her label. Barbara Newman writes,

My mother-in-law was diagnosed with diabetes. It’s helpful for me to know this when she comes to my home. It helps me understand why we have needles in the garbage. It helps me stock up on the right kind of foods before she arrives for a visit. It also helped me understand the day she felt so strange in the grocery store and asked me to give her some orange juice before I had even paid for it. But it would be a mistake to overly focus on my mother-in-law’s condition and fail to appreciate her unique personality and interests. We don’t think about diabetes all the time; we laugh, talk, cry, shop, and watch movies together. Although I am grateful to be aware of the diabetic piece of my mother-in-law, it is only a portion of the complex and delightful person she is. (*Autism and Your Church*, p. 21)

Similarly, knowing the particular disability a person lives with will help churches to better understand and help that person, but people are individuals with wonderfully complex needs, gifts, joys, challenges, and interests. As advocates for people with disabilities, we must encourage the people in our churches to focus on people and relationships, and not be overly concerned with labels. So when the education team thinks about how best to include Kyle in Sunday School, they take his Down syndrome into account, but they also note Kyle’s likes and dislikes, things that calm him and things that make him agitated, ways that he learns best, and classroom activities that are challenging for him. Most importantly, they consider Kyle’s gifts and encourage him to use them in the classroom and the church.

Barbara Newman says that naming someone's disability is like telling what state her family visited on their last vacation. It gives you a general idea what the vacation was about, but until you talk with the Newmans about what they did on vacation, you don't know much about it. In the same way, we will not get to know the people with disabilities in our churches until we develop relationships with them.

For further information:

- ⇒ Brett Webb-Mitchell, *Unexpected Guests at God's Banquet: Welcoming People with Disabilities Into the Church*
- ⇒ Erik W. Carter, *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families, and Congregations*
- ⇒ National Organization on Disability, *That All May Worship: An Interfaith Welcome to People with Disabilities*

Starting Out

In the first month:

1. Connect with others in your church who have the same passion. Be an advocate *with* persons with disabilities, not just an advocate *for* them. (As self-advocates like to say, “Nothing about us without us.”) Also, connect with Church Advocates and Regional Advocates in your area.
2. Make sure your congregation receives enough copies of *Breaking Barriers* for each individual/family. Ensure that these are distributed individually to the congregation (not lain on a table somewhere).
2. Many church bulletins include a phrase, “Please stand, if you are able” which separates people. Request that the bulletin instead say, “Please rise in body or in spirit,” which unites. Ask that worship leaders explain this change to the congregation, and use that phrase when leading the worship service.
3. Provide large print bulletins for people with visual impairments.
4. Distribute print copies of lyrics displayed on the overhead screen to people who cannot stand.
5. Make an appointment with your pastor to discuss how the church can best include people with disabilities in your church life. Ask if a disability awareness worship service can be scheduled. Disability Concerns has been designated for the third Sunday in October by our denomination, but this service can be held at any time during the year.

In the first year:

1. With a member who has a mobility impairment and with church leadership, do an accessibility audit of your church building and programs. See www.crcdisabilityconcerns.org then search for “Accessibility Audit Guide” for the guide available from Disability Concerns. Take notes, and take action.
2. Begin working at the list of “General Tips and Accommodations” on the next page.

General Tips and Accommodations

- ⇒ Talk with the person with disabilities and with the family. They know their needs and gifts best! Questionnaires starting at page 24 can be used by council or care team members to interview people. Ask your council to ask all congregation members what needs they may have. (Some disabilities are “invisible.”)
- ⇒ Encourage your council to adopt the Church Policy on Disabilities (see p. 32) if they have not done so already.
- ⇒ Keep the confidentiality of the person, especially in public prayer. Ask for permission to openly pray for him or her.

Physical Impairments

- ⇒ Many physical accommodations should be considered. First on the list should be accessibility to the sanctuary, pew cutouts, and accessible restrooms. (“If they can’t go, they won’t come.”) Second, consider making other areas of the building accessible including fellowship and education rooms, and things like drinking fountains.
- ⇒ Keep accessible parking and entrances clear of snow, clean, smooth, and well lit.

Visual Impairment

- ⇒ Ensure adequate lighting where your church meets.
- ⇒ Offer large print bulletins, song sheets, and other church publications (and Braille when requested in advance).
- ⇒ Have simple, non-busy backgrounds on projected slides.

Hearing Impairment

- ⇒ Make sermon manuscripts available to people before the worship service (so that someone who is hard of hearing can follow along).
- ⇒ Ensure that the sound system is in good working order.
- ⇒ Consider installing a hearing loop system. (See www.hearingloop.org.)

- ⇒ Arrange for sign language translation (when requested in advance).

Allergies and Chemical Sensitivity

- ⇒ Encourage your congregation to become a scent-free zone to help people with asthma, emphysema, or others who have chemical sensitivities. Asking people to avoid wearing aftershave, cologne, or perfume to church is a good first step.
- ⇒ Offer grape juice and gluten-free bread for those who need these alternatives to wine and regular bread at communion.
- ⇒ Ask your congregation members to label food at potlucks, especially those containing peanuts and tree nuts.

General Accommodations

- ⇒ Provide valet parking for disabled people and older church members, especially in inclement weather.
- ⇒ Have a few volunteers who would be willing to provide transportation to and from worship services and other church events.
- ⇒ Always have some sort of snack or juice available especially for someone who has diabetes.
- ⇒ Provide a person who is willing to take notes for others.
- ⇒ Encourage your worship leaders to strive for multi-sensory worship remembering the importance of texture, taste, color, and movement as they prepare. This is great for all people since all people learn things and experience God in different ways.
- ⇒ Work to create a “climate” or “culture” in your congregation in which standing up or walking out by people with disabilities is seen as an aid to worship, not a disruption.
- ⇒ Some disabilities cause the person to have difficulty following rules or exhibiting correct behavior. Be aware of this, but do not let this behavior reach the point where it endangers anyone - including themselves. See “Tips for Preventing Negative Behavior” below on page 23.

Tips—Etiquette

Principle: Treat everyone with dignity and respect.

- ⇒ Shake or touch hands (or the prosthesis); shaking the left hand can be appropriate too.
- ⇒ Ask before you assist a person and listen carefully to instructions. Do not interfere with a person's full control over his/her own assistive devices.
- ⇒ Allow the disabled person to serve you and others.
- ⇒ Speak directly to the person with a disability rather than to a companion.
- ⇒ Relax. Don't be embarrassed to use common expressions such as "I've got to run now," "See you later," or "Have you heard about" even if the person doesn't run, see, or hear.
- ⇒ Avoid expressions such as "crippled," "deaf and dumb" and "wheelchair-bound." Use "people first" language such as, "Mary is hard of hearing;" "Denise uses a wheelchair."
- ⇒ Avoid excessive praise when people with disabilities accomplish normal tasks.
- ⇒ Don't lean on a person's wheelchair—it's considered an extension of personal space.
- ⇒ Don't pet a guide or companion dog while it's working.
- ⇒ Give unhurried attention to a person who has difficulty speaking.
- ⇒ Speak calmly, slowly and directly to a person who is hard of hearing. Don't shout or speak in the person's ear.
- ⇒ Greet a person who is visually impaired by telling the person your name and where you are. When offering assistance, let the person take your arm and then tell him when you are approaching inclines or turning right or left.
- ⇒ When you talk with a person in a wheelchair for more than a few moments, try to position yourself at eye level.
- ⇒ **Whatever you do, don't let fear of saying or doing something "wrong" prevent you from getting to know a disabled person. If you are unsure of what to say when you first meet, try "Hello" or "I'm glad to see you."**

Tips—Grief

When parents discover that their child has a disability, when injury or illness brings disability into the life of someone and his or her family, when another skill is lost due to a progressive disability, grief is a common response. Many people who develop a disability pray first for a cure. God might not cure the person, but he will heal.

- ⇒ Cure - the total removal of an illness or disability
 - ⇒ Heal - growth toward inner integration, well-being, and a sense of meaning, purpose, and value
- Help them to understand the difference.

Since God goes before us, ask God to equip you with

- ⇒ A listening ear. Avoid the temptation to tell your story, or say, “When I experienced this, I”
- ⇒ An empathetic heart
- ⇒ A reluctance to judge
- ⇒ A willingness simply to be present
- ⇒ Openness and transparency
- ⇒ A reliance on God’s presence

For further information:

- ⇒ Encourage your church council and care team to study together *A Compassionate Journey: Coming Alongside People with Disabilities and Chronic Illness* by John G. Cook.
- ⇒ *The Compassionate Congregation: A Handbook for People Who Care* by Karen Mulder and Ginger Jurries.
- ⇒ *90% of Helping Is Just Showing Up* by James R. Kok
(All three of the resources above are available from Faith Alive Resources.)

Tips—Chronic or Terminal Illness

- ⇒ Acknowledge the illness. For example, don't avoid use of the word "cancer." It is very real to the ill person. "I know you must be having a difficult time dealing with your diagnosis of cancer."
- ⇒ Be there; offer a listening ear.
- ⇒ Be honest that you "may not know exactly what to say or how to help."
- ⇒ Offer to accompany the person to appointments if there is no family member available.
- ⇒ Do not dominate conversation with you own story of illness or recovery.

For further information:

- ⇒ *A Compassionate Journey: Coming Alongside People with Disabilities or Chronic Illnesses* by John G. Cook
- ⇒ On multiple sclerosis, fibromyalgia, and chronic migraines, contact Barbara Alexander, Regional Advocate for classis Yellowstone, db.alexander@comcast.net
- ⇒ On muscular dystrophy and multiple sclerosis, contact Pat Huisinigh, Regional Advocate for classis Zeeland, pdhuisinigh@yahoo.com; also on muscular dystrophy, contact Hank Kuntz, Regional Advocate for classis Toronto, hkuntz@pathcom.com.
- ⇒ On geriatrics and end-of-life care, contact Elly Van Alten, Regional Advocate for classis Alberta North, ellyv@telus.net
- ⇒ On stroke rehabilitation and dementia, contact Liz Wagner, Regional Advocate for classis Hamilton, lizbet1942@hotmail.com

Tips—Deaf and Hard of Hearing

- ⇒ Speak clearly, not **overemphasizing**, a little slowly, in short sentences.
- ⇒ Reduce background noise. Close doors; turn off TV.
- ⇒ Face the listener.
- ⇒ Allow adequate light to fall on your face. Do not stand in front of a window or light source.
- ⇒ Give the listener a clear view of your face. Keep hands or other objects down. Don't chew gum.
- ⇒ Avoid talking while writing or walking around the room.
- ⇒ Gain the person's attention before beginning to speak. Say the listener's name at the beginning of the sentence.
- ⇒ Have the person repeat to be sure the message was understood. In a group setting, repeat any questions asked before beginning with answers.
- ⇒ Be redundant. Repeat or rephrase. Or say things in different words, redundantly.
- ⇒ Write key words if the person can read and see what you are writing.
- ⇒ Arrange seating in small groups, preferably in circles or at round tables.
- ⇒ In large meetings, have speakers provide outlines for persons to refer to.

For further information:

- ⇒ Liz Wagner, Regional Advocate for classis Hamilton and a director on the board of the Canadian Hard of Hearing Association, lizbet1942@hotmail.com
- ⇒ Canadian Association of the Deaf – www.cad.ca
- ⇒ National Association of the Deaf – www.nad.org
- ⇒ Information on hearing loops – www.hearingloop.org

Tips —Visual Impairment

- ⇒ Identify yourself by name when you approach a person with a vision disability and tell them when you are leaving the conversation or area.
- ⇒ Use a normal tone of voice (for some reason, people with vision disabilities are often shouted at).
- ⇒ It is okay to use vision references such as see or look.
- ⇒ Give a person with visual impairment a brief description of the surroundings. For example: There is a table in the middle of the room, about six feet in front of you.
- ⇒ Use descriptive phrases that relate to sound, smell, and distance when guiding a visually impaired person.
- ⇒ Offer the use of your arm. If your assistance is accepted, the best practice is to offer your elbow and allow the person with the vision disability to direct you. Walk as you normally would.
- ⇒ Guide dogs are working animals and should not be treated as pets.
- ⇒ Do not grab or try to steer the cane of a person with visual impairments.
- ⇒ Always determine the format in which a person with visual impairments wants information such as Braille, large print, audiotape, or computer disk/electronic text. Do not assume what format an individual uses or prefers.
- ⇒ Direct your comments, questions or concerns to the person with a visual impairment, not to his or her companion.
(Abridged from “Basic Etiquette: People with Visual Impairments,” National Center on Workforce and Disability, www.onestops.info)

For further information:

- ⇒ American Council of the Blind – www.acb.org
- ⇒ American Foundation for the Blind – www.afb.org
- ⇒ Canadian National Institute for the Blind – www.cnib.ca
- ⇒ Canadian Council of the Blind – www.ccbnational.org

Tips—Mobility Impairments

- ⇒ Assist people in wheelchairs to be as independent as possible by helping them only when they request it. If they appear to need help, ask before helping.
- ⇒ If it is necessary to transport a person in a wheelchair up or down stairs, lift only where and how you are instructed to lift. It is easy to tip people out of their wheelchairs. Their disabilities often prevent them from protecting themselves, and the end result could be serious injury.
- ⇒ If you are going to converse for a fair amount of time (two minutes or more) with someone sitting in a wheelchair, try to seat yourself so you are talking at eye level.
- ⇒ Make sure you speak directly to the person in the wheelchair and not just to the able-bodied friend who may be there too.
- ⇒ If you are planning an outing, make sure that the destination is barrier-free to avoid embarrassment for people who use wheelchairs or have other special needs.

For further information:

- ⇒ Click on “Accessibility and Awareness Resources” on the DC website – www.crcdisabilityconcerns.org
- ⇒ Molli Brunsting, Regional Advocate for classis Grandville, has a below the knee prosthesis, mollibrun@aol.com
- ⇒ Congregational Accessibility Network – www.accessibilitynetwork.net
- ⇒ Click on “Religion and Disability Program” then click on “Accessible Congregations Campaign” – www.nod.org
- ⇒ Search for “Building Accessibility Resources” – www.joniandfriends.org
- ⇒ United States Access Board, includes Am. with Disabilities Act Architectural Guidelines – www.access-board.gov
- ⇒ Search for “Accessibility” to find Canadian accessibility guidelines – www.tbs-sct.gc.ca

Tips—Mental Illness

- ⇒ Greet the person normally, making brief eye contact with “Hello” and the person’s name.
- ⇒ Avoid asking, “How are you doing?” or “How do you feel?” These phrases are extremely painful, especially when other people are present.
- ⇒ Don’t be afraid to make “small talk.”
- ⇒ “I’m glad to see you,” is one of the most helpful phrases.
- ⇒ Do not push or pressure other people when they say they cannot do something you ask them to do.
- ⇒ Listen when they try to talk about their difficulty. It’s important to them that you know and care.
- ⇒ Do not try to make light of the difficulty. It may seem like a small problem to you, but it is a big problem to them.
- ⇒ Do not try to determine what people can or cannot do from what you observe them doing. Sometimes people can do things in one environment that they cannot do in another.
- ⇒ Above all, realize that most people are doing the best they can at any given moment with the abilities they have and in the environment surrounding them.

For further information:

- ⇒ Canadian Mental Health Association – www.cmha.ca
- ⇒ Mennonite Central Committee, Mental Health and Disabilities – www.mcc.org/canada/health
- ⇒ Pathways to Promise: Ministry and Mental Illness – www.pathways2promise.org
- ⇒ National Alliance on Mental Illness – www.nami.org
- ⇒ Salem Christian Mental Health Association – www.salem.on.ca

Tips—Dementia

- ⇒ Be patient and calm.
- ⇒ Touch is very important.
- ⇒ Don't use baby talk.
- ⇒ Really listen to what she is trying to say.
- ⇒ Think about the feelings behind the words she is trying to say.
- ⇒ If he looks angry or upset, then ask him if he is.
- ⇒ Treat her with dignity and respect.
- ⇒ Don't argue with her. Don't try to reason with her.
- ⇒ Don't say "I just told you that." Just repeat the answer you have already given him.
- ⇒ Don't ask her to remember things that happened in the past. Talk about what you remember or know happened and how she was a part of it. (Adapted from J. Frank Broyles, *Coach Broyles' Playbook for Alzheimer's Caregivers*.)

For further information:

- ⇒ Contact Elly Van Alten, Regional Advocate for classis Alberta North, ellyv@telus.net
- ⇒ Alzheimer's Association – www.alz.org
- ⇒ Alzheimer Society Canada – www.alzheimer.ca

Tips—Child with a Disability

- ⇒ Ask these parents about their child and allow them to talk, or respect their wishes not to talk at that time.
- ⇒ Realize that life with a child who has a disability is extremely difficult mentally, physically, and emotionally, regardless of how passive the child appears to be out in public.
- ⇒ Realize that the parents are doing the best they possibly can under the given circumstances.
- ⇒ Ask the parents, or someone who knows them, if there is any way you can lend a helping hand.
- ⇒ See to it that your church welcomes children with disabilities and accepts responsibility for their spiritual, educational and social needs.

For further information:

- ⇒ *Autism and Your Church* by Barbara Newman
- ⇒ Friendship Ministries – www.friendship.org
- ⇒ *Helping Kids Include Kids with Disabilities* by Barbara Newman
- ⇒ National Dissemination Center for Children with Disabilities – www.nichcy.org
- ⇒ “Welcome to Holland” by Emily Perl Kingsley – www.our-kids.org/Archives/Holland.html. The author compares having a child with a disability to planning a trip to Italy and discovering you arrived in Holland.

Tips—Autism

Common characteristics of people with Autism Spectrum Disorder (Source: Autism Society of America)

- ⇒ Lack of or delay in spoken language
- ⇒ Repetitive use of language and/or motor mechanisms (e.g., hand-flapping, twirling objects)
- ⇒ Little or no eye contact
- ⇒ Lack of interest in peer relationships
- ⇒ Lack of spontaneous or make-believe play
- ⇒ Persistent fixation on parts of objects

Relating with a Person with Autism

- ⇒ Give a normal greeting with brief eye contact, whether or not a response is forthcoming or possible. Say the person's name when greeting him/her.
- ⇒ Offer, but don't demand, a handshake.
- ⇒ Aides/helpers necessary for Sunday school, small-group meetings.
- ⇒ Routine is very important for many autistic people. Surprises are often scary.
- ⇒ Confusion may be expressed as anger.
- ⇒ Sudden, loud noises—including unexpected applause—may cause fear.
- ⇒ Remember that for some people certain sensations that most people take for granted are distasteful or even painful.

For further information:

- ⇒ *Autism and Your Church*, by Barbara Newman
- ⇒ The Gray Center for Social Learning and Understanding – www.thegraycenter.org
- ⇒ *Autism and Faith: A Journey into Community*, edited by Mary Beth Walsh, Alice F. Walsh, William C. Gaventa

Tips—Cognitive Impairments

- ⇒ Get to know him as an individual with his own personality, likes and dislikes. Do not assume what he can or cannot do.
- ⇒ Extend common courtesies such as shaking hands.
- ⇒ If you are having difficulty understanding what he is saying, ask him to repeat, rather than pretending to understand.
- ⇒ Have a family or individual within the congregation welcome and sit with the adult who has a cognitive impairment in worship and assist if needed.
- ⇒ Think of her by chronological age rather than mental age or cognitive ability. Treat adults as adults.
- ⇒ Do not refer to them as “kids” or with cute names such as “God’s special people.” Just show respect and love.
- ⇒ Include children or adults with cognitive impairments in as many church programs as possible.
- ⇒ Encourage him to use the gifts God has given to him. Ways to serve can include testimonies, hospitality, prayer partners, singing in the choir, reader for scripture or litany (rehearsal may be needed), dramas or dance.
- ⇒ Liturgies that allow participation without a lot of reading are helpful. Also helpful are repetitive phrases such as “Lord, have mercy,” and “Thanks be to God.”

For further information:

- ⇒ Friendship Ministries - www.friendship.org. Friendship programs are great ways to prepare people with cognitive impairments for fuller participation in worship, the sacraments, and full church membership.
- ⇒ *Helping Kids Include Kids with Disabilities*, by Barbara Newman.
- ⇒ *Including People with Disabilities in Faith Communities*, by Erik W. Carter
- ⇒ *Building a Developmental Disability Ministry: A Manual for Congregations* by Bethesda Lutheran Homes and Services

Tips for Preventing Negative Behavior

- ⇒ Listen. Be flexible. Use a lot of positive encouragement.
 - ⇒ Give 5 minute warnings when switching between activities
 - ⇒ Limit visual and auditory distractions. Head phones can work great!
 - ⇒ Have a safe, structured, predictable environment
 - ⇒ Allow the person 5 seconds to respond after giving a direction
 - ⇒ Have a space that the person can go to when they begin to lose control
 - ⇒ Expect the person to be respectful
 - ⇒ Avoid power struggles; give the person some choices
 - ⇒ Talk with the person and/or their family for suggestions on how to deal with the behaviors. Develop a plan on how to deal with the behavior when it happens. Talk about behavior expectations for classroom/youth group. Agree on a “secret” sign from the leader to help settle the person before behavior gets out of hand.
 - ⇒ What is happening when the behavior occurs? What can be done to avoid that situation in the future?
 - ⇒ Explain to the person why the behavior is unacceptable when everyone is calm and ready to listen. Work with the person for finding acceptable consequences.
 - ⇒ Try ignoring negative behavior when it occurs if it is not dangerous. Sometimes it is attention seeking
 - ⇒ Look at the environment! Some things that many people never notice can really bother people (especially those with an autism spectrum disorder, or sensory integration dysfunction). For example, the humming of florescent lights, the scent of someone’s body wash, the feel of a tag on the inside of their shirt or the breeze on their skin, etc.
- (Adapted from Ashley Peterson, *Disability Resource Manual: A Practical Guide for Churches and Church Leaders*, Appendix D. To view, search for “Disability Resource Manual” at www.covchurch.org.)

Respite Care—Caring for the Care-givers

- ⇒ Doing the scheduling for caregivers of persons with disabilities is one of the most onerous jobs. Appoint a person to arrange respite care for them.
- ⇒ Help to organize a Circle of Support or Wraparound for the person and his or her family.
- ⇒ Help care for children during worship so parents can worship in a relaxed setting.
- ⇒ Be available for child care or to take children of single-parent families on outings.

Consider the specific tasks that people with disabilities (or their caregivers) face from day to day. Find ways to give assistance.

- ⇒ Physical Tasks – eating differently, dealing with medical staff, using a walker
- ⇒ Social Tasks – overcoming isolation, belonging. One simple action could be to send a card, preferably a “blank” one, in which you write a message expressing your support.
- ⇒ Psychological Tasks – self-esteem, talking about one’s feelings
- ⇒ Spiritual Tasks – faith, hope, meaning for life, connection with God. Avoid any pretence of “knowing why God did this [tragic] thing. References to God’s plan or intention or other interpretation of tragic events are painful in most cases.

For further information:

- ⇒ *Beyond Casseroles: 505 Ways to Encourage a Chronically Ill Friend* by Lisa J. Copen
- ⇒ *A Compassionate Journey: Coming Alongside People with Disabilities or Chronic Illnesses* by John G. Cook
- ⇒ Wraparound information: www.rtc.pdx.edu/nwi
- ⇒ A web-based system to organize meals and other help for families: www.carecalendar.org

Accessibility Audit Guide for Churches

Reducing Barriers of Attitude:

- 🍏 People with disabilities and their caregivers have been asked whether they feel welcome in worship, leadership, and church programs.
- 🍏 People with disabilities serve on congregational committees or in other leadership roles.
- 🍏 Our church has a committee and/or Church Disability Advocate so that people with disabilities can offer suggestions for reducing barriers without being made to feel like complainers.
- 🍏 Our church has an annual Disability Awareness Sunday and/or other awareness training for the congregation.
- 🍏 People with disabilities are encouraged to participate in the life of the church (for example, to attend social events, participate in service projects, be involved in small groups).
- 🍏 Ushers, Sunday School Teachers, Youth Group, Cadet, and GEMS leaders have been instructed regarding appropriate ways to greet and meet the needs of people with disabilities.
- 🍏 Transportation is offered for people with disabilities who can not drive.
- 🍏 The church library includes resources about various disabling conditions.
- 🍏 Our church is intentional about including people with disabilities by adopting the Church Policy on Disabilities.
- 🍏 Private discussions with particular attendees concerning their disabilities have identified unique requirements not covered by normal solutions. Be creative and improvise so that all individuals may worship in comfort.

Reducing Barriers of Communication:

- 🍏 Our church has assistive listening devices (Infrared, loop or FM) available for people with hearing impairments.

Audit Guide continued on pages 26 and 27.

Audit Guide continued from page 25:

- 🍏 Sign language interpretation is provided when prior arrangements have been made.
- 🍏 The overall lighting is adequate for signing or for individuals with low vision.
- 🍏 Songbooks, Bibles, bulletins and handouts are available in alternative format (large print and Braille, when requested in advance) and are displayed where they are readily accessible.
- 🍏 Written copies of the current sermon and of all spoken parts of the service are available for people with impaired hearing, and captioning is used with visual projection.

Reducing Barriers of Architecture and Environment:

- 🍏 Accessible parking is provided. The path to church is barrier free with no gravel or curbs, and is not blocked by other parked cars.
- 🍏 The main entrance door is automatic.
- 🍏 Entrance and hallways are free from barriers which can halt a wheelchair such as door bases, grates, and thick mats.
- 🍏 Door handles are lever style on all inside doors, not round knobs.
- 🍏 A ramp allows access into the building which has a slope no greater than a 1:12 rise and is no less than 36 inches (0.91 metres) wide with a smooth handrail 32 inches (0.81 metres) above the ramp.
- 🍏 Doors to rooms, especially washrooms, are a minimum 36 inches (0.91 metres) in width.
- 🍏 All public sinks have lever style handles or automatic motion sensors.
- 🍏 Towel dispensers or other hand drying items are reachable from a sitting position (no higher than 40" (1 metre) from the floor).
- 🍏 Proper handrails are installed in all toilet areas for assisting in transfer and standing. All rails are at hospital fixture height. All sink area fixtures and cabinets allow for knee access.

- 🍏 At least one toilet stall has space next to the toilet for side transfer, and has room to turn a large, power wheelchair around. Even better: an accessible, unisex bathroom.
- 🍏 Light switches, phones, phone books, etc., are placed at a level for wheelchair accessibility.
- 🍏 Coat racks are useable for all people.
- 🍏 All floors of the building are accessible from the inside.
- 🍏 Elevator/lift is big enough to accommodate two people.
- 🍏 People who use wheelchairs have a choice where to sit in the sanctuary besides the very front and the very back.
- 🍏 The main pulpit area is accessible.
- 🍏 Church mailboxes are accessible.
- 🍏 Bold signage at the very least indicates location of elevator and accessible restrooms.
- 🍏 Bright tape or paint on stairs aids visual perception.
- 🍏 Worshipers are asked to make church functions "fragrance free" and urged to refrain from wearing perfume and after-shave. Unscented candles, soaps, detergents, cleaning supplies, air fresheners, and facial tissues are used exclusively.
- 🍏 The air filters on the furnace/air conditioning units are changed as directed.

A Questionnaire For Parents Of Children With Disabilities

This questionnaire is a tool to use in talking with parents to understand their needs for assistance from the Christian community. Listed below are suggestions for assistance that could possibly help a family with basic needs they might have in caring for their children who have disabilities. These are questions parents helped to formulate when they were asked what their church should do to help them.

1. Can we assist you with respite care?
 - Time away with your spouse
 - Time with other family members
 - Time for some of your favorite hobbies
 - Time to serve others, using your gifts
 - Time to sit in church together as a family
 - Time for your child to have social outings with others
 - Other? Please list

2. Can we assist you with household chores?
 - General housecleaning duties
 - Outside chores, lawn mowing, leaf raking, etc.
 - Meals brought in, how often?
 - Baked goods brought in, how often?
 - Grocery shopping
 - Others? Please list

3. Can we assist you with transportation?
 - Transportation for medical appointments
 - Help with car maintenance
 - Transportation to recreational or other social events
 - Rides to church functions
 - Others? Please list

4. Can we assist you in the following ways:
 - Someone to inquire for you regarding medical opinions
 - Someone to help you with insurance issues
 - Someone to help writing letters seeking state/federal aid
 - Someone to give you spiritual support during doctor appointments
 - Someone to be your advocate, to visit you, how often?
 - Is the church nursery adequate to meet your family's needs?
 - Others? Please list

5. Can we assist you with financial support?
 - Help to defray disability expenses
 - Regular visits from the deacons, how often?
 - Payment for your child at camp for disabled children
 - Professional estate planning
 - Others? Please list

6. Can we assist you to become more involved in church life?
 - Serve on a committee
 - Teach Sunday school
 - Worship team, usher, greeter, or other Sunday morning activity
 - Help with nursery
 - Join a Bible study group, couples' group, etc.
 - Would you need respite care to do this?
 - Other? Please list

Please comment on any other assistance your church should give.

A Questionnaire For People With Disabilities And Care Givers

This questionnaire is a tool to use in talking with people with disabilities and their care givers to understand their needs for assistance from the Christian community. Listed below are suggestions for assistance that could possibly help a family with basic needs they might have in caring for their children who have disabilities. These are questions parents helped to formulate when they were asked what their church should do to help them.

1. Can we assist you with respite care?
 - Time away with your spouse
 - Time with other family members
 - Time for some of your favorite hobbies
 - Time to serve others, using your gifts
 - Time to sit in church together as a family
 - Other? Please list

2. Can we assist you with household chores?
 - General housecleaning duties
 - Outside chores, lawn mowing, leaf raking, etc.
 - Meals brought in, how often?
 - Baked goods brought in, how often?
 - Grocery shopping
 - Others? Please list

3. Can we assist you with transportation?
 - Transportation for medical appointments
 - Help with car maintenance
 - Transportation to recreational or other social events
 - Rides to church functions
 - Others? Please list

4. Can we assist you in the following ways:
 - Someone to inquire for you regarding medical opinions
 - Someone to help you with insurance issues
 - Someone to help writing letters seeking state/federal aid
 - Someone to give you spiritual support during doctor appointments
 - Someone to be your advocate, to visit you, how often?
 - Others? Please list

5. Can we assist you with financial support?
 - Help to defray disability expenses
 - Regular visits from the deacons, how often?
 - Professional estate planning
 - Others? Please list

6. Can we assist you to become more involved in church life?
 - Serve on a committee
 - Teach Sunday school
 - Worship team, usher, greeter, or other Sunday morning activity
 - Help with nursery
 - Join a Bible study group, couples' group, etc.
 - Would you need respite care to do this?
 - Other? Please list

Please comment on any other assistance your church should give.

Church Policy on Disabilities

In keeping with biblical teachings, with our doctrinal standards, and with various decisions of the synods of the Christian Reformed Church in North America regarding people with disabilities we, the council of _____, adopt the following policy.

1. In this church of Christ we value people with disabilities, like all other people, as created in the image of God, as partners to his covenant and as subjects in his kingdom.
2. We consider all people, those with and without disabilities, to have gifts from the Holy Spirit, and we encourage them all to enrich congregational life by practicing their faith and using their gifts and talents in worship, service, study and leadership.
3. We will endeavor to integrate people with disabilities into all programs and activities sponsored by the church. This includes worship services, church education, support groups, study and prayer groups, book clubs, and sports activities, etc...
4. We will ascertain and attend to the special spiritual, physical and psychological needs of those affected by disabilities, and will offer training to office bearers to deal with disability issues and to raise awareness in our congregation.
5. We will modify any policy, practice, procedure or architecture that tends to exclude people with disabilities from any aspect of congregational life.

Church Advocate Job Description

The Church Advocate is a volunteer who seeks to promote the full inclusion of persons with disabilities in the life of the local congregation.

As time, talents, and opportunities permit, this task is done by

- ⇒ Identifying the needs of church members affected by disabilities and informing appropriate church leaders of those needs;
- ⇒ Encouraging the inclusion of those members in the life of the church so that their God-given abilities are utilized fully;
- ⇒ Being in communication with the Regional Advocate who in turn is supported by the staff of Disability Concerns;
- ⇒ Helping people with disabilities and their families find resources for counseling, advocacy, and other agencies that provide information and legal and financial support, including support from governmental sources at all levels;
- ⇒ Offering Disability Concerns resources to the congregation, including the distribution of *Breaking Barriers*;
- ⇒ Participating in the Disability Concerns network, especially training opportunities.

For further information:

- ⇒ Contact your Regional Advocate who has additional resources and may know or be able to help you find local resources.

Regional Advocate Job Description

The Regional Advocate is a volunteer who promotes the full inclusion of persons with disabilities in the life of the congregations in a specific geographical area, usually a classis.

As time, talents, and opportunities permit, this task is done by

- ⇒ Advocating for people affected by disabilities.
- ⇒ Participating in recommended training.
- ⇒ Enlisting a Church Advocate in each congregation to be an indispensable link in the Disability Concerns network.
- ⇒ Providing training, resources, and regular encouragement to the Church Advocates, making sure *Breaking Barriers* and other resources are available to the congregations.
- ⇒ Making regular reports to the classis either in writing or in person.
- ⇒ Promoting the ministry through speaking, writing and personal contacts.
- ⇒ Providing training of office bearers, especially as this pertains to pastoral care.
- ⇒ Assessing needs and resources, assisting in accessibility audits of church facilities and providing information and advice.
- ⇒ Helping people with disabilities and their families find resources for counseling, advocacy, and other agencies that provide information and legal and financial support, including support from governmental sources at all levels.

Agency Advocate Job Description

The Agency Advocate is a volunteer who promotes the full inclusion of persons with disabilities in all aspects of the Christian Reformed agency's ministry.

This task includes:

- ⇒ Participation in interaction with Regional Advocates/Consultants in an annual training event
- ⇒ Being fully conversant with the services and resources offered by the Disability Concerns ministry
- ⇒ Promoting the removal of all barriers to employment or participation in the agency's work and vision
- ⇒ Promoting the full inclusion of persons with disabilities in the material taught and distributed by the agency
- ⇒ Providing links to counseling, advocacy and outside agencies that provide information and legal and financial support

Additional Resources

Anabaptist Disabilities Network – www.adnetonline.org

Bethesda Lutheran Homes and Services – www.blhs.org

Calvin Institute of Christian Worship – Has a variety of worship and caring resources for ministry with people with disabilities and people with Post Traumatic Stress Disorder. Go to www.calvin.edu/worship/ then click on “A-Z Index.”

Center for Religion and Disability –
www.religionanddisability.org

Christian Horizons – www.christian-horizons.org

Christian Learning Center Network – www.clcnetwork.org

Deaf Opportunity Outreach – www.doorinternational.com

Disability Ministries of the Evangelical Lutheran Church of America – www.elca.org/disability

Disaboom – www.disaboom.com, a for-profit website with information on disabilities and accessibility

Episcopal Disability Network – www.disability99.org

Friendship Ministries – www.friendship.org

Joni and Friends – www.joniandfriends.org

Mennonite Central Committee, Mental Health and Disabilities –
www.mcc.org/canada/health

National Dissemination Center for Children with Disabilities
www.nichcy.org

Notes

The most important resources are local people and organizations. Please use the space below for noting the resources in your area.