



Pioneers and Prophets: Moving Toward the Inclusive Church

Table of Contents

Pioneers and Prophets: Introduction.....

Beyond Disability Inclusion Sunday.....

Worship Resources

 Call to Worship

 (2006)

 Rev. Robin Lostetter (2008)

 Sarah Nettleton (2014)

 Prayer of Confession

 Rev. Donna Whitmore (2009)

 Rev. Mary Austin (2011)

 Rev. Rick Roderick (2014)

 Prayer of the People

 Rev. Raymond Meester (2013)

 Rev. Dr. Timothy Little (2014)

 A Litany of Inclusion.....Rev. Jo Taliaferro (2013)

 A Litany of Thanksgiving.....Rev. Bebe Baldwin (2006)

 Affirmation of Faith

 Rev. Raymond Meester (2014)

 Rev. Rick Roderick (2014)

 Scripture Suggestions.....Rev. Bebe Baldwin (2014)

 Hymn Suggestions.....Cindy Merten (2014)

 Benediction

 Terry Chaney (2013)

 Rev. Ernest Krug, M.D. (2013)

 Lisa Larges (2014)

 Access Your Heart.....Sarah Nettleton (2011)

 God In Us.....Sarah Nettleton (2011)

 A Planning Process for a Rejoicing Spirits Community.....Rev. John Judson (2013)

 Litany for Rejoicing Spirits Service.....Terry Chaney (2013)

 Worship Rituals and Practices.....Cindy Merten (2013)

 Baptismal Liturgy; Adapted by..... Rev. Amy Morgan (2016)

 for the Rejoicing Spirits worship,

 First Presbyterian Church, Birmingham, Michigan

 Baptizing Ricky.....Cindy Merten (2016)



PRESBYTERIANS FOR DISABILITY CONCERNS

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Disability Awareness

- An Affirmation.....Rev. Don Milloy (2012)
- The Fix, Cure, and Kill SyndromeRev. Sue Montgomery (2008)
- People First Language.....Kathy Snow (2011)
- Interdependence, A Biblical Concept.....Rev. Rick Roderick (2009)

Inclusion

- Be With God.....Rev. Joanne Blair (2016)
- Alternative Formats, A Tool for Full Inclusion.....Rev. Rick Roderick (2007)
- A Congregation, My Journey through Accessibility
and Accommodations.....Rev. Rick Roderick (2016)

Advocacy

- Advocacy: a Young Person's Perspective.....Sarah Nettleton (2007)
- Advocacy: a Mother's Perspective.....Susan Nettleton (2007, revised 2016)

Veterans: The Wounds of War

- The Church and Moral Injury.....Amy Blumenshine (2016)
- Walking with Wounded Warriors.....Presbyterian News Service (2012)

Families, Children, and Youth

- Ten Things Your Student with Autism Wishes You Knew.....Ellen Notbohn (2011)
- The Word in Action.....Rev. Tammy Rider (2006)
- Confirmation: Tools for Inclusion.....Cindy Merten (2011)
- Tips for Church School Teachers: Working with Children
Who Have High Energy and/or Challenges with Focusing
and Staying on Task.....Lynn Cox (2011)
- My Faith Journey.....Cameron Scott (2014)

Aging

- Journeying Well During Your Later Years.....Trish Herbert (2012)
- Letting Go: A Mother's Story.....Roxanne Ezell (2012)
- Facets of Aging and Disability:
A Vision for Community, Dignity, and Well Being.....Milton Tyree (2012)

Pastoral Care

- Healing vs. Curing: Reflections for Pastoral Caregivers...Rev. Bebe Baldwin (2008)
- Practical Guidelines for Starting a Circle of Friends
within Your Faith Community.....Rev. Donna Whitmore (2008)
- Dementia as Disability.....Rev. Mary Austin (2012)



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Mental Illness

Created in the Image of God.....Cathy Smith (2016)

No Room in the Inn: Ellen's Story.....Rev. Bebe Baldwin (2016)



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Pioneers and Prophets: Moving Toward the Inclusive Church

Presbyterians for Disability Concerns is offering our 2016 Disability Inclusion Sunday resources with thanksgiving and a challenge. We give thanks for the pioneers who had a vision of a church that welcomes people with all abilities. Our challenge is for each of us to join in a prophetic ministry that affirms that every person is created in the image of God and has gifts to bring to the church.

Presbyterians for Disability Concerns (PDC) was born out of the life experiences of Presbyterians who remained faithful to their calling as Christians even as they faced barriers in their churches and communities. One of these early pioneers was Nancy Jennings, one of the first PDC moderators. Nancy lived with seizures and encountered the fear and prejudice of people who believed that she had an “evil eye.” Some neighbors refused to allow their children to play with Nancy’s children because they believed that she was demon possessed. Every year we honor Nancy’s courage and faithfulness by presenting the Nancy Jennings Award to an individual or group that exemplifies her commitment.

Since its organization as a caucus in 1981 and its inclusion as a network of the Presbyterian Health, Education & Welfare Association (PHEWA) in 1987, PDC has spoken with clarity and courage to change attitudes and to advocate for inclusion of people with disabilities in worship, education, service, fellowship, and leadership in the church. Each year, beginning in 2002, we have offered resources for Disability Inclusion Sunday which we celebrate this year on June 12. We have developed and collected excellent resources but this year, the PDC leadership team chose to bring together some of the outstanding worship resources, articles, and stories from past years. A few first-time articles address urgent issues facing our churches and communities.

Among our most utilized resources are our suggestions for worship. We are privileged this year to include an adaptation of the baptismal liturgy by the Rev. Amy Morgan of First Presbyterian Church in Birmingham, Michigan, and the story behind the service.

The editorial committee has chosen articles and stories that inform ministry, stimulate creativity, and model strategies for inclusion.

Disability Awareness offers a foundation for ministry and includes articles helpful for people struggling with the onset of disabilities.



A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Inclusion focuses this year on adjustment to blindness and that connection and relationship are basic to inclusion.

Advocacy pairs the experience of one young person with that of her mother's.

Veterans: The Wounds of War challenges the church to respond to the needs of veterans and their families in a first-time article, "The Church and Military Moral Injury."

Families, Children, and Youth gives very practical tools for ministry along with two incredibly moving personal stories.

Aging invites older people into a creative journey.

Pastoral Care begins with a vision of wholeness and continues with practical suggestions for pastoral caregivers.

Mental Illness presents a beautiful article by a woman who lives with serious mental illness and concludes with a new article on a tragic problem facing our society.

We are able to include only a sample of the excellent work contributed by our writers. To access the complete packets from 2010-2015, go to <https://www.presbyterianmission.org/ministries/phewa/presbyterians-disability-concerns/> and <http://www.phewacomunity.org/pdcdisabilityconcerns/pdcresources.html>.

Disability Inclusion Sunday is only a beginning. We believe that God is "about to do a new thing." (Isa. 43:19) So let us join the pioneers in a prophetic ministry that proclaims that all persons are created in the image of God and are valued members of the body of Christ. We challenge you to make every Sunday – and every day of every week – a day when no one is excluded, when all are welcomed. Only then will the church be healed and the Body will be whole. Thanks be to God!



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Beyond Disability Inclusion Sunday

Did you know that the Presbyterian Church (U.S.A.) has a policy that calls every church body to include people with disabilities in its life and leadership? In **2006** the PC(USA) General Assembly approved [*Living into the Body of Christ: Towards Full Inclusion of People with Disabilities*](#). The church it envisions treasures the gifts of every person and eliminates barriers to inclusion in our faith communities and society.

Unfortunately, it is often easier to pass policies than to implement them. *Better Together: Transformed by God's Variety of Gifts* was developed to move the policy into action. This four session study guide includes Bible study that calls us to be inclusive, true stories about real people and the barriers they faced (and sometimes overcame), questions for lively discussion, case studies that challenge our creativity, and a “tool box” with practical strategies for inclusion.

A committed team of disability advocates from PDC, the Office of the General Assembly, the Presbyterian Publishing Corporation, the Presbyterian Investment and Loan Program, the Presbyterian Foundation, and the Presbyterian Mission Agency worked together to design *Better Together*.

We recommend the course for adult study and fellowship groups, intergenerational groups, leadership training, and more. *Better Together* is available online at: <https://www.pcusa.org/resource/better-together-transformed-gods-variety-gifts/>

If you would like more information on how to use *Better Together* in your own setting, call upon our PHEWA staff persons, Susan Stack (800) 728-7228, x5800 or [Send email](#), or email [the Rev. Trina Zelle](#).



Call to Worship

One: Gather around, people of God,

All: Members of God's household,

One: Welcome all who are members of this body—

All: Of all nationalities, and races,

One: With our abilities and limitations,

All: Women and men,

One: Rich and poor—

All: Are members of God's household,

One: Drinking from the one Spirit.

All: Come, let us worship our God.

Responsive Call to Worship

*(adapted from June 22, 2008 lections: Jer 20:13; Ps 69:4; Gen 21:17-20; Mt 10:29-31;
Ps 86:7, 10, 12)*

One: Sing to the LORD;
praise the LORD!
for God is our deliverer.

**All: More in number than the hairs of my head
are those who hate me without cause;
many are those who would destroy me,**

One: Yet God opens eyes blinded by fear,
and abides with those who are marginalized.

**All: I will not be afraid,
for my life is cherished by God,
the living God who values even the sparrow.**



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

One: I have called on God, who will answer me,
the Holy One, who alone is God.

**All: I give thanks to you, O Lord my God,
with my whole being,
and I will glorify your name forever.**

The Rev. Robin Lostetter, 2008 PDC Leadership Team member

Call to Worship

One: God calls us to gather together.

All: We gather together to worship.

One: God calls us to sing praise.

All: We sing together in praise.

One: God calls us to pray.

All: We gather together for worship, for praise, and for prayer.

One: Sing praise as we gather together for worship.

All: Alleluia! Let us worship our Lord.

Sarah Nettleton

Prayer of Confession

We confess, oh God, that we have so often been preoccupied by our own interests. We have not sought to hear your voice or follow your example. We confess the ways we have failed to show love, mercy and compassion to others. We have ignored the touch of those seeking to know and be known, we have been indifferent to others' calls for inclusion and participation and tuned out cries for justice.

God of infinite tenderness and strong compassion, weave your will into the fabric of our lives and our community of faith. Give us a new heart. Use us to touch the lives of others walking lonely roads, those who are brokenhearted because they have been ignored and labeled as "needy" rather than as "bearers of the image of God." Open our hearts that we may celebrate the dignity of all. And, Dear God, may our lives echo your desire that all might have life and have it to the fullest. In Jesus' name, Amen

The Rev. Donna Whitmore

Prayer of Confession

O God, you have made us all in your image, and in your sight we all have ability and disability. We confess that we have failed to see our disabilities. We have been blind to each other's needs, clumsy in our walk to help each other, deaf to another's pain. We confess that we have failed to see our abilities, our strength of character, our lively courage, our loving spirits. We have ignored the gifts you gave us, and been ashamed of who we are. We forget that you made us all as your reflection, and that all of us belong to you, and show the world your image. Forgive us, O God, and claim us all again as your children. Amen.

The Rev. Mary Austin

Prayer of Confession

Although we see ourselves as open-minded, we often close ourselves off to many who are in our midst. We don't see the importance of people whom we perceive as different from us. May God help us to see both the needs and gifts that others offer to the Church, in general, and to our congregations, in particular. Amen.

The Rev. Rick Roderick

Prayer for the People

Creator God, we praise you that you have made your people
a diverse group, a world of different races, genders, and nationalities,
We are young and old, people of various gifts and abilities,
temporarily able-bodied and persons with disabilities.
Help us to be appreciative of, and not fearful of, the wonderful diversity of your world.
Persuade your church to never reject or neglect any of your people.
May we not be the eye that says to the ear,
“Because you do not hear, you are not a part of us,”
nor the body to the legs,
“Because you cannot walk, you have nothing to offer us.”
As Jesus sought to tear down the walls that divide us,
make us more determined to remove those barriers, physical and attitudinal,
which prevent your people from participating in and contributing to your church.
May we not only welcome, but also include, all of your people
in the ministries of your church.
Help us to see the gifts in each other,
to value those gifts that the Holy Spirit has given to all,
and to encourage the use of God-given gifts
for the church and the world,
for your glory and for the edification of the church.
Help us, as your church, to be not only an example of—
but also an advocate for—inclusion.
May we set before the world your vision of the day when
“The eyes of the blind shall be opened,
and the ears of the deaf unstopped;
the lame shall leap like a deer
and the tongue of the speechless sing for joy.”
Help your church to understand that it is in including people
that people experience healing and wholeness.
May we be your hands so that your healing power may work through us and in us.
We pray for all your people who are suffering,
for those who are homeless, who are hungry, who are poor, the orphan, the refugee,
the victims of violence.
Make us your caregivers in ministering not just to, but also with your people
so that all may enjoy the riches of your earth.
We pray in the name of Jesus, our Lord. Amen.

The Rev. Raymond Meester



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Prayer of the People

Father Mother GOD, we gather in this sacred space to affirm again, together, our commitment to be your faithful servants. Give us courage to truly welcome all of your people, both the old and the young, the rich and the poor, those who believe they have no disability, and those who experience daily the challenge of living creatively with a physical, mental, or spiritual disabling condition. Help all of us to be open to confess our shortcomings and with gratitude, receive your embracing love and acceptance. As we gather in this INCLUSION Sunday Celebration, help us to renew again our sensitivities to those who are challenged by a disabling condition. Help us to be proactive in planning ways to make the path of life easier for all of your people. Help us especially to remember that we need to befriend our neighbors, not only when it is convenient, but throughout the day and the week. Teach us again and again how to be faithful in being instruments of your redeeming love. It is with gratitude that we place ourselves in your everlasting and powerful hands. Amen

The Rev. Dr. Timothy H. Little

A Litany of Inclusion

Leader: The earth is yours, O Lord, the world and all who dwell on the planet.

People: You have given us the privilege of caring for the earth and each other from the smallest to the greatest of all creatures. You command us to love neighbor and self, teaching us in story and parable how to do so.

Leader: By example you sent your only son, Jesus, as a little child when we wanted a conqueror, one who would rout the enemy, glorify the chosen, defeating forever, all but the worthy.

People: Jesus grew in stature and wisdom, teaching, healing, encountering people where they were, no matter their race, gender or ability.

Leader: Have we not heard? Have we not known? We are the ones to help the wounded stranger left for dead beside the road, to stretch out the hands of the leper and invite the beggar without sight to our homes.

People: We are compelled to love the neighbor who cannot love in return and to show by our actions that love means getting our hands dirty, working, worshiping and going to Sunday school with neighbors unable to read, unable to comprehend, unable to express themselves except by sounds we call disruptive.

Leader: We are the reticent, the fearful, and the patronizing, believing that if we use only our dollars to build ramps and widen doors, we may be missing the need to intentionally cultivate relationships with people in wheelchairs, scooters, or partnered with service animals.

People: We want to do the right thing: to go shopping with the person who is autistic, to incorporate the person with dementia or Alzheimer's into our lives, our communities, our churches, and to embrace veterans needing to talk of war, of lost loved ones in combat, of the PTSD that plagues them, and the flashbacks that come when least expected.

Leader: People with disabilities are our mothers, our fathers, our children, our teachers, our pastors.

People: We advocate for family members, cry out for justice and inclusion when our loved ones are shunned, bullied, set aside, impeded by the behaviors and attitudes of neighbors with good intentions.

Leader: God calls us to do the same for ALL people, to be the one who lowers the paralyzed man through the roof or describes scenes in a movie to the person without eyesight.

People: I, as one person, with or without a disability, can make a difference. I can learn to embrace disability in myself, to turn my attitudes into acts of inclusion praising God for technologies that enhance or bestow new ability. I can spread the good news about hearing devices, phones that talk, eReaders that speak curriculum, church bulletins, bibles, newspapers and restaurant menus.

Leader: I will adapt to a new norm of inclusiveness of all God's people. I will welcome the stranger as neighbor and not cast out those who manage life differently.

People: For even though you may not know, I, too, have been marginalized, laughed at, judged for difference of opinion, the constant shaking of my hands or the numerous times I have to ask someone to repeat themselves.

Leader: Let us reach out to neighbors across the street and around the globe, as the family of God's own making, the whole body of Christ, including one another because of, rather than in spite of, our diverse adaptations to life's challenges.

People: Let us sing a new song of inclusion where every voice is valued, every note a gift and every gift a hymn and every hymn an exclamation of praise to the triune God, creator, redeemer and sustainer who declares, "I am with you even to the close of the age."

The Rev. Jo Taliaferro



A Litany of Thanksgiving
(Based on I Corinthians 12:4-13)

One: Now there are varieties of gifts, but the same Spirit; and there are varieties of services, but the same Lord; and there are varieties of activities, but it is the same God who activates all of them in everyone. To each is given the manifestation of the Spirit for the common good.

All: Let us celebrate the gifts of all for we are one in Christ.

One: To those who live with disabilities and those who now are able-bodied, God has given gifts to use with joy and thanksgiving.

All: Let us celebrate the gifts of all for we are one in Christ.

One: To some is given the gift of wisdom. We celebrate the wisdom of those who each day face the challenge of full participation in the life of the community. We celebrate the wisdom of those who, through imagination and creativity, use the gifts they have been given.

All: We thank you, O God, for the gift of wisdom.

One: To some is given the gift of knowledge. We celebrate the knowledge of those who discover new gifts in themselves and in others and of those who learn new skills that enable them to use these gifts.

All: We thank you, O God, for the gift of knowledge.

One: To some is given the gift of faith. We celebrate the faith of those who trust in the new life Christ offers and the assurance of God's gracious presence which is freely given to all.

All: We thank you, O God, for the gift of faith.

One: To some is given the gift of healing. We celebrate the healing of our community when we welcome all persons and value their gifts.

All: We thank you, O God, for the gift of healing.

One: Help us, O God, to accept and treasure the gifts of all. We all have limits and we all have gifts to share. Help us to learn new ways to pray, worship, and serve together. Help us to support each other as we work together for the common good.

All: Together we are the Body of Christ. Thanks be to God!

The Rev. Bebe L. Baldwin



Affirmations of Faith

Based on Isaiah 35:5-6; Luke 7:22

Christ Jesus,
though he was in the form of God,
came among us as one of us,
in a form vulnerable to brokenness,
to tear down attitudinal and physical barriers that exclude.
He brought healing and wholeness to those deprived of dignity and self-respect.
He came so that the blind shall walk with confidence,
the deaf shall understand with joy,
the lame shall have full access everywhere,
and the mute shall be heard.
All shall profess that Jesus Christ is Lord of all
and be enabled to serve in God's kingdom!

Based on 1 Corinthians 12

God created us as diverse people,
giving each different gifts to complement each other
as we seek to use our God-given abilities for Christ's body, the church.
In the one Spirit we have all been baptized into one body,
and the Spirit activates gifts for all of God's people.
Such gifts cannot be denied nor neglected,
no more than the hand can say to the foot, "I have no need of you,"
nor the eye declare, "Since I am not an ear, I am not needed."
For all are needed and are to be welcomed in God's kingdom,
as equal partners in service to God.

The Rev. Raymond Meester

We believe in God who created all of us, regardless of ability, education, and religious background, in the Divine image. God enabled Moses and Aaron to work together in an interdependent relationship, so that each of their strengths could be used in Israel's deliverance.

We believe in Jesus Christ who encouraged all the children to come to him, who broke down social barriers, and who cared about people whom society shunned.

We believe in the Holy Spirit who encourages us to bring the Gospel to all people and who enables Christ's ministry of reconciliation and empowerment.

We believe that all people are equal before God and can be used for the establishment of God's rule on earth.

The Rev. Rick Roderick



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Scripture Suggestions Disability Inclusion Sunday

For All the Seasons of Life:

Genesis 1:26-31

Deuteronomy 6:4-9

Psalms 1, 139

Ecclesiastes 3:1-8

I Corinthians 12:4-13

Galatians 3:27-28

Matthew 22:34-40

James 1:5, 3:13-18

For a Focus on Children and Youth:

Exodus 2:1-10

I Samuel 3:1-10

Jeremiah 1:4-10

Luke 2:41-52

Mark 10:13-16

Deuteronomy 6:4-9

For a Focus on Older Adults:

Psalm 71:7-9

Luke 2:25-38

Compiled by the Rev. Bebe Baldwin

The Rev. Bebe Baldwin is a retired member of the Presbytery of the Twin Cities Area.

She serves in the leadership of the Presbyterians for Disability Concerns (PDC)

Network of the Presbyterian Health, Education & Welfare Association (PHEWA), and is

active with the [Presbytery Disability Concerns Ministry](#).



Hymn Suggestions from *Glory to God: The Presbyterian Hymnal*

Published 2013 by Westminster John Knox Press

#3 Womb of Life and Source of Being

Text: Ruth Duck, 1986, 1990, alt.

Music: Skinner Chavez-Melo, 1983

#19 God of Great and God of Small

Text: Natalie Sleeth

Music: Natalie Sleeth, 1973

#27 Sacred the Body

Text: Ruth Duck, 1997

Music: Colin Gibson, 1992

#297 In Christ Called to Baptize

Text: Ruth Duck, 1995

Music: Welsh folk melody; adapt in *Caniadau y Cyssegr*, 1839

#302 When Hands Reach Out and Fingers Trace

Text: Carolyn Winfrey Gillette, 2001

Music: English folk melody; harm. John Weaver, 1988

#372 O for a World

Text: Miriam Therese Winter

Music: Carl Gotthelf Glaser, 1828; arr. Lowell Mason, 1839

#653 Give Thanks to God Who Hears Our Cries

Text: Ruth Duck, 2007

Music: Wyeth's *Repository of Sacred Music, Part Second*, 1813; harm. Richard Proulx, 1975

#692 Spirit, Open My Heart

Text: Ruth Duck, 1994

Music: Irish melody; arr. Alfred V. Fedak, 2011



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

#754 Help Us Accept Each Other

Text: Fred Kaan, 1974

Music: Doreen Potter, 1974

#769 For Everyone Born

Text: Shirley Erena Murray, 1998

Music: Brian Mann, 2006

#770 I'm Gonna Eat at the Welcome Table

Text: African American spiritual, alt.

Music: African American spiritual; arr. Carl Diton, 1980, alt.

#806 I'll Praise My Maker

Text: Isaac Watts, 1719, adapt, John Wesley, 1736, alt.

Music: Attr. Matthaues Greiter, 1525; harm. V. Earle Copes, 1963

#807 When We Must Bear Persistent Pain

Text: Ruth Duck, 2004

Music: Walker's *Southern Harmony*, 1835; harm. David N. Johnson, 1968

#808 When Memory Fails

Text: Mary Louise Bringle, 2000

Music: Jean Sibelius, 1899; arr. *The Hymnal*, 1933, alt.

List compiled by Cindy Merten, *Director of Christian Education and [All Abilities Inclusion Ministry](#), First Presbyterian Church of Birmingham, Michigan (Everybody's Church).*

Benedictions

Let us go forth from this place, striving to know all of our brothers and sisters in the same way as God does.... the God to whom in life and death we belong. May we see and celebrate the gifts of all, as we see the wonder of how God weaves all gifts into the tapestry of life in God's kingdom.

Terry Chaney

Friends, life is short and there is little time to build up others on this journey of faith with Christ. So be quick to love and make haste to be kind to all God's children. In this way, our faithfulness to God's command to love others may be a beacon of light to the world, now and every day. Amen.

The Rev. Ernest Krug, M.D.

Now, by the power of the one who formed you from the dust of the stars,
The source and wellspring of all that is,
Who set a seal upon you,
Who called your name from the beginning of time,
Who knew you and knows you,
Beautiful, beloved, in your whole embodied self,
And by the grace of the one who redeems your life,
The Christ who came to bear a body,
To share all of life with us,
Who knows your shame and pride, your pain and courage,
And who loves you with a love beyond measure,
And by the hope that is in you,
Which is the fire of the Holy Spirit
That burns with an undiminished flame through all the seasons of your life,
By the power and the love and the hope,
Go now and be the power of love,
And share the hope that is in you,
For you are the beloved of God.
Amen.

Lisa Larges



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Access Your Heart

By Sarah R. Nettleton

Please include us.
It hurts to be excluded.
A quick hi and a hug are not enough.
We need real inclusion.
When will you understand?

We are all members of the body of Christ.
Some of us communicate in different ways.
Some of us see differently.
Some of us behave in ways we can't control.
Some of us need wheelchairs.
Some of us walk differently.
Some of us hear less.
Some of us never get to come to church.
Some of us are just left out.

We are all members of Christ's family.
Why can't you be more welcoming?

We are all in need of a church which welcomes and accepts us for who we are.
We are made in God's image.
When you forget to include us you are forgetting to include God.

Access is more than ramps and accessible bathrooms.
The hearts of everyone need to be open and welcoming.
When hearts are open we can really be a family in Christ.

Open your heart.
And let us in.

© Sarah R. Nettleton 2000

Sarah R. Nettleton lives in Fairport, New York. She is a member of PHEWA's Presbyterians for Disability Concerns (PDC) network. She also served on the task force which drafted the policy which became "[Living into the Body of Christ: Towards the Full Inclusion of People With Disabilities](#)," a 2006 social witness policy of the Presbyterian Church (U.S.A.).



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

God in Us

By Sarah R. Nettleton

Please understand we hear God.
We are touched by God's presence.
We see God in others.
We taste the goodness God gives us.
We smell God near us everyday.

Please let us help you.
You can see God in our bodies.
You can feel God in our hugs.
You can hear God in our words which may not be spoken out loud.
You can taste God on our skin.
You can smell God when you are with us.

We may have bodies that don't work well.
We may have ears that can't hear sounds.
We may have eyes that can't see clearly.
We may have voices that aren't verbal.

We know God in ways you haven't experienced.
We can teach you.
All you need is patience and an open heart.
Be real.
Be Genuine.
Be sincere.
We may become true Christian friends.
Open your heart and mind.
Let us in.

Sarah R. Nettleton lives in Fairport, New York. She is a member of PHEWA's Presbyterians for Disability Concerns (PDC) network. She also served on the task force that drafted the policy that became ["Living into the Body of Christ: Towards the Full Inclusion of People With Disabilities."](#) a 2006 social witness policy of the Presbyterian Church (U.S.A.).

"God in Us" was written by Sarah in 2003.

A PLANNING PROCESS FOR A REJOICING SPIRITS COMMUNITY

The Rev. Dr. John Judson

The Rejoicing Spirits Community (RSC) at First Presbyterian Church Birmingham is an intentional community in which persons of all abilities, as well as a variety of religious backgrounds are building relationships and honoring the spiritual needs and gifts of all. The life of our RSC consists of three parts: worship, intentional community wide social events and individual, family or group home interactions.

The [worship life of the Rejoicing Spirits Community](#) consists of two no-shush services a month during the school year and one worship service a month over the summer. The planning process follows the calendar year which means the planning team, consisting of both clergy and laity, begins the planning for each year in October or November of the preceding year.

Step one is choosing an annual theme and accompanying scriptures. The theme directs the selection of scripture passages which then guide the content of the services. The first service of the month is based on an Old Testament text and the second service of the month is centered on a New Testament text. Our theme for 2013 is “water.” The stories we have selected run from Moses striking the rock at Massah for water in the wilderness to Jesus stilling the storm.

Step two is organizing the two services for the coming month. We begin by choosing a summary phrase around which the two services will be organized. The phrases chosen have ranged from God Gives Us Peace, to God Gives us Helpers, to God Doesn’t Lose Us. This phrase is used as the heart of the call to worship, the prayer of confession and the interactive sermon. The signing for the phrase is taught at the beginning of each service in order that people sign it together every time it appears in the service. The planning continues with a discussion about appropriate music. We try and use simple and repetitive music that is accessible to all worshippers and is thematically tied to the monthly phrase. Next we plan as many ways as possible for worshippers to be actively involved in the service. This can range from “Setting the Table of Community” (bringing forward Bible, candle and offering plate), to being actors in the retelling of the story, to taking up the offering, to helping with prayer time.

Step three is dividing up the responsibilities. The team clearly lays out who is responsible for the overall PowerPoint presentation, creating the music slides, getting any props necessary for retelling the weekly story, writing prayer liturgy, leading the service and the service music, reading particular portions of the liturgy, carrying the roving microphone for prayers, organizing the welcome tables and organizing after service snacks/meal. In this way the services, while often appearing to be chaotic (remember it is truly a no-shush service) run smoothly and honor the gifts and spirituality of all members of the community.



A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Our intentional community-wide social events occur quarterly. They can include events such as dances, movies, ice-cream socials and game nights. These events are planned at the end of one calendar year for the following year. Our All Abilities Inclusion Ministry team, in consultation with representatives from the various group homes and families who are part of the community, set out the schedule and divide up responsibilities for each event.

The final piece of our RSC focuses on individual, family and group home interactions. The most significant aspect of this portion of our community involves one of our members who provides regular spiritual enrichment for several of the group homes. In addition we have individual members, along with our Inclusion Coordinators, who occasionally share their gifts (crafts, etc.) with members of the RSC.

The Rev. Dr. John Judson is the pastor, head of staff at First Presbyterian Church of Birmingham- Everybody's Church- where he has led the Session and congregation in living into their vision statement to "serve Christ by cultivating mission, inclusion and community." He can be contacted at: First Presbyterian Church, 1669 W. Maple Rd., Birmingham, Michigan 48009. Phone (248) 644-2040
johnjudson@everybodyschurch.org



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Litany for Rejoicing Spirits Service

Terry Chaney

The first thing that we do when planning a Rejoicing Spirits service at First Presbyterian Birmingham is to discuss, often at great length, what God's good news for our worshiping community is, the good news that is contained in a particular passage. I admit that we don't necessarily articulate it in that way, nor do we articulate what we are doing as working out the hermeneutical challenge, but that is in fact what we are doing. We seek to arrive at a pithy, short, and easily memorized phrase that also will be usable in sign language. This litany seeks to follow these principles.

One: When others tell me that I don't think, or talk, or move fast enough I will not be ashamed because

Many: I know that I am a beloved child of God

One: When others tell me of people, "just like me" who have climbed mountains, played in the Olympic games, or done other "amazing" things, I will celebrate their triumph and not be ashamed that I may not have done those things because I know that...

All: I am a beloved child of God

One: When I am told that I can be "just like everyone else" if only I work harder, purchase certain technology, or subject myself to this or that training program I will listen and decide, but I will not be ashamed because I know that...

Many: I am a beloved child of God

One: Let us celebrate the many gifts that we have all been given as we worship the God who alone can see how it all wonderfully fits together, feeling no lack or shame because we know that...

All: we are the beloved children of God

Worship Rituals and Practices

Cindy Merten

In [*Welcome them Home, Help them Heal: Pastoral care and ministry with service members returning from war*](#), the authors commit a chapter to suggested healing rituals to be used throughout the church year. A series of spiritual exercises that correspond with the church year are intended to provide a means for healing and restoration. These include an Advent and Lenten heart-cleansing ritual, a midweek worship series on *How to be a People of Faith in a Time of War*, a mid-week Lenten series on How to be a People of Faith in a Time of War, and suggestions for Memorial Day, Independence Day, All Saints Day, and Armistice/Veteran's Day.

A Veteran's Processional

Healing rituals can take many forms. One particularly meaningful ritual in our congregation included inviting veterans of different generations to lead in a processional as they carried in the Bible, the baptismal pitcher, the communion cup and plate at the beginning of our worship service. On the Sunday closest to July 4th, we invited four members who had all served in the armed forces over several decades to participate together. Four men smartly dressed in their uniforms and spit shined boots proudly processed the elements down the aisle to begin worship. Others who watched were moved as the eldest serviceman walked with his cane and was assisted up the chancel steps by the army chaplain. It seemed that the memories of all who had served merged with the promise of hope as these men walked together in footsteps of faith.



We added a procession of the elements that provides:

- ✚ A visual reminder of the focal points of worship in the Reformed tradition
- ✚ An opportunity for many people, young and old, of all abilities to participate

A Prayer Wall

For the last two Lenten seasons, we have created a place where children, youth and adults can write and tuck their prayers in a wall set aside for that purpose. This concept is reminiscent of the Western or Wailing Wall in Jerusalem where pilgrims come to pray leaving prayers written on small pieces of paper tucked into the crevices of the blocks.

Lenten Prayer Wall



In the tradition of the Western or Wailing Wall, as it is sometimes known, you are invited to write or draw your prayers of thanksgiving, lament, petition and praise. Fold them up and tuck them into the “rock” pockets. Your prayers are private and will not be read, but they will collectively be offered to God in worship.

Sit a moment, read a Psalm, write or draw a prayer, and put it on the wall.

Prayer Shawl Ministry

Many churches now have Shawl Ministry groups who meet together for the purpose of prayerfully knitting or crocheting shawls. Sometimes the shawls are called Prayer Shawls, Peace Shawls, Comfort Shawls, etc. The shawl maker begins with prayers and blessings for the recipient, and throughout the process continues in prayer. Upon completion, the shawl is blessed by the group and given to someone in need. Several groups throughout the country send shawls to veterans and families of those fallen. The shawls may be dedicated in the context of a worship service or more privately with the group that made them. See the following websites for more information on Prayer Shawl Ministry.

<http://shawlministry.com>

http://www.shawlministry.com/ministry_outreach.htm

Praying in Color

Sometimes we simply do not have the words to pray, and as Paul says, the spirit intercedes with sighs too deep for words. Sybil MacBeth, in her book *Praying in Color*, introduces a method of intercessory prayer that has the potential to engage the spirits of children, youth and adults in an active and visual way. Drawing with markers or crayons and carrying the prayer with you serves as a visual reminder of your prayer. For people whose hearts ache, who don't always have words to express difficult emotions, this form of prayer offers a way to pray for family, friends and the world. For more information, see <http://www.prayingincolor.com/MacBeth.html> or <http://www.prayingincolor.com/examples.html>



Cindy Merten

[First Presbyterian Church](#)

Director of Christian Education and All Abilities Inclusion Ministry

1669 W. Maple Rd.

Birmingham, MI 48009



Baptism Liturgy

Adapted by the Rev. Amy Morgan, for the Rejoicing Spirits Worship at First
Presbyterian Church Birmingham (Michigan)

Minister:

Jesus gave his disciples a special mission:
to go to everyone in the world,
teaching them how God wants them to live,
showing God's love to everyone,
and baptizing them in God's three-in-one name – Father, Son, and Holy Spirit.
Baptism is a celebration, a happy and holy event,
when we welcome one of God's children into God's family.
Baptism shows us God's love for us by
bringing us close to God and to each other,
making us able to live and love the way Christ lived and loved,
and helping us to remember that Christ died and was raised to life
to give us hope for life with him.

Clerk of Session:

On behalf of the Session, the leaders of this church,
I present *N.* to receive the sacrament of Baptism.

Minister:

N., do you want to be baptized?
The one coming for baptism responds in the affirmative.

Clerk of Session:

Do you, the family of God in Jesus Christ,
promise to help *N.* to know Jesus and follow Him
by praying for *him/her* and showing *him/her* God's love in what you do and what you
say?
The congregation responds in the affirmative

Minister:

N., in baptism, we agree to follow Jesus and turn away from what is wrong.
I'm going to ask you some questions before you are baptized



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

so that you can share with all of us your faith in Jesus and your love for him.

Do you want to do what is right, what God wants us to do, instead of what is wrong and hurtful?

The one coming for baptism responds in the affirmative.

Do you love Jesus and trust in him?

The one coming for baptism responds in the affirmative.

Will you follow Jesus and show his love to others?

The one coming for baptism responds in the affirmative.

Will you be a part of this family of God,
coming to worship and pray with us,
helping others and loving God?

The one coming for baptism responds in the affirmative.

With the whole church, let us stand and confess our faith:

Insert Confession of Faith

THANKSGIVING OVER THE WATER

Minister:

The Lord be with you.

All:

And also with you.

Minister:

We thank you, God, for giving us the gift of water, which helps all things live and grow.

This water reminds us that:

You created the world, bringing life out of water.

In the time of Noah, water destroyed evil so that goodness could have a chance.

When you freed the people of Israel from slavery in Egypt,

you parted the water of the Red Sea so they could pass through on dry land.

Jesus was baptized by John in the Jordan River.

Going down into the water, we are reminded of Jesus's death, and coming up out of the water, we remember his resurrection.

Baptism gives us hope for our own life forever with God.

And so we thank you, God, for the gift of water,



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

and especially for the water of baptism.
Send your Spirit on this water, God,
and bless the one who comes to be baptized.

Help them to love and follow you,
and to be a caring member of your family.
Give them strength to help others and joy to praise you,
through Jesus Christ, our Lord. Amen.

N., I baptize you in the name of the Father, and of the Son, and of the Holy Spirit.
Amen.

LAYING ON OF HANDS

Minister:

Loving God,
Give *N.* your Spirit,
to help them be good and loving and strong.
Help them grow in love for you and for others
every day of their lives. Amen.

Clerk of Session:

N. has been welcomed into the family of God through baptism. Let us thank God as we
welcome them with joy.

The Rev. Amy Morgan, MDiv., serves as Associate Pastor for Missions and Community
for the [First Presbyterian Church of Birmingham, Michigan – Everybody's Church.](#)



Baptizing Ricky

See what love the Father has given us that we should be called children of God; and that is what we are. 1 John 3:1

On a recent Sunday at First Presbyterian Church (FBCP in Birmingham, Michigan), we held a worship service in the style of our Sunday afternoon bi-monthly [Rejoicing Spirits services](#). This service was especially meaningful because we were celebrating the baptism of an adult who is active in our congregation and in our Rejoicing Spirits Community.

Richard Perkins Lee, Jr. (Ricky) was born with Down syndrome nearly 50 years ago in South Georgia. His parents divorced in 1970, and his mother placed him in a state institution where he lived from the age of 7 to 25, followed by several group homes and a nursing home for ten years. Fast forward to 2014 when Ricky's half-sister, Amy Montri, found the brother she had never met and for whom she'd been searching since the 1990s. Just weeks later she took her husband, Michael, back to meet Ricky, and a few months later they brought Ricky to Michigan where he has become a vibrant part of the Montri household and our FPCB congregation and Rejoicing Spirits Community.

There are many gaps in what is known about Ricky's upbringing, but we do know that he likes music and knows many church songs. The first time Ricky attended our Rejoicing Spirits service he sang "Jesus Loves Me" into the microphone during the prayer time. We did not know at the time that it his signature song. He sings it every night at bedtime.

Pastor Amy: Ricky, do you love Jesus and want to follow Jesus?

Ricky: Love Jesus Yes!

Pastor Amy: Will you be a part of this church?

Ricky: (Signing) Church, yes!

Pastor Amy: (Interpreting) Ricky loves church!

Ricky leaned with eager anticipation over the font waiting for the baptismal waters to flow over him. He was clearly excited for this moment and wanted to share the joy of it with his nephew, Carter. When he was presented with a cross as a reminder that Jesus loves him as we do, too, he took the cross off and placed it around Carter's neck. Ricky



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

knows Jesus' love for him and shares it with all of us by his very presence among us.
Thanks be to God!

Loving God, thank you for the gift of Ricky and his love for you. May the eyes of our hearts be opened as we witness resurrection moments of your love at work in the world and in us. We pray in the name of the One who loves us so much that we all are called Children of God. Amen.

You can watch a video of the baptism here:

<https://www.youtube.com/watch?v=wEcnOY74G0A>

Cindy Merten
Director of Christian Education, FBCB



**PRESBYTERIANS FOR
DISABILITY CONCERNS**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

An Affirmation

The Rev. Donald S. Milloy

Then God said, “Let us make humankind in our image...”
Genesis 1:26a

We are those who are called “disabled.” We are those who are challenged, physically or mentally. We may hobble; we may not have voice, song, sight, or sound. We may not be in control of our muscles or our minds. Yet, we join together with each other, in and with our communities, as God’s daughters and sons.

We bear witness that we are made in the image of our Parent-God and capable of being God-self to the world. We raise our voices and our bodies even though we may be incapable of doing so “perfectly.” We praise and proclaim the holiness of our Parent-God who has proclaimed us holy by dwelling in us.

May we get beyond the stereotypes to be who we truly are, the presence of God’s Spirit in and for the world, a voice that speaks as clearly and as powerfully as any others, and a reflection of Jesus of Nazareth, the Christ.

The Rev. Don Milloy

Don Milloy was born in 1934. After graduating from Louisville Presbyterian Theological Seminary, he was ordained and served churches in Illinois, Wisconsin, and Minnesota. He was an ardent advocate for social justice and, before his stroke, acted in a number of community theater productions.

Even after his stroke in January of 1993, he remained active in the Presbytery of the Twin Cities Area. Until his death on January 5, 2012, he was an active member of the Disability Concerns Ministry of the Presbytery of the Twin Cities Area. We are grateful for Don’s faithful ministry.

The Fix, Cure, and Kill Syndrome of Life with a Disability

The Rev. Sue Montgomery

PC(USA) Disability Concerns Consultant for accessibility/mobility issues

Over the years attitudes and understandings of life with a disability have changed dramatically. Years ago, children were routinely placed in institutional settings. The parents were told to go home and forget the child had ever been born. In the 1950's parents began to stand up to such advice and kept their children home where they were nurtured, educated, and loved just as they were. The Deaf Community was the earliest voice to defy standard medical care and to say deafness is not an aberration to be fixed or cured. The Deaf Community goes so far to say that deafness is not a disability. Instead, deafness is a linguistic minority and as such is human diversity. Deafness is as integral and as natural to a person's identity as their DNA.

The larger disability community has learned from the Deaf Community. No longer are people living with disabilities looking for ways to take our disabilities away or hide them so that we can "pass" as normal people. The emerging consciousness and affirmation of life with a disability is a radical change. Disability is no longer "a problem" that sets us apart from others. Disability is no longer something that takes us from doctor's office to doctor's office searching for a cure or a fix. Instead, disability is what it is, a part of who we are, and as such, for the first time, disability is positive. No one denies that living with a disability can be difficult, yet like any other form of diversity, disability brings new dimensions and understandings to life.

Religious faith and how faith traditions and understandings are taught play a significant role in the spiritual formation of people who live with disabilities. Again, as people with disabilities begin to explore their faith, not the faith of their parents, teachers, etc., but THEIR faith, new understandings of faith and of God are also emerging. When a colleague's father died, he was given the task of sharing his deaf father's instructions for his funeral with the officiating pastor. During the funeral—and at all times—there was to be no discussion that his father, once deaf, now hears in heaven. There were to be no statements that his father was healed in heaven and now heard the birds, the wind, and the ocean. The son went so far as to say, if such statements were made, his dad would rise from the coffin and correct them. The questions of heaven, the resurrected human body, are very real. They tug at our hearts; we question, wonder, and are perplexed by the mystery. At the same time, we project our understandings and wishes for life and the human body onto the image of the bodily resurrection. Ultimately this has a significant influence on how the body of a person with a disability is perceived and valued in life and in death.

Medical care has always sought to enhance and improve life, especially in the presence of illness or disability. The escalating technology that enables surgeons to repair injured joints, treat traumatic brain injuries and perform organ transplants has contributed to the numbers of survivors of traumatic injury and catastrophic illnesses. These medical miracles are at the heart of the drive to cure or fix the human body. The difficulty comes

when, due to injury or illness, such miracles cannot be performed. Eyesight cannot be restored when eyes are blown out by a roadside bomb; limbs cannot be replaced when a motorcycle accident severs a leg. However, many make the statement of faith that when they die, they will be made complete and whole, the heavenly body will have the broken limb restored, the missing limb will appear, the disability will be cured and fixed in death. This understanding is always a statement of faith geared to the individual. The difficulty comes in that it is not a universal statement of faith for everyone. This understanding deals a terrible blow and inflicts spiritual abuse and pain on many people who are living with disabilities. Such statements also carry the message that we who have disabilities have more value and are better off when we are dead. The final act of fixing or curing in heaven has more value than our lives here on earth.

During the summer, I was riding my handcycle on the bike trail. My cell phone rang. The call was for me to come to the hospital, a member of my congregation had been in an accident. As I was rolling through the hospital hallways one of the physical therapists stopped to talk. Being that I rarely, if ever, wore shorts at the hospital, this therapist was focused on all the surgical incisions that my bicycling shorts made quite visible. He looked at me and said: "Just keep telling yourself, the day will come when you will dance in heaven and all those scars will be gone, then you will be made perfect." His words struck my heart loud and hard. They were upsetting as first of all, I dance in life now; two, I'm proud of my battle scars, they represent twenty years of therapy, surgery, and medical attempts to be fixed and cured; three, I don't need to be perfect to be loved by God; and four, Jesus was raised from the dead with his scars, why not mine? What was most upsetting is that this physical therapist was demeaning everything about who I am, what I do, and how I live by giving my life value only in heaven—in death—when my disabled body was made perfect.

Children also are asking the questions. Children perceive how people value them just as they are. In 2000, Walt Disney Productions filmed the biographical story of Justin Yoder. Justin was born with Spina Bifida and discovered the sport of soapbox derby racing. Because fluid accumulates on Justin's brain, careful monitoring of his shunt to drain that fluid is critical. After one of his surgeries he has a dream where he is talking with God—who just happens to be a racecar driver. He asks to see heaven. As the clouds part, Justin sees children flying through heaven, in their wheelchairs! It is a moment where the movie affirms Justin, just as he is, in life and in death. In terms of film history, this was a breakthrough moment for children who are learning to live with their disabilities. Disability culture breaks through with the message that disability is not something to be fixed, cured, or killed to give a person value.

Bodily images are significant issues for people living with disabilities. How people with disabilities understand and value ourselves is significantly tied to how disability became a part of life. A person who is born with a disability has a different perspective than someone who acquires his or her disability through accident or illness at a later time in life. How we, as pastors, develop our approaches to counseling, preparing funeral services, providing grief counseling, and respecting people with disabilities, who are seeking to live abundant lives in faith, is crucial to the development of healthy spiritual



A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

formation. It's time to learn from the Deaf Community. Disability is not an aberration to be fixed or cured. Disability is a form of diversity and has a culture of its own. People do not have to die to find value in their lives. Instead, we need to reclaim the statement of faith, "in life and in death we belong to God." Heaven will be what it is. It is in the hands of God. The time is now to make the statement of faith that all have value and worth. People with disabilities have a variety of gifts to share. One of the greatest gifts is the value of life itself, as life is, in the present. No one has the right to take that away from anybody—Jesus never did; Jesus reached out and accepted each person who came to him, just as they were. Such is the depth of spiritual love and grace.

Sue is one of four [Disability Concerns Consultants](#) who serve the PC(USA) in the areas of vision, mobility, hearing, and intellectual disabilities. Visit the PHEWA web site, www.pcusa.org/phewa to learn more. You may also call the PHEWA office, 888-728-7228, extension 5800.

To ensure INCLUSION, FREEDOM, AND RESPECT
for all, we must use

PEOPLE FIRST LANGUAGE

by Kathie Snow

WHO ARE THE SO-CALLED “HANDICAPPED” OR “DISABLED”?

According to stereotypical perceptions, they are:

- People who *suffer* from the *tragedy* of *birth defects*.
- *Paraplegic heroes* who *struggle* to become *normal* again.
- *Victims* who *fight* to *overcome* their *challenges*.

Categorically, they are called *retarded*, *autistic*, *blind*, *deaf*, *learning disabled*, etc., etc., etc.—*ad naseum!*

WHO ARE THEY, REALLY?

Moms and Dads • Sons and Daughters
Employees and Employers • Friends and Neighbors
Students and Teachers • Leaders and Followers
Scientists, Doctors, Actors, Presidents, and More
They are people. *They are people, first.*

People with disabilities constitute our nation's largest minority group (one of five Americans has a disability). It is also the most inclusive and most diverse: both genders, any sexual orientation, and all ages, religions, ethnicities, and socioeconomic levels are represented. Yet people who have been diagnosed with disabilities are all different from one another. The only thing they have in common is being on the receiving end of societal misunderstanding, prejudice, and discrimination. Furthermore, this largest minority group is the only one which *any person can join at any time!* You can join at birth or later, through an accident, illness, or the aging process. If and when it happens to *you*, will you have more in common with others who have disability diagnoses or with family, friends, and co-workers? How will you want to be described? And how will you want to be treated?

—THE POWER OF LANGUAGE AND LABELS—

Words are powerful. Old, inaccurate descriptors, along with the inappropriate use of medical diagnoses, perpetuate negative stereotypes and reinforce an

incredibly powerful attitudinal barrier. *And this invisible, but potent, attitudinal barrier—not the diagnosis itself—is the greatest obstacle facing individuals with disabilities.* When we make the diagnosis the most important thing about a person, we devalue and disrespect him/her as an individual. Do *you* want to be known primarily by your psoriasis, gynecological history, the warts on your behind, or any other condition?

Sadly, disability diagnoses may be used to define a person's value and potential, and low expectations and a dismal future are often the predicted norm. Once we know a person's diagnosis, we (mistakenly) think *we know something important about him*, and this information is then used to decide how/where the person will be educated, what type of job he will/won't have, where/how he'll live, and more, including what “services” he needs. And those “special” services frequently result in the social isolation and physical segregation of millions of children and adults in special ed classrooms, congregate living quarters, day programs, sheltered work environments, special (segregated) recreational activities, and more. (Are other people isolated, segregated, and devalued because of *their* diagnoses?) With the diagnosis in hand, we work on people's bodies and brains, while paying scant attention to their hearts and minds. Far too often,

the misuse of a diagnosis can lead to harm, instead of help—and *can ruin people's lives.*

—INACCURATE DESCRIPTORS—

“Handicapped” is an archaic term (it's no longer used in any federal legislation) that evokes negative images of pity, fear, and more. The origin of the word is from an Old English bartering game, in which the loser was left with his “hand in his cap” and was thought to be at a disadvantage. A *legendary* origin of the “H-word” refers to a person with a disability begging with his “cap in his hand.” This antiquated, derogatory term perpetuates the stereotypical perception that people with disabilities make up one homogenous group of

***The difference between the right word
and the almost right word is the
difference between lightning
and the lightning bug.***

Mark Twain

pitiful, needy people! Other people who share a certain characteristic are not all alike; similarly, individuals who happen to have disabilities are not alike. *In fact, people with disabilities are more like people without disabilities than different!*

“Handicapped” is often used to describe modified parking spaces, hotel rooms, restrooms, etc. But these usually provide *access* for people with physical or mobility needs—and they may provide *no benefit* for people with visual, hearing, or other conditions. This is one example of the inaccuracy and misuse of the H-word as a *generic descriptor*. (The accurate term for modified parking spaces, hotel rooms, etc. is “accessible.”)

“Disabled” is also not appropriate. Traffic reporters frequently say, “disabled vehicle.” They once said, “stalled car.” Sports reporters say, “the disabled list.” They once said, “injured reserve.” Other uses of this word today mean “broken/non-functioning.” *People with disabilities are not broken!*

If a new toaster doesn’t work, we say it’s “defective” or “damaged” and return it. Shall we return babies with “birth defects” or adults with “brain damage”? The accurate and respectful descriptors are “congenital disability” or “brain injury.”

Many parents say, “I have a child with special needs.” This term generates *pity*, as demonstrated by the usual response: “Oh, I’m *so sorry*,” accompanied by a sad look or a sympathetic pat on the arm. (*Gag!*) A person’s needs aren’t “special” to him—they’re ordinary! *I’ve never met an adult with a disability who wanted to be called “special.”* Let’s learn from those with real experience, and *stop inflicting this pity-laden descriptor on others.*

“Suffers from,” “afflicted with,” “victim of,” and similar descriptors are inaccurate, inappropriate, and archaic. A person simply “has” a condition, period!

WHAT IS A DISABILITY?

Is there a universally-accepted definition of disability? No! First and foremost, a disability descriptor is a medical diagnosis, which becomes a *sociopolitical passport* to services or legal status. Beyond that, the definition is up for grabs, depending on which service system is accessed. The “disability criteria” for early intervention is different from early childhood, which is different from vocational-rehabilitation, which is different from special education, which is different from worker’s compensation, and so on. Thus, “disability” is a *social construct*, created to identify those who may be entitled to services or legal protections because of *certain characteristics* related to a medical diagnosis.

—DISABILITY IS *NOT* THE “PROBLEM”—

Because society tends to view disability as a “problem,” this seems to be the #1 word used about people with disabilities. People *without* disabilities, however, don’t spend a lot of time talking about *their* problems. They know this would promote an inaccurate perception of themselves, and it would also be counter-productive to creating a positive image. A person who wears glasses, for example, doesn’t say, “I have a *problem* seeing.” She says, “I wear [or need] glasses.”

What is routinely called a “problem” actually reflects a *need*. Thus, Susan doesn’t “have a problem walking,” she “needs/uses a wheelchair.” Ryan doesn’t “have behavior problems,” he “needs behavior supports.” *Do you want to be known by your “problems” or by the multitude of positive characteristics which make you the unique individual you are?* When will people *without* disabilities begin speaking about people *with* disabilities in the respectful way they speak about themselves?

Then there’s the “something wrong” descriptor, as in, “We knew there was *something wrong* when...” What must it feel like when a child hears his parents repeat this over and over and over again? How would *you* feel if those who are supposed to love and support you constantly talked about what’s “wrong” with you? Let’s stop using this word about people!

THE REAL PROBLEMS ARE ATTITUDINAL AND ENVIRONMENTAL BARRIERS!

A change in attitude can change everything. If educators believed children with disabilities are boys and girls with the potential to learn, who need the same quality of education as their brothers and sisters, and who have a future in the adult world of work, we wouldn’t have millions of children being *segregated and undereducated* in special ed classrooms.

If employers believed adults with disabilities have (or could learn) valuable job skills, we wouldn’t have an estimated (*and shameful*) 75 percent unemployment rate of people with disabilities. If merchants saw people with disabilities as customers with money to spend, we wouldn’t have so many inaccessible stores, theaters, restrooms, and more. If the service system identified people with disabilities as “customers,” instead of “clients/consumers/recipients,” perhaps it would begin to meet a person’s *real* needs (like inclusion, friendships, etc.) instead of trying to remediate his “problems.”

***If thought corrupts language,
language can also corrupt thought.***

George Orwell

And if individuals with disabilities and family members saw *themselves* as first-class citizens who can and should be fully included in all areas of society, we might focus on what's really important: living a *Real Life in the Real World*, enjoying ordinary opportunities and experiences and dreaming big dreams (like people without disabilities), instead of living a *Special Life in Disability World*, where low expectations, isolation, segregation, poverty, and hopelessness are the norm.

—A NEW PARADIGM—

“DISABILITY IS A NATURAL PART OF THE HUMAN EXPERIENCE...”

U.S. Developmental Disabilities/Bill of Rights Act

Like gender, ethnicity, and other traits, a disability is simply one of many natural characteristics of being human. Are *you* defined by your gender, ethnicity, religion, age, sexual orientation, or other trait? No! So how can we define others by a characteristic which is called a “disability”?

Yes, *disability is natural*, and it can be *redefined* as “a body part that works differently.” A person with spina bifida has legs that work differently, a person with Down syndrome learns differently, and so forth. Yet the body parts of people *without* disabilities are also different. It's the *way* these differences affect a person (or how a person is *perceived*) which creates the eligibility for services, entitlements, or legal protections.

In addition, a disability is often a *consequence of the environment*. Why are many children not diagnosed until they enter public school? Is it because physicians are ignorant or parents are “in denial”? Or is it because as toddlers, they were in environments which supported the way they learned? Then in public school, if a child's learning style doesn't mesh with an educator's teaching style, he's said to have a “disability.” Why do we blame the child, label him, and segregate him in a special ed classroom? Why don't we modify the regular curriculum (per special ed law) to meet his learning needs?

When a person is in a welcoming, accessible environment, with the appropriate supports, accommodations, and tools, does he still have a disability? No! *Disability is not a constant state*. The *diagnosis* may be constant, but whether the condition represents a “disability” is more a *consequence of the environment* than what a person's body or mind can/cannot do. We don't need to change people with disabilities through therapies or interventions. We need to change the *environment*, by providing assistive technology devices, supports, and accommodations to ensure a person's success!

USING PEOPLE FIRST LANGUAGE IS CRUCIAL!

People First Language puts the person before the disability, and describes what a person *has*, not who a person *is*.

Are you “myopic” or do you wear glasses?
Are you “cancerous” or do you have cancer?
Is a person “handicapped/disabled”
or does she have a disability?

If people with disabilities are to be included in all aspects of society, and if they're to be respected and valued as our fellow citizens, we must stop using language that sets them apart and devalues them.

Boys and girls with disabilities are *children, first*. The only labels they need are their names! Parents must not talk about their children using the medical terms used by professionals. Educators must not use terms like “sped kids,” “LD students,” “inclusion students,” or other stigmatizing descriptors. Children in school are *students* and some *receive special ed services*.

Men and women with disabilities are *adults, first*. The only labels they need are their names! They must not talk about themselves using professional lingo. Service providers must not use terms like “MR client,” “quads,” and other diagnostic terms.

The use of disability descriptors is appropriate *only* in the service system (at those ubiquitous “I” team meetings) and in medical or legal settings. Medical diagnoses have no place—and they should be irrelevant—within families, among friends, and in the community.

We often use a diagnosis to convey information, as when a parent says, “My child has Down syndrome,” hoping others will realize her child needs certain accommodations or supports. But the outcome of sharing the diagnosis can be less than desirable! A diagnosis can scare people, generate pity, and/or set up exclusion (“We can't handle people *like that...*”). In these circumstances, *and when it's appropriate*, we can simply describe the person's *needs* in a respectful, dignified manner, and *omit the diagnosis*.

Besides, *the diagnosis is nobody's business!* Have individuals with disabilities given us permission to share their personal information with others? If not, how dare we violate their trust! Do *you* routinely tell every Tom, Dick, and Harry about the boil on your spouse's behind? (I hope not!) And too many of us talk about people with disabilities *in front of them, as if they're not there*. We must stop this demeaning practice!

The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind.

William James

My son, Benjamin, is 19 years old. His interests, strengths, and dreams are more important than his diagnosis! He loves politics, burned fish sticks, classic rock, and movies—and he’s great at mimicking actors and politicians! He’s earned two karate belts, performed in children’s theater productions, and recently won a national award for his *Thumbs Down to Pity* film. Benj is attending college and wants to be a film critic. He has blonde hair, blue eyes, cerebral palsy, and a service dog, Riley. His diagnosis is just one of many characteristics of his whole persona. *He is not his disability, and his potential cannot be predicted by his diagnosis.*

When I meet new people, I don’t disclose that I’ll never be a prima ballerina. I focus on my strengths, not on what I cannot do. Don’t you do the same? So when speaking about my son, I don’t say, “Benj can’t write with a pencil.” I say, “Benj writes on a computer.” I don’t say, “He can’t walk.” I say, “He uses a power chair.” It’s a simple, *but vitally important*, matter of perspective. If I want others to know what a great young man he is—more importantly, *if I want him to know what a great young man he is*—I must use positive and accurate descriptors that portray him as a valuable, respected, and wonderful person, instead of as a collection of “deficits,” “problems,” or “challenges.”

A person’s self-image is strongly tied to the words used to describe her. For generations, people with

disabilities have been described by negative, stereotypical words which have created harmful, mythical perceptions. We must stop believing (and perpetuating) the myths—*the lies*—of labels. We must believe children and adults who have been diagnosed with conditions called “disabilities” are unique individuals with unlimited potential, like everyone else!

The Civil Rights and Women’s Movements prompted changes in language and attitudes. The Disability Rights Movement is following in those important footsteps. People First Language was created by individuals who said, “We are *not* our disabilities.” It’s not about “political correctness,” but good manners and respect. Some reject People First Language, saying it’s unimportant; others say they *prefer* descriptors like “special needs.” But the feelings and preferences of people *without* disabilities are irrelevant. What *is* relevant? The *feelings* of the people we’re talking *about* and the *perceptions* of them which we create with our words!

We can create a new paradigm of disability. In the process, we’ll change ourselves and our world—as well as the lives of millions of children and adults.

Isn’t it time to make this change?

If not now, when? If not you, who?

People First Language is right.

Just do it—NOW!

EXAMPLES OF PEOPLE FIRST LANGUAGE

SAY:	INSTEAD OF:
People with disabilities.	The handicapped or disabled.
Paul has a cognitive disability (diagnosis).	He’s mentally retarded.
Kate has autism (or a diagnosis of..)	She’s autistic.
Ryan has Down syndrome (or a diagnosis of..)	He’s Down’s; a Down’s person; mongoloid.
Sara has a learning disability (diagnosis).	She’s learning disabled.
Bob has a physical disability (diagnosis).	He’s a quadriplegic/is crippled.
Mary is of short stature/Mary’s a little person.	She’s a dwarf/midget.
Tom has a mental health condition	He’s emotionally disturbed/mentally ill.
Nora uses a wheelchair/mobility chair	She’s confined to/is wheelchair bound.
Steve receives special ed services	He’s in special ed; he’s a sped student.
Tonya has a developmental delay	She’s developmentally delayed.
Children without disabilities	Normal/healthy/typical kids.
Communicates with her eyes/device/etc.	Is non-verbal.
Customer.	Client, consumer, recipient, etc.
Congenital disability	Birth defect.
Brain injury	Brain damaged.
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs . . . or she uses	She has a problem with. . . /She has special needs.

Keep thinking—there are many other descriptors we need to change!

You may copy & share this 4-page document as a handout; please tell me how/when you use it (kathie@disabilityisnatural.com).

Do not violate copyright law: *request permission before reprinting in any publication newsletter, web site, list serve, etc.*

Interdependence, a Biblical Concept

The Rev. Rick Roderick

Exodus 4:10-16

1 Corinthians 12:4-28

Independence is a very strong component of our social fabric. We have all heard of rugged individualism. Independent living centers and programs exist across the country to assist in this effort. Dependence is shunned. We are often taught that the more we can do for ourselves, the better off we will be. Yet, this is not always possible. People who are blind can't drive and those who are deaf may find that participation in a conversation has certain hurdles. People with limited movement may need assistance with different tasks. Rugged individualism becomes just that...rugged. How can we solve this dilemma? I believe that the Bible teaches a different way.

In the fourth chapter of Exodus, Moses is told by God to bring the Israelites out of Egypt and lead them into the land that we know as Palestine. Moses sees this task as overwhelming and he looks for any possible way he can get out of it. He tells God, "You don't want me. I am slow of speech." We don't know exactly what this means, but it appears that he probably had some kind of speech impediment. God says, "I will be with you." But Moses is unconvinced. "Send someone else," he says.

God could have responded in several ways. God could have said, "OK, I'll do it myself. Don't bother. I'll get someone else." This would have meant total dependence on Moses' part. God could have said, "Moses, you're on your own." That would have created rugged individualism, and Moses could have received total independence, but little would have gotten done.

Instead, God said, "Aaron is coming out to meet you. He will speak for you." Moses would have the ideas. Aaron would express them.

It was a good arrangement. Each man had strengths. Moses was the idea person. He kept the people together, even when they tried to fall away. He did not lose sight of his mission. Aaron made sure the day-to-day tasks got done. It was because of the efforts of both of them that the children of Israel made the long pilgrimage successfully.

1 Corinthians 12 has much the same theme. The Church is one body that is made up of many members. Just as each part of the human body can't function without the others, the same is true with the Church. Some people will be elders and deacons, preachers and teachers, mission volunteers, musicians, janitors, etc. It is only through this division of labor that the Church can fulfill its mission.



A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Both of these passages emphasize one thing: interdependence. We can't go it alone but we can accomplish much together. In life, we may be able to go it alone, but at some point, this will break down. By being in community, we can accomplish a great deal. I believe that the Church has a mission to society. We can be a beacon of interdependence, a force for building community. In this way, we can help others to feel the work of the Holy Spirit who makes community possible.

Prayer: Our gracious God, help us to see your realm. In the Lord's Prayer, we say, "Thy Kingdom come." Help us to bring it about by showing others the meaning of interdependence and community. May we be guided by your Holy Spirit who makes all this possible. We ask this in Jesus' name. Amen.

The Rev. Rick Roderick serves as the PC(USA) Disability Concerns Consultant in the area of visual disabilities. Read more about Rick and this program at:

<https://www.presbyterianmission.org/ministries/phewa/disability-concerns-consultants/>

Be With God

The Rev. Joanne Blair



I'm busy- sometimes too busy. Aren't we all?

Somewhere in that busy-ness I was rushing around "working for God" but forgetting to be with God, and my prayers had become rote.

At [Rejoicing Spirits services](#) we always sign and sing the Lord's Prayer, following the direction of an interpreter. A verse is sung and signed, and then we repeat it. Scott is a man living in a group home, with limited verbal skills, but I could tell one Sunday that he was interested in, yet struggling with, what was going on.

I asked him if he would like me to help him with the movements and he acknowledged "yes." So I stood behind him, reached over to take his hands, and we went through the movements together. I was forever changed. It was one of the most incredible spiritual experiences I have ever had.

On that evening, I shared a very intimate moment with Scott, and with God, as we slowly and meaningfully prayed.



A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

Scott gave me the gift of intention. He reminded me of the importance of being connected to another, and of staying connected to God. This gift of intention grounds me and calls me to be present in the moment.

Thank you, God, for putting people like Scott in my life to remind me that the words are not nearly as important as the intent. Help me stay connected to you always, so the Spirit can intercede.

The Rev. Joanne Blair serves as Associate Pastor for Inclusion and Pastoral Care for the First Presbyterian Church of Birmingham, Michigan. She is among the leadership of Presbyterians for Disabilities Concerns (PDC), a network of the Presbyterian Health, Education & Welfare Association (PHEWA).

Alternative Formats, a Tool for Full Inclusion

The Rev. Rick Roderick

The Apostle Paul wrote that God arranged the members of the body, each one of them, as God chose. If all were a single member, where would the body be? (1 Cor. 12:18-19) We all have varying talents and abilities and can contribute to the Church in many ways. The body as a whole can empower its members to serve. Full inclusion is more than hospitality, though that is important. It means giving members both the abilities to serve and be served.

For people who are blind, or who have low vision, providing materials in alternative formats is a way to do this. Information is power, the power to understand and contribute to the life of the congregation, the community, and the world.

What are alternative formats? They are other ways of reading than regular print. They include large print, audio, Braille, or computer access.

What form of access is preferred? That depends on the person. Needs vary by person and by situation.

Large Print

Many people who have low vision use large print. It can be used in just about any application of church life--from worship to newsletters to study materials. The size and style can vary widely. If enlargement is all that is needed, a copier can be used to magnify pages. If more is needed, this can be done on a computer.

Here are some things to remember about large print:

1. The size of letters can vary from 14 points to 26 points.
2. Greater contrast may be needed for ease of reading. A boldface font can be used, as well as different color schemes.
3. A simple font may be helpful--that is, one without extra ornamentation. Some people prefer Arial or the APH Font to Times New Roman. To obtain the APH Font, go to the American Printing House for the Blind website www.aph.org.

Recording

Recording is a very popular way of conveying information to those who are blind. Many people, who lose vision, do so later in life. If they know Braille at all, they may not be able to read it quickly. Recording works well for newsletters, announcements, and studies. It is not as applicable to worship because one cannot use a recording to keep up with hymn lyrics during worship, though it can be used to learn words to anthems and hymns.

Recording may be done on a cassette recorder or a CD, depending on what equipment is available to the individual and the church. Here are some things to keep in mind:

1. People who record should speak clearly with vocal variety.
2. Background noise should be kept to a minimum.
3. Be about a foot away from the microphone. Experiment with volume, so that the recording is loud enough but not distorted.
4. When narrating church publications, read page numbers if they may be needed in study.

Braille

A relatively small number of people with blindness and low vision use Braille, but to those of us who use it, it is vital. People read with varying speeds, but some can read at 200 words per minute. It is applicable for all aspects of church life. Here are some things to keep in mind:

1. If a church obtains a Braille printer, someone will need to be trained to use it and the Braille translation software that must also be purchased.
2. If a transcriber is used, find out his or her needs. Generally, word processing formats work better than publishing formats.
3. Does the transcriber have access to the hymns, or do these need to be transcribed into the bulletin?
4. Include the announcements in the bulletin, not just the worship material. This will convey an attitude of welcoming and inclusiveness.
5. Talk to those who use Braille about needs other than worship.

Computer Formats

Several screen readers and magnification programs are now available for computers. This is a great way to convey information. This can be done through email, websites, and on a storage medium, such as a floppy disk, a CD-ROM, or a compact flash card. Some people will access documents with a portable Braille notetaker, rather than, or in addition to, a computer. Here are some things to keep in mind about computer documents:

1. Make sure all websites are fully accessible. As the consultant on blindness and low vision for the denomination, I am available to assist you with this at no charge.

2. Word processing formats, HTML and text generally work well. Adobe PDF files can be problematic. For information on producing them correctly, go to:
<http://access.adobe.com>.
3. Scanning and the use of optical character recognition software can be an excellent method of reproducing material that is not available from another source. However, it is necessary to clean up the material produced. This will avoid recognition errors.

Full inclusion is a state of mind, but for it to succeed, it must be backed up by actions. Providing alternative formats for worship and other activities will allow full communication and give people who are blind, or have low vision, an opportunity to fully participate in your congregation.

The Rev. Rick Roderick, Consultant for Blindness and Low Vision,
[PC\(USA\) Disability Concerns Consultants](#)
rickrod@twc.com

A Congregation, My Journey through Accessibility and Accommodations

By Rick Roderick

PC(USA) Disability Concerns Consultant and
Teaching Elder in Mid-Kentucky Presbytery

Participation in the life of the church is at the heart of the feeling of belonging. I have always felt it important to be part of a congregation, but certain things have blocked me from fully realizing my potential. Both on my own and with the support of my congregation, I have been able to make many of the adaptations necessary to deal with the issues involved. I am totally blind and have a significant hearing loss. Here is some of my story:

Reading

Singing is an important part of worship. I was able to get electronic versions of bulletins from my church, first on disk and then by email. However, at the beginning, hymns were not included, except for those that were printed in the bulletin for everyone.

During the mid-eighties, I was able to get a Braille copy of the Worship book. This was in several volumes, which meant that I had to bring the appropriate ones for each service. Our last two hymnals have been in electronic format. I can now save hymns as files and insert them into the appropriate places in bulletins that I Braille.

One of the difficulties of sensory disabilities is being out of the loop, not knowing what is going on within the life of the congregation and the wider church. Reading my church's newsletter was a hit or miss process for me during the eighties. I would get them on disk, but it was easy for people to forget my need for it. Now it is emailed to everyone in the congregation. Universal access is often what makes true accessibility possible. Other church information is also emailed to everyone.

Much the same thing has happened on the presbytery level. Daily announcements and materials for meetings are emailed to all involved.

WHAT CONGREGATIONS CAN DO: Reading is important for all of us. For people who are blind or have very low vision, it is imperative. Scanners and optical character recognition have provided many tools to make this process easier, but they have limitations. Perusing several short documents can be time-consuming. Pictures and handwriting cannot be recognized.

If these members have a computer, make the newsletter and other materials available in accessible format. Agree on which format. Microsoft Word usually works well.

Keep informed about resources. *Glory to God: The Presbyterian Hymnal* is available from www.bookshare.org, and members can download it.

For people who are not computer users, members might take turns recording the newsletter.

Members might also read mail and other documents for people who are blind.

Transportation

For those of us who are blind, getting around can be relatively easy or difficult, depending on the circumstances. People who are totally blind cannot drive. A few people who have low vision can drive, but often, they can only do so during the daytime.

WHAT CONGREGATIONS CAN DO: Transportation to and from worship and church functions may do much to facilitate participation in the life of the congregation. Helping members with grocery shopping and medical appointments is also helpful. In the church I attend, this is coordinated by the Board of Deacons.

Another approach is possible for certain functions. I am a member of my congregation's worship council. Because my wife's driving has become more limited than it used to be, she is often unable to drive at night. A member of the council and I both have iPhones. He did a Facetime call that allowed us to hear each other. He actually called twice, once for the unified gathering and again for the actual council meeting. I was able to participate in both gatherings, and I love to say, "I was and wasn't there at the same time."

This brings up an important point. Don't be afraid to be creative.

I Can Hear Clearly Now

In addition to my blindness, I have a significant hearing loss. I wear a hearing aid in one ear and a cochlear implant processor in the other. Noisy situations and low volume can both be problems. One of the difficult challenges that I encounter is reverberation. Many church sanctuaries and other rooms do not absorb sound. A great deal of clarity is lost for me. In other words, I can hear, but I don't understand.

Our sanctuary had soundproof tile that deadened sound, so that no echo or reverberation occurred. In remodeling, this was removed. I worked with members of the congregation to get FM assistive listening devices. I needed a neck loop because my hearing loss did not allow me to use headphones or earbuds well. The clarity that was lost to me has returned.

Our fellowship hall and gathering room had significant problems with echo. Noise levels could be high, and even when people were quiet, speech did not sound clear. When our building was remodeled, proper soundproofing was installed, and the situation was improved significantly.

WHAT CONGREGATIONS CAN DO: When remodeling or starting new construction, take acoustics into account. With our emphasis on the Word, make sure that the Word can be heard by all.



A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

If you install assistive listening devices, make sure they can be used by everyone who needs them. There are several types of systems and various output devices. FM, infrared and looped rooms are all methods of providing enhanced listening. Headphones, earbuds, and neck loops are output methods.

Get a good sound system, and make sure that it is used properly. Make sure that microphones are neither too close or too far away from the person speaking.

When a discussion is broken up into small groups, make sure each group can meet in a quiet place. The sound of different people talking at once can be a cacophony to someone who is hard-of-hearing.

I hope that some of these ideas have helped you think through ways of being a more inclusive congregation. If you have any questions or comments, please contact any of the PC(USA) Disability Concerns Consultants. We would love to hear from you.

Our website is:

<https://www.presbyterianmission.org/ministries/phewa/disability-concerns-consultants/>



Advocacy: A Young Person's Perspective

As a young woman with multiple disabilities, I am very aware of the need for advocacy in my life. I have been blessed with parents who are wonderful advocates. They have taught me well and understand they advocate **with me** not **for me**. I took a class on self-advocacy skills for youth with disabilities and learned the lesson, "nothing about me without me." This lesson applies to advocacy in church life as well as society.

People with disabilities need to advocate in their congregations. We need to speak up about things that affect us. Advocacy can be simple, like asking for the proper size font for large print bulletins or more complex, like making a bathroom accessible. People with disabilities have knowledge and information to share. A church is best when all the gifts and talents of every member are shared.

As a self-advocate, the greatest struggle I face is finding people who will truly listen to my opinion. I often feel as if I am "crying in the wilderness." Churches need to find "champions" who will help the voices of people with disabilities be heard. "Champions" advocate **with** not **for** people with disabilities. They help get people's attention so that the voices in the wilderness can be heard.

Together we can become a powerful witness as a community of believers. Find the time to make a difference in your congregation. Let your voices be heard. Champion the voices in the wilderness. "I am the voice of one crying out in the wilderness, 'Make straight the way of the Lord.'" John 1:23

Sarah Nettleton, member of Presbyterians for Disability Concerns (PDC) network

Sarah Nettleton served as the youth member of the task force which drafted the General Assembly policy, ["Living into the Body of Christ: Towards Full Inclusion of People with Disabilities."](#) She has served as a member of the Presbyterians for Disability Concerns Leadership Team. Sarah is working on a Self Determination Consolidated Support and Services plan for her life. In her free time, she enjoys canoeing, kayaking, downhill skiing, and writing. Sarah communicates by typing one letter at a time with support at the wrist.

Advocacy: A Mother's Perspective

“Come to me, all you that are weary and are carrying heavy burdens and I will give you rest. Take my yoke upon you, and learn from me; for I am gentle and humble in heart, and you will find rest for your souls. For my yoke is easy, and my burden is light.”
Matthew 11:28-30

The burdens and challenges of being the parent of a child with disabilities can be overwhelming. People will often comment that, “God chose you to be the parent of a child with disabilities because you are such a wonderful person” or “you handle things so well.” Their comments on the “gift” feels like they are really saying “better you, than me.” Sometimes the “gift” of a child with disabilities feels a lot like being a 13 year old and getting a birthday present from Great Aunt Florence of frilly, pink ballerina pajamas. Yes, it is a gift but not one you asked for let alone a gift you think you might want.

In my work with parents of children with special needs, it doesn't matter what their faith tradition, parents want their children to be nurtured and included in their faith community. Parents are not only weary and heavy laden from the day to day job of caring for a child with disabilities, but also for advocating for their child with the school system, the medical system, and the disability service provider system. The last place parents want to use their advocacy skills is at church. I have heard, “I just want to go to church without doing an in-service on Molly every time we are there.” “Sunday school is only an hour. We care for Craig every day. Can't you figure out how to include him for an hour?”

During baptism in the Presbyterian Church (U.S.A.), the congregation is charged to nurture and love the child and to assist them to be a faithful disciple. A wise mother pointed out that there is no clause in the congregational charge that says we promise to nurture and love the child and assist them to be a faithful disciple “except when the child has a disability” or “except when disabilities make it too hard to include them.” Congregations need to work together with parents to maximize the inclusion of children with disabilities. Parents must communicate their goals for their children. For some parents, it is more important that their child learn the love of God than to be able to recite all the books of the Old Testament. Families should share what works best to include their child. Sam listens better when he can be doing something with his hands. Loud noises scare Mary, but she loves music, so have her sit at the near the back of the room, not in front of the piano. Tina needs a buddy to find a ride in the junior high carpool to the soup kitchen. Chances are, adjustments that will be beneficial for the inclusion of children with disabilities will help other children as well.

Congregations need to listen with open hearts and minds and not put the burden of including a child with disabilities on the parents. Parents have a right to be in worship, not glued to their child. They should help like any typical parent with cut out nights, driving to bowling events, or helping to sell car wash tickets, but they don't need to do

everything with their child. What child or young adult wants their parents around all the time?

Parents want children to grow in faith so that they will have a foundation for life. Parents of children with disabilities are no different. The desire for their children to have a foundation for life and a place to belong is apparent whether the child is 2, 12, 15, 20, or 50 years old. Being truly included as members of the body of Christ has no age or disability provisions.

How is your congregation sharing the yoke of parents of infants, children, and young adults with disabilities?

Susan L. Nettleton is a lifelong Presbyterian. She is the retired Finger Lakes Regional Coordinator for [Parent to Parent of New York State](#). She and Jack are tireless advocates for Sarah. Susan is a member of Presbyterians for Disability Concerns (PDC), a network of the Presbyterian Health, Education & Welfare Association (PHEWA).

The Church and Military Moral Injury

by Amy Blumenshine

Moral injury is a concept that is newly discussed among Veterans Administration (V.A.) psychologists but has been identified by surviving warriors for eons. The authors of the 2009 groundbreaking [article](#) on moral injury describe it as “lasting psychological, biological, spiritual, behavioral, and social impact of perpetrating, failing to prevent, or bearing witness to acts that transgress deeply held moral beliefs and expectations.”ⁱ

The V.A. researchers identified that vets with moral injury were far more needy of V.A. services of all kinds, physiological as well as mental. Having killed, in particular, was associated with on-going problems.

Soul Wound

This is how the medical professionals approach the concept voiced so long by veterans as soul wounds, or “violating the Geneva Convention of the soul.” To some veterans, it’s as though there are actual laws written in the heart, primal laws that individuals may not even recognize until they’ve been violated, such as taking life, hurting children and the elderly, destroying people’s livelihoods, failing to give assistance to the needy. Capt. William Nash has put together a [helpful assessment tool](#) listing common causes of military moral injury.ⁱⁱ

Kent Drescher, a Presbyterian pastor and PTSD psychologist has been an early expert, noting that the [spectrum of disturbances](#) to a person’s moral core range from a diminished sense of oneself as a worthwhile human being on the mild end to, to, on the extreme end, identifying oneself as a pariah who deserves punishment.ⁱⁱⁱ Too many veterans find their rage triggered without awareness of the root cause and many self-medicate with harmful substances. For some, a skewed moral compass can lead to law-breaking of all kinds, including the laws of relationship. So many veterans become entangled with the criminal justice system that many jurisdictions have specialized courts exclusively for veterans. The murder-suicide rates are disproportionately high among veterans.

The manifestations of moral injury are multitudinous but, like other impacts/toxins/risk factors, different reactions can result from the same experience. Even more confusing is when someone, like the veteran’s spouse, appears to be suffering much more than the veteran. From a family systems perspective, we know that often the individual identified with problem behavior (the symptom bearer) may not be the person in the family with the underlying problem. As spiritual teacher Richard Rohr explains: “If we do not transform our pain, we will be sure to transmit it.”

In addition to damaging the sufferer’s capacity for relationships, moral injury can lead to suicide and other self-injurious behavior (like substance abuse). As a consequence of self-injurious behavior, a host of physiological ills, including those caused by constant high stress, can result.

All of these problems tend to be magnified for the youthful soldier. The hippocampus

part of the brain, which is involved in both risk assessment and moral judgment, does not fully develop until after age 25. Accordingly, people under 25 are more likely to engage in behavior that they will later regret.

Because of youth, a person may not have a well-defined and strong sense of personal identity. The young adult may not be able to distinguish the difference between doing or just seeing horrible things and identifying oneself as a horrible person. Because of their exposure to war-time horrors, some will never feel comfortable in church again. One soldier told his mother, “The son that you used to love is gone.”

In addition, a young person’s developing moral judgment could become arrested. Some will rigidly hold that “Since nothing I did could have been bad, nothing the United States did could have been wrong, and every man, woman, and child who died in Iraq deserved it.” A more sophisticated, evaluative moral reasoning can never be tolerated without the vet confronting his/her own behavior. All exploration of the inner life, then, is avoided.

The armed forces work hard at training troops to overcome their natural resistance to killing by trying to objectify and dehumanize the “targets.” Unfortunately, some soldiers recognize that they or their comrades actually enjoy hurting or killing, having stoked the potential sadist in each of us. Some admit that “playing God” and using the powerful instruments of war can be satisfying or even fun. Much that seemed appropriate in the context of others at war can, in later years, lead to self-loathing, self-sabotage, and alienation—especially as one’s body energy flags with age or illness.

Intervening in Military Moral Injury

Moral injury, however, cannot be understood without also realizing the many other maladies that beset veterans. Detailing those, like chronic body pain, sleep difficulties, exposure to toxins, hearing impairment, military sexual trauma, post-traumatic stress disorder (PTSD), and traumatic brain injury, is beyond the scope of this paper. Veterans rarely ask for help for moral injury although many seek pastoral conversation. A pastoral care provider can provide an “anchor” of consistent relationship and concern over time for the veteran as the veteran addresses the particularities of their maladies with appropriate resources. The anchor concept is from [Belleruth Naparstek](#), who has developed excellent guided imagery resources to help veterans cope and heal.^{iv} [A national chaplains network](#) is available to provide help in navigating the complexities of the whole person.^v

PTSD and moral injury have been confused and often travel together but are not the same. PTSD is best understood as being stuck in a physiological survival reaction to the body being in mortal peril. Moral injury, however, wrecks a person’s sense of themselves as a moral person and their sense of the world as a place where other people abide by moral laws. The recommended treatment for PTSD of re-experiencing the trauma teaches the body that the body is now in safety. Repetitive re-experiencing of the memory of the moral injury, like the killing of a little girl (or whatever the soul violation) is more likely to hurt than help the veteran. I, personally, am hopeful that the

current sub-optimal success rate of PTSD treatments can be improved once moral injury is also addressed.

Congregational Help

We, in the Beloved Community, look to the wholeness of body, mind, and spirit with a different lens than the medical model. We encourage each other to lead moral lives in right relationship with God and our neighbors for a lot of reasons that can be capsulized as “a better life,” human flourishing, or our covenant with God. We also support cultivating the inner life of prayer and self-understanding, with the expectation that we continue to grow, that God is never done with us. The church has a unique and significant role for those seeking to mend the torn fabric of trust while spiritually growing into “right relationships” after war exposure.

The [Center for Soul Repair at Brite Divinity School](#) has done ground-breaking work related to healing moral injury, under the leadership of Rita Nakashima-Brock.^{vi} They have been described as “exploring how measurably the character and conscience and souls of our military are impacted by what they are sent to do in our name.” They also are among the pioneers in developing pastoral care models for repair in the aftermath of moral injury. They promote “Deep Listening” in which a sacred connection is made that allows safety for the wounded soul. So many veterans cannot articulate what troubles them. Indeed, one vet explained: “There are things that I don’t tell my therapist because my therapist couldn’t handle it.” Stephen Muse, who has long counseled military chaplains, advises, “Listen, witness, and weep.”

Catastrophic trauma, such as often encountered in war, is a moral and spiritual maelstrom. Survivors often have questions about God. Many wonder why God would permit certain things or how God will judge their own behavior. Human beings make meaning and judgments about what they have done that are often not rational. A [handbook](#) made for military chaplains gives numerous techniques practiced by chaplains that help individuals begin to make sense of their world and find an acceptable meaning out of their experiences.^{vii} One of the important techniques is to reflect rationally on percentages of responsibility for a particular action. This “Percentage of Guilt” discussion, which I’ll address later, is intended to help the veteran understand that many others share the responsibility, so that the weight, the burden of guilt, is distributed and less dis-abling to the veteran.

Group healing modalities can be very helpful especially since we are each other’s moral universe. Churches can support these opportunities. The 12-step programs (used so commonly to heal substance abuse) can be understood as fundamentally about healing from moral injury. One gives up the illusion of control, makes a fearless and searching moral inventory, with confession, and sets about making amends and living a life of service enlightened by the ongoing learning.

My organization promotes [Healing of Memories workshops](#) for veterans and those who love them.^{viii} Their creator, the Anglican Fr. Michael Lapsley has found that it is important that troubling memories be acknowledged, revered—treated with appropriate dignity, and given a moral context. Part of healing involves the restoration

of the moral order. Prayer, love, and support create the safe space necessary for this healing, particularly when evaluating one's own moral agency. There can be knowledge without acknowledgement, however, like the denial that operates in an alcoholic family. There also can be storytelling as a means of keeping hatred alive, Lapsley warns. He urges seeking to remember and to heal rather than to bury and forget. Toxic memories eventually infect whole systems. People give themselves permission to do terrible things to others because of what was done to them.

Obviously, the church has a long history of helping people with the moral injury that can occur when someone has been party to something that violates their deeply held beliefs. Simply participating in healthy congregational life can be an opportunity to have a corrective experience of love and care and forgiveness amongst trustworthy people. Participating in the weekly worship liturgies have often been cited by veterans as fundamental to their healing. For instance, one military prosecutor cited the language of baptism as giving him the capacity to refuse to participate in torture. It is also sometimes appropriate to offer special spiritual activities to veterans and their families. I've provided some examples in our book and that chapter is [posted online](#)^{ix}

The Church's Larger Responsibility

The church, however, has a much larger responsibility in working towards the healthy character and conscience and souls of veterans and their families and their communities. The challenge of putting an appropriate moral frame around one's military experiences is far too much for any one person or family to do on their own. The church can be a place of moral deliberation where people of faith responsibly reflect on war efforts, which are a collective responsibility. We can pay attention to the suffering of our veterans and their families. We can learn to converse about topics that are as significant as how our country is investing its blood and treasure.

Military commanders recognize that only a fraction of the troops actually engage in combat with the enemy; the bulk of the military are there to make that fighting possible. Those who fight can be envisioned as the point of the spear and the support personnel are at various places along the shaft. Returning to the "Percentage of Guilt" discussion, in which chaplains help sufferers determine who else holds responsibility for a regrettable act, all of us are somewhere on the shaft. We have a duty to review what is being done in our name and together to put an appropriate moral frame around it. As civilians, we hurt veterans and their families by categorizing them alone as carrying the moral weight of war; civilians, too, are complicit in every action.

Unfortunately, while some of us, especially those related to the military, are facing the mortal and moral peril of war, too many Americans appear disinterested or confused. Let us not confuse the moral weight of exposure to death with the spectator sports which preoccupy our society. Let us not confuse real killing and death with our dominant fiction where the good guy kills the bad guy and nobody suffers. Churches must stand counter to these false narratives and affirm that each life matters. The stakes couldn't

be higher: wild and precious life itself along with one's moral soul. No one is disposable. We are in this together. We matter to each other. We are one body.

And together, as experienced in the Healing of Memories workshops, we have the capacity to help each other heal. Survivors of the catastrophic trauma of war can find ways in which their pain can be transformed into something meaningful and constructive for society. Our faith communities, too, by confronting the moral and spiritual maelstrom through the experiences of those who fight in our name may reach a deeper level of social and spiritual engagement. May we not fail each other in this endeavor. May we together rise to the challenge.

*AMY BLUMENSHINE is called as a diaconal minister by the Minneapolis Area Synod of the Evangelical Lutheran Church in America (ELCA) to address the suffering of veterans and their families. She founded and convenes the Coming Home Collaborative, an open and growing volunteer association of people who are concerned with the psychological and spiritual healing of veterans, especially those currently reintegrating with their families and communities. For more information, see <https://www.facebook.com/Coming.Home.Collaborative>, www.listentovets.org, and www.mpls-synod.org/veterans-ministry. Blumenshine co-authored *Welcome Them Home, Help Them Heal: Pastoral Care and Ministry with Service Members Returning from War with John Sippola, Don Tubesing, and Val Yancey (Duluth, MN: Whole Person Associates, 2009)*.*

ⁱ "Moral injury and moral repair in war veterans: A preliminary model and intervention strategy" Brett T. Litz, Nathan Stein, Eileen Delaney, Leslie Lebowitz, William P. Nash, Caroline Silva, Shira Maguen
Clinical Psychology Review 29 (2009) 695–706
<https://msrc.fsu.edu/system/files/Litz%20et%20al%202009%20Moral%20injury%20and%20moral%20repair%20in%20war%20veterans--%20a%20preliminary%20model%20and%20intervention%20strategy.pdf>
(Last accessed February 19, 2016.)

ⁱⁱ "Psychometric Evaluation of the Moral Injury Events Scale"
William P. Nash, Teresa L. Marino Carper, Mary Alice Mills, Teresa Au, Abigail Goldsmith, Brett T. Litz
<http://publications.amsus.org/doi/full/10.7205/MILMED-D-13-00017>
(Last accessed February 19, 2016.)

I would add one to his list. For the average well-fed American member of the armed forces, the mere exposure to extreme poverty can create a moral crisis.

ⁱⁱⁱ “When They Come Home: Posttraumatic Stress, Moral Injury, and Spiritual Consequences for Veterans” Kent D. Drescher and David W. Foy

Reflective Practice: Formation and Supervision in Ministry, Vol. 28,

p. 91 <http://journals.sfu.ca/rpfs/index.php/rpfs/article/view/158> (Last accessed February 20, 2016.)

^{iv} Belleruth Naparstek’s extensive set of products and studies related to veterans can be accessed at, <http://www.healthjourneys.com/Store/For-Our-Military/27> (Last accessed February 19, 2016.)

^v The Healthcare Chaplaincy Network has a website oriented to veterans and their families with many helpful interactive features. <http://chaplaincareforveterans.org/veterans.html> (Last accessed February 19, 2016.)

^{vi} The Soul Repair Center is foremost in the country in providing training and resources for moral injury related ministry. <http://brite.edu/academics/programs/soul-repair/resources/> (Last accessed February 19, 2016.)

^{vii} This handbook was created for Navy military chaplains before the term Moral Injury became current. http://www.healthcarechaplaincy.org/userimages/Spiritual_Care_PTSD_Handbook1.pdf (Last accessed February 19, 2016.)

^{viii} Fr. Michael Lapsley developed the Healing of Memories workshops in South Africa in the aftermath of apartheid. The workshops have helped people around the world related to a variety of traumatic experiences. See his book *Redeeming the Past: My Journey from Freedom Fighter to Healer*. Orbis Books. 2012. ISBN 978-1-60833-227-4 The North American website is <http://na.healing-memories.org> (Last accessed February 19, 2016.) Workshops for veterans are currently being offered in Minnesota and Arizona.

^{ix} “Twelve Spiritual Exercises for Use During the Church Year,” available online, are featured in our book *Welcome Them Home--Help Them Heal: Pastoral care and ministry with service members returning from war*

Copyright 2009 John Sippola, Amy Blumenshine, Donald A. Tubesing, Valerie Yancey
<http://static1.squarespace.com/static/525c0463e4b030e5f071b18b/t/52ced42be4b0df4f2bf6ef43/1389286443094/Church+Year+Activities+%282%29.pdf>

(Last accessed February 19, 2016.) Permission for use link at <http://www.mpls-synod.org/veterans-ministry>

Our book was also published prior to the use of the term moral injury.

Walking with wounded warriors

PRESBYTERIAN CHAPLAIN WORKS WITH SOLDIERS, FAMILIES TO
PROVIDE HEALING, HOPE
AUGUST 23, 2012



The Rev. Lucy Der-Garabedian plays with an orphaned Iraqi child. Dergarabedian is a chaplain who works with wounded soldiers and their families. —*courtesy of Lucy Der-Garabedian*

Special to Presbyterian News Service

TONI MONTGOMERY
MONTREAT, N.C.

When we hear about casualties of war, we tend to think about those who don't return home. But many in the military do return home with wounds of various types and degree.

For the Rev. Lucy Der-Garabedian, who serves with a wounded warrior unit, helping these men and women has been part of her job for the past two years.

Der-Garabedian, an active duty Army chaplain with 16 years of service, was among the chaplains who recently took advantage of a chance to connect and relax at **Montreat Conference Center** during the Aug. 6-9 **Presbyterian Council for Chaplains and Military Personnel** retreat.

"This is called a Warrior Transition Unit and we take them from combat to something else," she explained about the overall mission of the unit. Der-Garabedian prefers not to name her base to help protect the confidentiality of the soldiers and families in her care. This confidentiality and the trust that goes with it are key for all chaplains to build relationships with their soldiers.

The soldiers that come in for help may have physical limitations due to injuries that will keep them from doing jobs they did before. Sometimes they've had head injuries and

can't process thoughts as they once did. Others suffer from post-traumatic stress disorder or other emotional issues and sometimes "self-medicate" or have substance-abuse problems, Der-Garabedian said.

"It's about healing and transition to something different in the military or something civilian," she said. "It's an educational opportunity to find things that suit them."

Each soldier faces unique challenges. There's no blanket solution, and Der-Garabedian and her unit work with each individual to address current needs and equip them for the future. She acknowledged that the tools they use might seem unusual but stresses that the focus is on helping the soldiers.

For one young man, it was giving him a birthday dinner — something he'd never had before — to help connect him to others and deal with issues of depression and substance abuse. For another family, Native American drumming proved therapeutic.

Der-Garabedian's job frequently involves not just soldiers but their families as well. For those who will have permanent physical or mental limitations, the military will bring in and house spouses, parents or even entire families and teach them to be non-medical assistants to take care of their loved ones.

"The families need to learn to tend them," Der-Garabedian said, adding that the presence of family also makes the healing process easier. "It also gives them an emotional connection with that family member. That's something they wouldn't have with a nurse."

Der-Garabedian's job requires a constant need to adapt to the changing situations and challenges of the soldiers and families she helps. That flexibility is something she and others in her unit try to pass on to the families they help, many of whom are facing lives quite different from what they knew before.

"What we do is about resiliency and adjusting to the new normal," she said. "Christ reached out to the marginalized and gave them hope, and that's what I'm trying to do as well, in whatever form it comes."

Toni Montgomery is a freelance writer in Statesville, NC, where she is also secretary for First Presbyterian Church.

<https://www.pcusa.org/news/2012/8/23/walking-wounded-warriors/>



Ten Things Your Student with Autism Wishes You Knew *These ideas make sense for other kids too*

by Ellen Notbohm

Please contact the author for permission to reproduce in any way, including posting on the Internet

Author's note: When my article, "Ten Things Every Child with Autism Wishes You Knew" was first published in 2004, I could scarcely have imagined the response. Reader after reader wrote to tell me that the piece should be required reading for all social service workers, teachers and relatives of children with autism. "Just what my daughter would say if she could," said one mother. "How I wish I had read this five years ago. It took my husband and me such a long time to 'learn' these things," said another. As the responses mounted, I decided that the resonance was coming from the fact that the piece spoke with a child's voice, a voice not heard often enough. There is great need – and ever-increasing willingness – for the general population to understand the world as the child with autism experiences it. Ten Things Every Child with Autism Wishes You Knew became a book in 2005, and the voice of our child returned in this article to tell us what children with autism wish their teachers knew. It too became quite popular and my book by the same title was published in 2006.

Here are ten things your student with autism wishes you knew:

1. Behavior is communication. All behavior occurs for a reason. It tells you, even when my words can't, how I perceive what is happening around me.

Negative behavior interferes with my learning process. But merely interrupting these behaviors is not enough; teach me to exchange these behaviors with proper alternatives so that real learning can flow.

Start by believing this: I truly do want to learn to interact appropriately. No child wants the spirit-crushing feedback we get from "bad" behavior. Negative behavior usually means I am overwhelmed by disordered sensory systems, cannot communicate my wants or needs or don't understand what is expected of me. Look beyond the behavior to find the source of my resistance. Keep notes as to what happened immediately before the behavior: people involved, time of day, activities, settings. Over time, a pattern may emerge.

2. Never assume anything. Without factual backup, an assumption is only a guess. I may not know or understand the rules. I may have heard the instructions but not understood them. Maybe I knew it yesterday but can't retrieve it today. Ask yourself:

- Are you sure I really know how to do what is being asked of me? If I suddenly need to run to the bathroom every time I'm asked to do a math sheet, maybe I don't know how or fear my effort will not be good enough. Stick with me through enough repetitions of the task to where I feel competent. I may need more practice to master tasks than other kids.
 - Are you sure I actually know the rules? Do I understand the reason for the rule (safety, economy, health)? Am I breaking the rule because there is an underlying cause? Maybe I pinched a snack out of my lunch bag early because I was worried about finishing my science project, didn't eat breakfast and am now famished.
3. **Look for sensory issues first.** A lot of my resistant behaviors come from sensory discomfort. One example is fluorescent lighting, which has been shown over and over again to be a major problem for children like me. The hum it produces is very disturbing to my hypersensitive hearing, and the pulsing nature of the light can distort my visual perception, making objects in the room appear to be in constant movement. An incandescent lamp on my desk will reduce the flickering, as will the new, natural light tubes. Or maybe I need to sit closer to you; I don't understand what you are saying because there are too many noises "in between" – that lawnmower outside the window, Jasmine whispering to Tanya, chairs scraping, pencil sharpener grinding. Ask the school occupational therapist for sensory-friendly ideas for the classroom. It's actually good for all kids, not just me.
 4. **Provide me a break to allow for self-regulation before I need it.** A quiet, carpeted corner of the room with some pillows, books and headphones allows me a place to go to re-group when I feel overwhelmed, but isn't so far physically removed that I won't be able to rejoin the activity flow of the classroom smoothly.
 5. **Tell me what you want me to do in the positive rather than the imperative.** "You left a mess by the sink!" is merely a statement of fact to me. I'm not able to infer that what you really mean is "Please rinse out your paint cup and put the paper towels in the trash." Don't make me guess or have to figure out what I should do.
 6. **Keep your expectations reasonable.** That all-school assembly with hundreds of kids packed into bleachers and some guy droning on about the candy sale is uncomfortable and meaningless to me. Maybe I'd be better off helping the school secretary put together the newsletter.
 7. **Help me transition between activities.** It takes me a little longer to motor plan moving from one activity to the next. Give me a five-minute warning and a two-minute warning before an activity changes – and build a few extra minutes in on your end to compensate. A simple clock face or timer on my desk gives me a visual cue as to the time of the next transition and helps me handle it more independently.

- 8. Don't make a bad situation worse.** I know that even though you are a mature adult, you can sometimes make bad decisions in the heat of the moment. I truly don't mean to melt down, show anger or otherwise disrupt your classroom. You can help me get over it more quickly by not responding with inflammatory behavior of your own. Beware of these responses that prolong rather than resolve a crisis:
- Raising pitch or volume of your voice. I hear the yelling and shrieking, but not the words.
 - Mocking or mimicking me. Sarcasm, insults or name-calling will not embarrass me out of the behavior.
 - Making unsubstantiated accusations
 - Invoking a double standard
 - Comparing me to a sibling or other student
 - Bringing up previous or unrelated events
 - Lumping me into a general category ("kids like you are all the same")
- 9. Criticize gently.** Be honest – how good are you at accepting “constructive” criticism? The maturity and self-confidence to be able to do that may be far beyond my abilities right now.
- Please! Never, *ever* try to impose discipline or correction when I am angry, distraught, over stimulated, shut down, anxious or otherwise emotionally unable to interact with you.
 - Again, remember that I will react as much, if not more, to the qualities of your voice than to the actual words. I will hear the shouting and the annoyance, but I will not understand the words and therefore will not be able to figure out what I did wrong. Speak in low tones and lower your body as well, so that you are communicating on my level rather than towering over me.
 - Help me understand the inappropriate behavior in a supportive, problem-solving way rather than punishing or scolding me. Help me pin down the feelings that triggered the behavior. I may say I was angry but maybe I was afraid, frustrated, sad or jealous. Probe beyond my first response.
 - Practice or role-play – *show me*—a better way to handle the situation next time. A storyboard, photo essay or social story helps. Expect to role-play lots over time. There are no one-time fixes. And when I do get it right “next time,” tell me right away.
 - It helps me if you yourself are modeling proper behavior for responding to criticism.
- 10. Offer real choices – and only real choices.** Don't offer me a choice or ask a “Do you want...?” question unless are willing to accept no for an answer. “No” may be my honest answer to “Do you want to read out loud now?” or “Would you like to share paints with William?” It's hard for me to trust you when choices are not really choices at all.

You take for granted the amazing number of choices you have on a daily basis. You constantly choose one option over others knowing that both *having* choices and

being *able* to choose provides you control over your life and future. For me, choices are much more limited, which is why it can be harder to feel confident about myself. Providing me with frequent choices helps me become more actively engaged in everyday life.

- Whenever possible, offer a choice within a 'have-to'. Rather than saying: "Write your name and the date on the top of the page," say: "Would you like to write your name first, or would you like to write the date first?" or "Which would you like to write first, letters or numbers?" Follow by showing me: "See how Jason is writing his name on his paper?"
- Giving me choices helps me learn appropriate behavior, but I also need to understand that there will be times when you can't. When this happens, I won't get as frustrated if I understand why:

"I can't give you a choice in this situation because it is dangerous. You might get hurt."

"I can't give you that choice because it would be bad for Danny" (have negative effect on another child).

"I give you lots of choices but this time it needs to be an adult choice."

The last word: *believe*. That car guy Henry Ford said, "Whether you think you can or whether you think you can't, you are usually right." Believe that you can make a difference for me. It requires accommodation and adaptation, but autism is an open-ended learning difference. There are no inherent upper limits on achievement. I can sense far more than I can communicate, and the number one thing I can sense is whether you think I "can do it." Encourage me to be everything I can be, so that I can continue to grow and succeed long after I've left your classroom.

© 2005, 2010 Ellen Notbohm

Ellen Notbohm is author of *Ten Things Every Child with Autism Wishes You Knew*, *Ten Things Your Student with Autism Wishes You Knew*, and *The Autism Trail*

Guide: *Postcards from the Road Less Traveled*, all ForeWord Book of the Year finalists. She is also co-author of the award-winning ***1001 Great Ideas for Teaching and Raising Children with Autism or Asperger's***, a Silver Medal winner in the 2010 Independent Publishers Book Awards. Ellen is a contributor to numerous publications and websites around the world. To contact her or explore her work, please visit www.ellennotbohm.com . Join Ellen's community of Facebook fans at Ellen Notbohm, Author: <https://www.facebook.com/ellennotbohm/>

The Word in Action

My brother Tony, age 31, recently joined the church he attends. This would not be so unusual, except that he has attended that same church just about every Sunday of his life. He was baptized there. He worships there. He brings his gifts there. But it took an interim pastor to ask the obvious question, "Why isn't Tony a member of this church?"

Tony has Down syndrome. Combined with hydrocephalus at birth, he functions at a lower level than most people with Down syndrome. He learned to sit up on his own at the age of five, to walk when he was ten. He communicates in sign language, with a vocabulary of perhaps fifty words, most of which have to do with sports or food – his favorite topics. He loves to show people the many medals he has brought home from the Special Olympics – including a gold medal for bowling, and a bronze medal for the softball throw. Tony's other event is the 50 yard dash. Unlike the other events, Tony has never won a medal for his racing skills; you see, whenever Tony hears anyone cheering for him as he runs, he stops right there and begins clapping for himself. Tony runs for the sheer joy of the running.

My brother and I could not be more different. He's never learned to read or write, while I have earned my Master's degree. I'm very seldom happy with where I am in life, always reaching for something more, another level of achievement. Tony is able to enjoy each day as it comes. I get caught up by all that I am unable to do – Tony celebrates everything that he is able to do. I am an ordained Minister of the Word and Sacrament, Tony just added his name to the membership rolls of his congregation. Unable to attend even a modified Sunday School class, much less a confirmation course, Tony had never taken this official step. And so we celebrated when he stood in front of the congregation and signed "yes" to the question, "Do you love Jesus?" and another "yes" to "will you share your gifts with this congregation?" And so Tony became a member of his church, confirming his membership in the Church Universal all along.

My brother will never stand in front of a congregation as I do each week and interpret scripture. He has never read any of the great theologians, never studied Greek or Hebrew....but Tony's life is his proclamation of the gospel: the love he extends to each person he meets, regardless of their station in life, the freedom with which he shares the love of the One who created him....this gives him his authority. Like Sign Language, he shows the word in action....and thus proclaims his faith in the Author of all life.

The Rev. Tammy Rider
First Presbyterian Church, Claremont, MN, 2001-2006

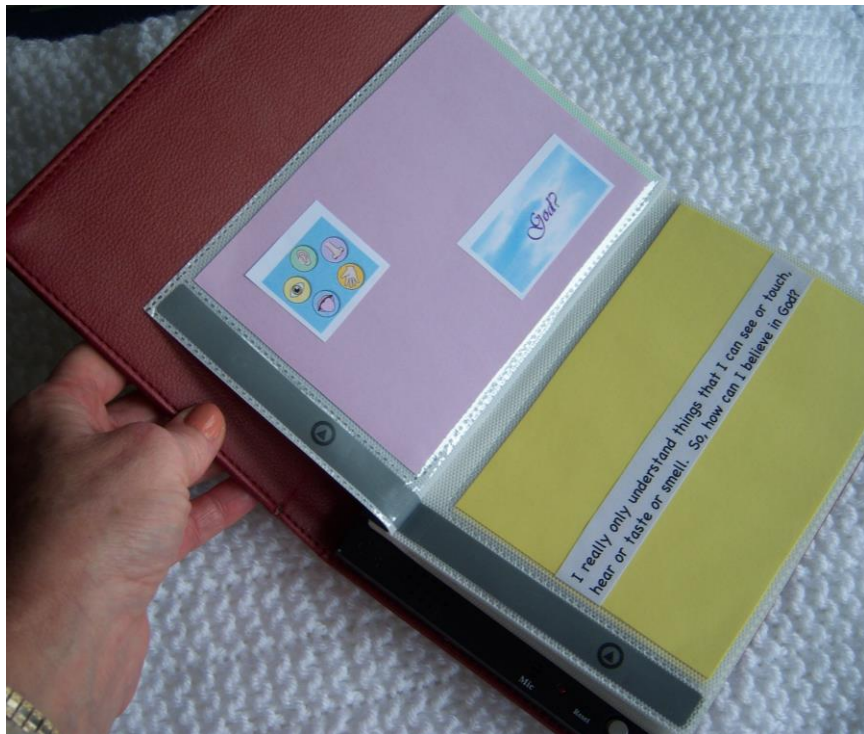
Confirmation: Tools for Inclusion

By Cindy Merten

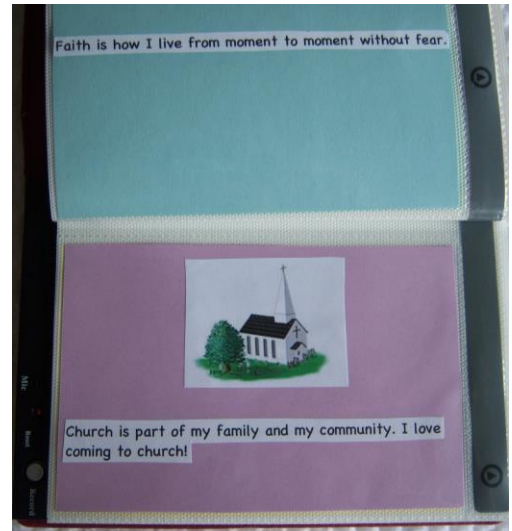
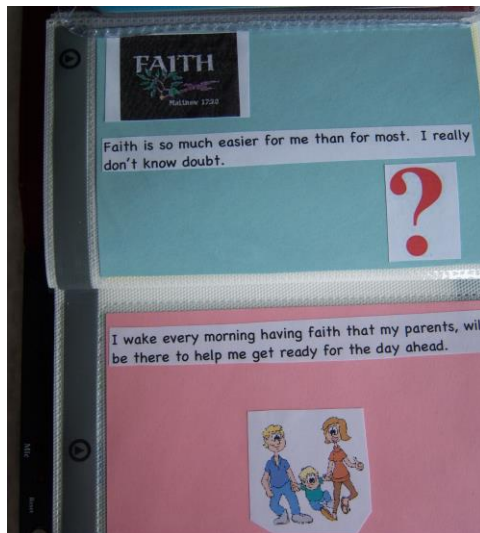
Several years ago I happened to see a photograph of three 8th grade girls in our confirmation class which filled me with deep sadness. Two stood smiling with arms draped around one another's shoulders, while the third stood slightly off to the side looking painfully uncomfortable. This was *not* a picture of inclusion, and it haunts me to this day. Emily had a rare developmental disability, and we struggled that year with fully including her in confirmation class. Inclusion of all our youth has been our goal, and yet we have all too often missed the mark.

Inclusion truly is one person at a time and there is no easy formula or one-size-fits-all method to ensure its happening. In our journey toward inclusion we have sought ways to help our youth, who are often uncomfortable in their own skin at the age of 13 or 14, to include their peers with disabilities.

A part of our confirmation experience has included the public presentation of faith statements to the session, parents and the class. That expression of faith may be a verbal statement or an artistic representation such as a poem, song, a collage or a painting. One tool used by a recent confirmand who did not have speech, is a talking photo album. As her mother said in her introduction to Elizabeth's presentation of her faith statement, "Elizabeth doesn't have speech, but she certainly has a lot to say." On each page of her talking photo album, a 10 second message was recorded in the voice of one of her friends. A script and pictures accompanied the recorded message on each page. Elizabeth then pushed the button marked with an arrow on each page to play the message accompanying the text and picture. You can see a video of Elizabeth presenting her statement of faith on our church website at <http://www.fpcbirmingham.org/disability-inclusion-resources.html>



The photographs below are pages from her album.



Talking photo albums are available at <http://www.attainmentcompany.com> and other places on the internet at a cost of \$29. We have found them to be a wonderful tool to provide opportunities for students to interact with one another and for persons with various disabilities to get to know a larger group of people. These photo albums have numerous applications as a tool to aid with communication both in and out of the classroom. Each album holds 24 4 x 6 inch photos and allows for a 10 second message to be recorded on each page.

In another application of the same album, we created a friendship book for a young man with multiple disabilities and visual impairment by inviting each of his classmates to record a 10 second message saying something on the order of "Hi Clay, my name is ____ and I like ____" or whatever message they chose to create for him. Now when he comes to class, his classmates greet him with something similar to their message in his book which he keeps at home and plays repeatedly. We also took a digital photograph of each person and inserted it in the page corresponding with the message so that someone who is sighted could follow along. We have since made more albums for other children and youth to help them become better acquainted with their classmates.

Since our confirmation class is a two-year program, we are working with Clay through the use of narrative stories, music and tactile manipulatives by using these albums as well as other tools we hope to create. The six concepts upon which we are focusing include: 1) God created the world including you and me, 2) Clay is a child of God, 3)



God gave us Jesus who loves us, 4) The church is the family of God, 5) In baptism we become part of God's family, 6) In communion we participate in a family meal.

By using the talking photo albums to present stories to teach these concepts,

others, including Clay's peers and his family, can work with him. During Advent we created a book that tells the nativity story and has a nativity set that is used along with the recorded story. A new character (an angel, Joseph, Mary, a shepherd) in the story is introduced one page and one figure at a time to reinforce learning. Dymo-tape Braille labels that say "Good News" were also added to each page to provide a tactile component for him.

Wherever Clay goes, he usually carries an MP3 player, and he loves to listen to music. We found that it was very simple to record a song in these talking photo albums one phrase at a time as well as on his MP3 player. "I Can See the Fingerprints of God" by Steven Curtis Chapman is a wonderful song for this purpose and can be purchased on iTunes.

Finally, we have used this same talking photo album to create a visual and auditory story about communion. We took photographs of communion in our church including the whole process from beginning to end and then recorded a message on each page. In addition to our confirmands, we are using this with younger children who are also learning about the sacraments. As we continue to seek ways to include all of our children and youth in the full life of the church, my prayer is that we will never again leave anyone standing uncomfortably alone off to the side, but together will find new and creative ways to partake of the gifts of God for *all* the people of God.

Cindy Merten currently serves as Director of Christian Education at First Presbyterian Church, Birmingham, Michigan and on the Presbyterians for Disability Concerns (PDC) Advisory Team.

Tips for Church School Teachers Working With Children Who Have High Energy and/or Have Challenges With Focusing and Staying on Task

By Lynn Cox

Knowing that each child in our church school classes is unique and brings his or her special gifts to the class, the following “teacher tips” are intended to provide a smorgasbord of options that may be helpful for assisting each child to be successfully included. No one suggestion will work for all children or all situations. A child’s age and developmental level may direct variations of the ideas suggested. Likewise the following suggestions are not presented in order of importance or intended to be a complete list but rather a starting point from which more ideas may emerge. They should be available to all the children in a class.

1. Design routines to allow children to get through transitions or tasks so the experience will be positive. Children may benefit from routines (i.e. arriving, greeting friends, getting out or putting away supplies, changing activities). Routines work best if instructions are brief, consistent and fun (once established, children will expect you to follow them). Lists and visual charts can help everyone remember the routine. They take away the need for adults to “tell kids what to do” (you might use photos or hand drawn pictures for young children). Class activities may need to have frequent breaks. Younger children may have better attention or make smoother transitions if directions are sung (create a little song). Some children respond well to routine and predictability of “first we do this, then _____”. When a change in schedule or instructions for an activity must occur, prepare the child by having cues/warning and then extra support for dealing with the transition. Make the change in small steps.
2. Start a class session with a highly motivating activity. Include multi-sensory activities. Vary sit-down activities with activities that are movement-based (movement songs, movement games related to the lesson, heavy work using many muscle groups at the same time such as lifting objects, moving furniture, cleaning up or passing out materials). Movement helps some children to divert excess energy. When unable to remain calm in a classroom, the child might go with an adult for a walk in a hallway or to a designated nearby room for some “active” movement before attempting to return to the class group in a calm manner.
3. Explore different ways to structure a lesson such as teacher-directed or activity centers/stations. Children may benefit from a predictable format of changing stations on a certain signal or free roaming at his or her own pace (for some children this is less threatening and they feel they have more control, but for a child who flits from one learning space/activity to another or gets “stuck” on a preferred activity, it is less effective). Minimize verbal directions. Supplement with pictures or charts. Speak in slow, even tones.

4. For children who have high energy and need to “wind-down” for a quiet individual or group activity, try activities that have a slow rhythmic movement or oral activity such as (with parent permission) chewing gum, sucking or licking a lollipop. Snacks might include healthy chewy food such as celery, carrots, fruit leather, or beef jerky. Create calming routines. Slow tempo music or picture cues may help. Some children may benefit by sitting at the edge of a group of children vs. in the middle of other children where they might feel threatened by others brushing against their back or coming up beside them from behind.
5. If children appear to be stressed or have disruptive behavior, explore what the behavior is trying to say, “I’m tired. I need more or less sensory input. I don’t understand. There was a sudden change that overwhelmed me. I’m bored. I’m afraid. I’m too excited. Pay attention to me. Stop the noise.” Some children may just need more time for a task/activity.
6. Physical Environment: Create a storage system for class materials so children can be independent in getting out and putting away materials (label containers and keep near where they will be used when possible). Reduce sensory stimulation and lesson distraction by resisting the temptation to cover every wall with posters and art work. Some children may benefit with different types of seating. Some may need a sturdy chair or one with rubber bottoms on chair or table legs. Others may attend better in a beanbag chair. If sitting on the floor, consider using carpet squares or other designated item to sit on which defines a child’s ‘place in space.’ Seating a child away from a window or the door may reduce excess stimulation from outside noise, movement and minimizing sights.
7. For children with additional challenges of regulating sensory input (touch, taste, smell, feel, hear, see): try providing choices of tactile materials during art projects. Try using a glue stick vs. glue or paste. A child may benefit from holding a “fidget toy” during a long period of listening. For some children who become upset in an over stimulating environment, reduce noise and strong odors, offer choices of food/drink (if it is snack time), and decrease the amount of light.
8. Explore additional support and resources from other church educators, public (or private) school educators, and children’s parents who know them well. Build a support system for yourself.

THANK YOU for including and appreciating the gifts each child brings.

Lynn Cox is an experienced teacher in public school special education, is a member of the Presbytery of the Twin Cities Area Disability Concerns Ministry, and is a member of the Advisory Team of Presbyterians for Disability Concerns (PDC), a network of the Presbyterian Health, Education & Welfare Association (PHEWA).

My Faith Journey

Cameron Scott

My twin, Clayton, and I were born May 15th 1997, 10 weeks early. We were tiny, frail, undeveloped, but strong, and we were about to enter the fight of our lives. Clayton contracted meningitis pseudomonas from the respirators meant to help us breathe. I had the bug as well, but with antibiotics I never got sick. Six babies before us got sick - Clayton was the only one to survive, from the 7 babies infected. He still wears his battle wounds, his eyes are gone, he has cerebral palsy, and intellectual/developmental disability.

By the grace of God, he survived. Clayton would soon show me his fighting spirit. He actually was first to go home, the first to learn how to eat, swallow, and breathe. Doctors predicted he would never be able to talk, but he proved them wrong. Clayton is the strongest person I know, yet at this point, I hardly knew him. At 6 years of age Clay went to a place called Penrickton Center, a residential home for blind, and multi-disabled children. Penrickton was invaluable for us; they provided Clayton with resources that we could not provide him. Clayton was at Penrickton 5 days a week and would come back home on the weekends. I hardly got to know him in this time. While he was gone, I struggled with guilt and anger that he was sick. How could God have let this happen to my brother? My faith was challenged in ways that I could not name.

When Clay was 13, he left Penrickton and moved home with us. These last 3 years have been when I've really developed a relationship with Clayton, and my faith changed and grew from it. Sharing daily meals and day-to-day rituals helped me to understand who Clayton is and allowed me to see first-hand what faith could be.

We soon started the journey of confirmation. Confirmation taught me a lot about Clay's faith and my own. His confirmation goal was to learn the Lord's Prayer, so that he could participate in the ritual we all share. Not only is Clay the strongest person I know, both physically and mentally, but he also has the strongest faith out of everyone I know. Clayton participated in the class just like me, which I thought was incredibly cool. Clayton freely shared his faith often - one Sunday in the middle of church he started yelling "GOTTA BE PATIENT." This is Clay's faith, simple, no flashiness or style. His faith is blunt, but that's how it *should* be; I have absolutely no doubt that Clay's spirited sermon was in fact that, spirited. Clay always has that spirit, a spirit overflowing with the love of Christ. He still says the Lord's Prayer. I believe Clay is the direct embodiment of the child which Jesus says is the greatest in the kingdom of heaven.

Clayton's spirit is more than I can even comprehend. I admire so much about him. Clayton has never felt the pain of unkindness; he's never caught up in the petty stuff; he's never had strife. He's happy with things that are often overlooked..... the presence of being around people, simple conversation, and the two letter greeting. As I've spent time with him and watched him, my own faith has grown and changed. Although I read the Bible and attend church regularly, I understand profoundly that the faith that Jesus taught us is simple – love each other, stick to the basics, trust that you will be provided all that you need, be who you are. Clayton reminds me of this daily. This is why I feel disability inclusion is so important for all of us. People with disabilities need to have a place to practice and share their faith. And in helping to provide that place, we can all learn about and deepen our own.

Cameron Scott is an active member of First Presbyterian Church of Birmingham, Michigan and was a junior in high school, as of this writing in 2014, View and use the 25 min. video, "Creating a Culture of Inclusion," produced, co-written, and co-directed by Cameron at: <https://www.youtube.com/watch?v=IkVjmn50zBw>

The Three Ups to Journeying Well During Your Later Years;

Wake Up, Show Up, Lighten Up

Trish Herbert

Wake Up. The recipe for living well is much the same for us all. Wake Up to who you are now and how you can best spend your remaining precious years. Reflect on how you have changed over the years, what is most important to you now, and how to get more of it. You are still a work in progress. You can choose to focus on the “growing” part of growing old. Wake up to choices you have, the tools that are out there for you to use to help buffer the rough spots and improve your chances for living life as fully and satisfyingly as possible. We change. Our values change. What unfinished business do I have? What do I have to do to have peace of mind and to like myself the most? What’s on my bucket list of things I want to do? I can wake up to who I am now and who I want to be.

Show Up. You honor life by pouring yourself into it, by showing up for every moment and noticing all the little things along the way. It’s about appreciating your cup of coffee or tea in the morning, marveling at the snow load on the branches in the winter, the incredible spectrum of greens when the leaves are in all their freshness in the spring. By doing what you love, like gardening, reading, grand-parenting, creating or appreciating the arts, or being of service in some way that is satisfying, you are making the world a little better place. When you do something congruent with your values, however tiny the action may seem, you are making a difference. Showing up means continuing to learn and grow with your heart wide open. Showing up says don’t just let the world happen to you. Even if you can’t make something happen, you can set the stage for what you want to have happen, and have a much better chance of getting what you want. Get out there. Put yourself into circumstances where good things are more likely to happen to you. Be the architect of your future.

Lighten Up. Many of the values that come with late life do lighten us up. The ways-of-being that lead to becoming wiser like being authentic, comfortable with paradox, befriending mystery, appreciating the ordinary, being more humble, rediscovering our awe, being hopeful and flexible, reduces tension and stress and does a part in lightening us up. Learning how to balance between taking ourselves seriously, yet not too seriously, is key. Get as much playing and appreciating into your life as you can. Having seen so many weird and unexplainable things by this time in our lives has increased our sense of the absurd, and ability to laugh at ourselves. What works for one of us won’t for another. We learn not to judge ourselves so harshly. We will screw up because we are human. Our truckload of experiences has shown us that we aren’t perfect but that we are survivors. The seriousness of having to prove ourselves has dissipated. It’s time to accept who we are, warts and all. The art of letting go of what we can’t control and being able to laugh at ourselves and appreciate our strengths means we are journeying well.

Dealing with the difficult times. People with chronic illness or disability follow much the same path as those dealing with the difficult parts and indignities of the normal aging process. You find yourself gradually crossing off things that you can no longer do. Whatever age you experience loss, diminishment, or get a diagnosis, there are adjustments to be made. You may have to eat differently, use a prosthesis, use inhalers, have a new medication regimen, lose some independence.

The process of grieving and dealing with loss is different for older persons than it is when younger. For the elderly there is often a certain readiness, whether conscious or not, a predictability, a knowing, that this is the time of life that you have more losses, physical and emotional. Older adults are very aware of their finiteness, the temporariness of bodies, and are less cocky about how much control they have over things in general. They have had a lifetime of easing into the reality of endings. They have observed at the very least their change in hair color or amount of hair, new aches, other shifts and sags, and a lowering of energy levels. Younger people, disabled in some way or with a chronic illness, still have the illusion of control mightily embedded in them so the shock of feeling helpless may be more terrifying and daunting at first. This predictability of some sort of expected loss leads to less protest, less denial than loss at an earlier age, less of "why me?"

Some of the diminishments that come with late life are already in progress. Loss loses some of its ferocity. There may have been a steady stream of adjustments and acceptances. There's been a subtle or open anticipation of decline approaching for a long time by both the individual and the caregivers... more time to get ready and to finish unfinished business.

Major differences in how one grieves in this stage revolve around the unacceptability for persons in the old-old age bracket to really feel comfortable about expressing their feelings. There are still persons in this age group who believe that "crying doesn't help anything," "not complaining is a virtue," "displaying any expression of feeling is a sign of weakness," and they certainly don't want to "fall apart"... out of consideration for others. There is a belief that it is unpleasant for others to witness emotional pain. This difference is changing. The young-old are more into expressing their feelings. Denial of feelings get some through the rough times without the discomfort of openness, but this denial takes energy and takes a toll on the body. Working with and working through pain and suffering is far more healing in the long run. Working through the pain may be more difficult in later life because you may be dealing with multiple losses.

Often it is more difficult for older people to adjust and move on because it is harder for them to redefine themselves, invest energy in new relationships, etc. This is a much, much harder task to do when you are very old yourself. There is less opportunity, time, energy, or often desire to do so. It is harder for older people to think in terms of starting anything...relationships, projects. Whereas younger persons may often desire new relationships the norm, in my experience, older people have less interest and expectation for this. Younger people hope to move on, find new relationships, etc. When

illness or disability strikes a younger person, however, they may have a harder time finding support because people their age haven't had to deal with loss and often back off. There is no timeline on how long it will take someone to get through the process of mourning. Your mind and body will indicate when you are moving on. You know you are recovering when you begin noticing things that make you glad you are here to experience them. Moments of joy sneak up on you.

Barriers to successful aging. Natural things happen that make aging a challenging time even without disability. You lose physical capacity gradually and this accumulates. Your eyes and ears aren't what they used to be, and you usually have less resilience and energy. Your rebound capacity slows down after illness or accidents. One person said, "You know you are old when everything sags, dries up or leaks."

Society imprints us with negative expectations about late life. Ageism is alive and well in our society. It is aimed more at the old-old than the young-old. Ageism is the term used to describe a societal pattern of widely held devaluative attitudes, beliefs, and stereotypes based on chronological age. Any "-ism" is the need of one group to feel superior over another. Ageism is really the only "-ism" that is still on top of the table, not under it. The media and advertisers make it hard to feel good about how you look when the continual emphasis is on avoiding wrinkles, baldness, white hair, and so on. "What I know is that I spend a huge amount of time with my finger in the dike fending off aging." (Nora Ephron)

Older people, like any oppressed or marginalized group, are asked to accept societal standards and assimilate. Just as people of color are pressured to "look" white, gay and lesbians are more accepted if they look straight; young women are asked to adopt male rules in the business world, and old people are driven to look young and adopt standards of middle age. Able body-ism is closely related, as if people with chronic illness or disability have a choice. Most ageism stereotypes of older people are pejorative, one extreme being patronizing and infantilizing "poor dears." It is a pervasive attempt by the young and even the young-old to distance themselves from even thinking about this later, less-able stage of life.

How Do I want to be treated? There is a variation to the Golden Rule called the Platinum Rule: "Treat others as they want to be treated." When dealing with the old-old or persons with disabilities you need to get to know how they prefer to be treated. You must communicate to find out how one wants to be treated. You ask. You cannot assume anything. You ask how they prefer to be addressed. You look at them. If you can't understand what the person is saying, you might ask them to spell the word...like T as in Tom. Don't pretend to understand. Stick with it. Talk directly to them, not to others in the room about them.

The Three Peaks of Life-- Physical, Productive, and Personhood. Being closer to the “whole” of our life we have most certainly passed the Physical Peak of our lives, healthy or not. Our biological decline begins at a relatively young age. Most studies say that it is downhill after the age of 30. We lose at a rate of about 1% our muscle mass, organ function, etc. Over a normal life span, such natural physiological declines are not preventable, although they may be accelerated or slowed by a variety of individual genetic factors, personal behaviors such as diet, smoking, and exercise, health care practices (e.g., screening and treatment for heart disease), and other environmental circumstances (e.g., working conditions).

We have most likely passed the Productive Peak of our lives, and have moved into the very important Spiritual or Personhood peaking time, which enables us to see the whole with a much broader lens. The best age to be is the age you are. Give some careful thought to how you can become closer to being the person you want to be... to live your last years congruent with your values-- and to have the best possible time doing it.

Trish Herbert is a retired Psychologist/Gerontologist. Much of the above is taken from her book “Journeywell: A Guide to Quality Aging.” To learn more about the book or to order a copy, go to her website: <http://www.trishherbert.com/Site/Welcome.html>

Letting Go: A Mother's Story

Roxanne Fredrickson Ezell

My parents eagerly volunteered to babysit for their first grandchild shortly after he was born. My husband and I were grateful for an evening away from home. When they arrived at our front door, I presented them with my son and a three-page list of instructions. I trusted them but couldn't resist telling them exactly what the baby and I expected. After some well-deserved teasing they promised to comply with as many items as time allowed. I like to imagine them sitting beside each other on the couch, my mother cradling David in her arms, my dad reading the list. Perhaps they heard echoes of their own parenting in my words.

A year later, David was diagnosed with several conditions that would profoundly affect his life and ours. The pediatrician said our son must learn to trust people besides his parents. That part we assumed; David had already had many happy (and list-free) experiences with his grandparents and others in his first year. The doctor went on to explain that David must also learn to trust doctors, therapists, teachers, and all the other professional people who would be part of his life. We agreed.

What the doctor did not say, however, was that David's parents had to learn to trust others, too. This has been harder than I had imagined. It was one thing to trust a doctor's diagnosis. It has been another thing to gradually let go of the day-to-day responsibilities of supporting his life and to trust that others' care will replace our own.

In the early years – my 'mother bear' stage – I felt that if a situation was not acceptable for David, it was up to me to summon the knowledge and power to change it. Over time and by some power of grace, though, I have learned better ways to support David and even to gradually 'let go,' trusting others to keep him safe, healthy, and independent from us. We owe him that.

Mother Bear made her first appearance in my own mother one day when my parents joined us at an appointment with a language therapist. The therapist announced that David, age two and a half, would never have an imagination. I suspected this wasn't true because he had recently pointed to a tin of cocoa stuck in the front corner of our grocery cart and said "car." The tin's indented circular lid was facing forward and David was pointing out one of the car's headlights. My mother didn't know this. Her claws came out. She looked at the therapist with such rage that I imagined her swiping the woman's face. Mother Bear's appearances in my life were rarely as dramatic. When David was in ninth grade, though, she stood up on her hind legs and roared.

Our son had thrived in elementary school with a combination of regular and special education classes. His middle school teachers in particular made countless accommodations to support his success. I was shocked when he was given only two

options for high school: regular classes with no accommodations or a completely self-contained classroom. The room was bad enough - eight boys crammed into a green-

walled cell devoid of resources, windows too high to see anything but sky - but worse was the teacher, whose idea of writing an Individualized Educational Plan (IEP) was to Xerox the table of contents from one of his textbooks. This man proudly told us that his students got real-life experience by taking turns walking to the cafeteria with a dollar bill to buy him a carton of milk for lunch. They counted out the change when they returned to his room.

David started the year in regular classes. I knew he would have trouble following lectures and had no idea how he would manage tests, but it seemed the only alternative. Sure enough, David had trouble processing much of what his teachers presented. Being a well-behaved child, he made no fuss, but when he couldn't learn the Latin names for the human bones in ninth grade science, Mother Bear had had enough.

Standing in our kitchen with a telephone in one hand and a list in the other, she read her demands to the Director of Special Education: a real IEP, regular contact with other students, and accommodations so he could succeed in academic courses as well as gym, and music; real-life skills like cooking one-handed, budgeting, socializing; work skills like interviewing, writing a resume, being a dependable worker, and career exploration to find work that fit his talents, interests, and abilities.

The Director of Special Ed said they had been waiting for input just like this from a parent. I suspected I was being "handled" but took her at her word. I did not dwell on why it had taken so long for a parent to suggest changes that seemed so obvious and important to me because the story had a happy ending. The high school developed several hands-on courses like "bachelor survival" – cooking, mending clothes, budgeting, even a session on ballroom dancing - and supported David in other classes.

Late one night his biology teacher called, exultant because David had gotten a 'B' on a test. I was overcome with gratitude for everyone who had made it possible for my son to learn that extremely hot weather makes millions of lightening bugs fill a prairie night with twinkling. I realized David needed interventions far beyond my own power but I gave silent thanks to Mother Bear for her courage and a peculiar, calm certainty of purpose. It felt good to have been part of this transformation.

High school graduation brought grief for David. At the Senior Breakfast, he listened to others share memories and laugh at 'in' jokes he had never heard. He realized how isolated he had been from other students in spite of sitting next to them in class all these years. He heard their plans for next year. Later that day he came to me in tears. "What will become of me?" he asked.

I hugged this beautiful young man, newly grown taller than his mother. I cried, too, weeping for both of us and the empty places in our hearts where visions of his future should have been. I told him the one true thing I knew.

“David,” I said, “Whatever happens, we’ll work it out together. We will never, ever abandon you. You will never be alone.”

Not long afterwards our family moved to a different state where David received three years of training in self-advocacy, career exploration, and training for getting and holding a job. By the time he had graduated from this program, he had landed a part-time job as a janitor in a local nursing home. Two years later he moved into an apartment served by a group home. He lives there happily still, among friends and support staff who have gradually shaped his adult life in positive ways beyond what his parents could have done for him.

Managing these changes was not a job for Mother Bear. She gets credit for perseverance and cunning, but a different image helps me understand how my husband and I, along with many others, supported David’s transition to adulthood. It also gives us a vision of a stable future for him, even when we are gone. Best of all, it is a gift of David’s imagination.

When he was ten, he explained how people get to heaven.

“You bounce on a trampoline, higher and higher and higher, until you get up there, and then there’s a big buffet everywhere, and you can eat whatever you want.”

Today David bounces sturdily on the strength and resilience of the trampoline that he and his family have woven over the past thirty-six years. We are humbled by our debt to the other weavers - teachers, doctors, school administrators, friends, job coaches, occupational and physical therapists, fellow church members, social workers, governors, legislators, psychologists, drivers, pharmacists, group home staff, employers, co-workers, neighbors, and everyone who pays taxes to help support David’s precious independence – for sharing their expertise, insight, experience, and power so this image can be more than a metaphor.

At this point Roger and I are David’s spotters. Legally we are his co-conservators, responsible for his person and his finances. We observe him bouncing, his angles and his height. We ask him whether he is happy where he lives and with the helping people in his life. Almost all of his day-to-day support, though, comes from the group home, his employers, and the employment agency. We depend more and more on others to maintain his mat.

Many blessings flowed from this process. David became a ‘neat-nick’ once he had his own place. He kept his new surroundings immaculate. Instead of becoming a recluse, he made friends and began to enjoy socializing. He could ask trustworthy people about things he’d rather not discuss with his parents. We felt advantages, too. We no longer

had to eat meals at exactly the same time every day to keep his medicine at a constant level in his blood. I had time to rediscover interests that I hadn't had time or emotional energy to pursue: writing, singing, yoga. Another humbling moment came when I realized that other people could sometimes handle situations better than me. The group

home staff calls David's neurologist instead of an ambulance when David has a severe seizure, sparing him an unnecessary three hours in the emergency room.

As my husband and I age, it's increasingly urgent for us to back up and spot from a distance. This is still hard. Although we know it's for David's sake, and our own, the letting-go still frightens me. We have given the group home legal responsibility for maintaining his health. Simply writing the sentence awakens guilt and the beginning of panic. Much to our chagrin we have become single-issue voters. We look for fellow weavers, evaluating a candidate by his or her intent to maintain the social safety net. We still face the most daunting task of all, finding someone David's age or younger to be his conservator when we are gone. Our son will always need a spotter.

These days I let other people make the lists. I dream, instead, of a future beyond my control. I dream of research that finds cures for epilepsy and birth defects, of good people continuing to make careers in medicine and human services, of citizens who continue to believe that justice, not pity, requires ensuring a life of dignity to even the most vulnerable ones among us.

I dream of David living with people he cares about and who care about him, of the joys he will experience, his pride and sense of contribution for the work he does, and of the contributions he will continue to make to those around him.

I pray that the people in his life will love and appreciate David for his courage, his integrity, his loyalty, his sense of humor, and his generous heart. I pray that David and all people with disabilities will receive the blessings Isaiah promised God would give to the Israelites mourning in Zion: a garland instead of ashes, the oil of gladness instead of mourning, the mantle of praise instead of a faint spirit.

**They will be called oaks of righteousness,
the planting of the Lord, to display his glory.
Isaiah 61:3**

Roxanne Fredrickson Ezell is a graduate of Carleton College and holds an M.A. in Music from the University of Iowa. She teaches private music lessons and tutors part-time after retiring from work as a public school music teacher, computer programmer, and choir director. She has always loved the music in words. She lives in Orono, Minnesota with her husband Roger. Their son David lives nearby.



Facets of Aging and Disability: A Vision for Community, Dignity, and Wellbeing

Milton Tyree

*To everything - turn, turn, turn
There is a season - turn, turn, turn
And a time for every purpose under heaven*

It was 1965. And thanks to the Byrds, a generation of Americans had Pete Seeger's tune stuck in their heads. And it wasn't just the tune. Whether or not the singing-along millions had ever peeled back the cover of a King James, they nonetheless could nail every word of Pete's rendition of Ecclesiastes 3:1-8. Well... even if not the entire song, any teenage pop fan worthy of his or her bell-bottoms and granny glasses could sing the chorus with conviction, "*To everything, there is a season, and a time for every purpose under heaven*" – appropriately inserting the requisite turn, turn, turns.

It's that pesky verse "*and a time to every purpose under heaven*" that causes so much grief nowadays. Aging just isn't cool anymore. Youth. Newness. Quickness. Independence. Self. These are the operational values of today's society. All too often, expectations are very low for leading a full and meaningful life in later years. Of course, it's not always been this way. Not long ago, elders were admired, their wisdom and experience valued, and the natural slowing down in life was anticipated.

In this article we're exploring positive possibilities for people with disabilities who are aging along with their parents, who are sometimes referred to as "aging caregivers." As with aging, our human construct of "disability" threatens the illusion of independence. It's often translated as a burden instead of a natural part of life. So adding "disability" to the aging equation intensifies the prejudice. Because even if social devaluation of elders is a phenomenon of modern times, devaluation of people with disabilities has been a part of societies before Jesus' days on earth and ever since.

The questions are many and weighty: What are ways of leveling the playing field for people at risk of social devaluation because of disability and/or aging? What will happen to my son or daughter after I'm gone? Where is safety to be found? The following introductory ideas are offered for consideration:

Avoid "special" – Special groups, special classes, anything that begins with the adjective "special" when it relates to grouping people requires careful analysis. Despite the best of intentions and possible benefits, the risks are significant. When a socially devalued characteristic, in this instance aging and/or disability, becomes the qualifying characteristic for group membership, then it reinforces ideas like "those people" are all alike; "they" need the same things, and "they" belong together. The wounding intensifies until the devalued conditions that landed a person in the special group begin to define his or her identity and life. (Hearing about "the man

who has Down syndrome and dementia” doesn’t tell us much about this person, his aspirations, interests, and gifts.) And by extension, people on the outside of the special group come to believe themselves to be fundamentally different, with nothing to offer and nothing to gain through relationships with “them.” It doesn’t have to be this way.

Seek what's typical, valued, and fitting for the person's interests and talents --

Devote time to know people – one person at a time. Build a community where all are welcome, each participating in meaningful ways according to personal gifts. The apostle Paul's familiar advice to the Corinthians rings true, “Now you are the body of Christ, and each one of you is a part of it.” (1 Corinthians 12:27) Wellbeing is rooted in relationships with trustworthy people in open settings. This is one often-overlooked way to address a loved-one’s present and future safety and security. Unknown, unconnected, and stigmatized people are more vulnerable to exploitation or abuse than are known, connected, and respected people.

Avoid competition -- A world that thrives on hyper-competition can cause people to lose perspective about themselves, others, and life.

Seek contribution -- A colleague who's assisted many people with disabilities secure fulfilling jobs taught me to look for things people have to contribute and then match these ways of contribution with employer needs. The same principle applies to other roles in life. Avoid competition. Memory, mobility, vision may fade over time. Just because people can't do everything they once did doesn't mean they can't do elements of former roles. So, let the contribution begin!

Avoid feeding the ageism stereotypes -- Disability and age carry stereotypes about what people can and can't do. And often they're centered on *can't*.

Seek purpose and fullness -- At a recent presentation about supported employment to a group that included job seekers with intellectual disabilities, “Carolyn,” a 70-year-old woman who's never been employed was adamant about needing a job, her first job, at age 70. She's actively defying the idea that one who's never worked should seek a life of retirement. Go, Carolyn!

Avoid doing it alone -- Many others have developed ways of pursuing lives centered in fullness -- not problem-free lives mind you, but lives lived well.

Seek like-minded people and community and congregational responses - A recently revised Mennonite publication, "[Supportive Care in the Congregation: Providing a Congregational Network of Care for Persons with Significant Disabilities.](#)" describes Supportive Care Groups, a radical approach of support for the entire family. It also provides introductory information about managing resources and planning for the future using "special needs trusts" and "pooled trusts."

A companion book through MennoMedia, "[After We're Gone](#)," provides additional information on wills, trusts, and guardianship.

Easter Seals and the National Endowment for Financial Education developed an informational and planning document, "*With Open Arms: Embracing a Bright Financial Future for You and Your Child.*," available for free download at: <http://es.easterseals.com/site/DocServer/WithOpenArms.pdf?docID=69583>

The Aging in Place movement provides alternative ways of thinking about and responding to the impact of aging. Here's one web site as a way of introduction: <http://www.ageinplace.org/>

Build lives of belonging, understanding, and mutuality. The benefits are many for each person, for our communities, and for society. *And a time for every purpose under heaven*

Note: This brief article relies on a variety of ideas, insights, and theories related to social integration and belonging -- none of which originated with the author.

Milton Tyree serves as [PC\(USA\) Disability Concerns Consultant](#) in areas of Intellectual & Developmental Disabilities. He can be reached at: PDCmtyree@me.com



Healing vs. Curing: Reflections for Pastoral Caregivers

Based on Mark 10:46-52

The Rev. Bebe Baldwin

My friend Barbara shared this story during a recent sermon. The incident she described took place in a Presbyterian-related care center.

One Thursday morning when I went to visit my mother in her nursing home, I was waiting, cane in hand, on a bench by the front door for my sister-in-law to arrive. Suddenly a woman (who I learned later was a volunteer leader of a Bible study) rushed up to me and said, "May I pray for you?" Too startled to think of a good answer, I replied, "If you want to." She prayed, "Gracious God, please heal her and lift the heavy burden of her blindness from her." Ungracious wretch that I am, I would have preferred her not to have made so many incorrect assumptions about my condition.

No doubt the volunteer meant well but she made the immediate assumption that Barbara needed to be "fixed." She saw only Barbara's disability; she saw only her blindness.

What a difference there was in Jesus' encounter with Bartimaeus! In contrast with most of the healing narratives, we know the name of the man Jesus healed. Names are important but the volunteer never asked Barbara's name. In the Bible, a name expresses the essence or the reality of a person. Bartimaeus means "son of the unclean."

In Jesus' culture, sin was believed to cause disability. To be unclean, however, did not mean sinfulness. A person was "unclean" if she or he failed to fulfill the demands of the ritual law. For example, Jesus' disciples were criticized because they did not wash their hands in the prescribed way before eating. They were eating with "unclean" hands. (Mark 7:1-4) We cannot know why Bartimaeus was given his name, but it appears that he was alienated both because of disability and because of some family disgrace.

Was it because of the man's status as "son of the unclean" that the crowd "sternly ordered" him to be silent as Jesus approached? Did they judge the man to be unworthy of healing or even approaching Jesus? Were they shaming him for sins they suspected or imagined that had caused his disability?

Jesus defied the demands of the crowd and called Bartimaeus to come to him. In doing so, he called into question the values of his culture. He turned shame into mercy.

But what Jesus said next was truly amazing. "What do you want me to do for you?" Jesus was affirming the man's right to be his own advocate. Jesus trusted a man who

had been marginalized by his blindness and his family status to know and say what he needed. Jesus showed respect as well as mercy for the “son of the unclean.” Jesus listened! He said nothing about sin or repentance or diligence in following the ritual laws. (In another story about a man who was blind, Jesus’ disciples asked, “Rabbi, who sinned, this man or his parents, that he was born blind?” Jesus answered, “Neither this man nor his parents sinned...” John 9:2-3)

Jesus’ words, “Your faith has made you well,” have often been used to “prove” that if we have enough faith, we’ll be “fixed by reversing our disability condition.” We usually understand faith as meaning “to believe” or “to trust.” In the Gospels, believing also implies obedience. It is difficult, however, to know exactly what faith meant in the healing stories. Nor do we know exactly what took place in Bartimaeus’ life or what form his healing took. I believe that the Greek word translated as “made well” is helpful here.

In the Gospels, healing was *never* limited to a physical cure. The Greek word means “to be made whole.” Healing involved the whole person. The meaning is similar to shalom in the Hebrew Scriptures. According to Kathy Black, the people in Jesus’ culture understood health as “one’s sense of being in the community.” * In the healing stories, restoration into the community is usually part of the healing. We are told that Bartimaeus “followed him on the way.” Bartimaeus found a new community.

Perhaps if the woman in Barbara’s story had understood the difference between “healing” and “curing,” the encounter would have been very different. She would have recognized Barbara as a person created in the Image of God. If she had taken time to know Barbara, she would have discovered her to be a member of the Body of Christ with valuable gifts to share. (I Cor. 12:4-6)

In our “enlightened” century, we confuse healing and curing. Healing may or may not include curing of the body. Healing, in contrast with a physical cure, includes the whole person. It means being at peace with our selves and our bodies. It includes our relationships with others and with God. Not all of us will be cured, but we are all called to be healed. When I was newly disabled and struggling to learn to live with my vision loss, a wise friend told me, “You are more than a pair of eyes.” Healing can begin when we know that we are more than our disabilities!

In fact, most of us who live with disabilities don’t feel a need to be “fixed” by a physical cure. Whether we were born with a disability or developed one later, our disabilities are part of who we are, part of our identities. Our disabilities have shaped our perspectives in profound ways.

What we do not want is pity. A popular and highly respected religious leader spoke recently of his “compassion” for blind people who cannot see a beautiful sunset. I was reminded immediately of a comment Barbara made to me, “Being able to see is not what I long for.” What we do want is to be accepted as we are and to have opportunity for inclusion and participation in our churches and communities.

Healing, therefore, goes beyond the individual. It involves the attitudes of the whole community. As long as people with disabilities are silenced, the community is in need of healing. As long as people with disabilities are relegated to the fringes of a

congregation, the community is broken. Writing of the Body of Christ, Paul said, "If one member suffers, all members suffer together with it; if one member is honored, all rejoice together with it." (I Cor. 12:26)

Are there modern stories of healing? Let me give you some examples.

- ❖ A man with cerebral palsy discovered new meaning in his life when he joined an advocacy group that was working for a more inclusive church for people with disabilities. Members of his congregation recognized his gifts and elected him to the Session.
- ❖ A child with Down Syndrome was invited to a birthday party for a member of his church school class. The children discovered that they could play games and have fun together.
- ❖ A woman with a developmental disability was elected to the Board of Deacons. People in the congregation who had questioned her ability to serve were surprised when she discovered her own unique ways of being faithful.

Let us pray for more "miracles" of healing!

* Kathy Black, [*A Healing Homiletic: Preaching and Disability*](#) (Nashville, Abingdon Press, 1996) pg. 46.

The Rev. Bebe Baldwin is a retired member of the Presbytery of the Twin Cities Area. She serves in the leadership of the Presbyterians for Disability Concerns (PDC) Network of the Presbyterian Health, Education & Welfare Association (PHEWA), and is active with the [Presbytery Disability Concerns Ministry](#).



Practical Guidelines for Starting a Circle of Friends Within Your Faith Community

The Rev. Donna Whitmore,
Past Moderator, Presbyterians for Disability Concerns (PDC)

Identification of a person for whom a Circle is desirable

Each congregation is unique and forming a Circle for a person who has a disability will be unique to your church and the individual for whom the Circle is being formed.

- Typically a church member, staff person, or pastor will become aware that an individual with a disability is not well connected with other church members in meaningful ways or the individual may be asking for more support from the pastor or congregation.
- A church member may feel that he or she is the only friend or support and wishes others were also involved in the person's life.
- An individual experiences major transitions or challenges that prompt the church to respond and provide additional ongoing support.

Identification of a facilitator

The pastor or church member identifies one or two persons they feel might be willing to participate in a Circle. Ideally, they will be the facilitator or co-facilitator. It is wise to have one or more persons committed to the Circle concept before approaching the person with a disability so that expectations are not shattered if no one chooses to participate in the Circle. A pastor or other informed person orients the people who agree to participate.

Exploration of the Circle concept with the person who has a disability – the “focus person”

Unless the facilitators know the focus person well, they should spend one-on-one time with the individual to get better acquainted and to deepen the relationship before suggesting the Circle. Taking time to develop a meaningful relationship is important. It is the basis on which everything else in the Circle depends. The pastor and/or church members can then present the Circle concept to the focus person to determine his or her interest. The facilitator and focus person explore together the individual's goals and dreams at this time in their life. This may involve some of the following questions. Some may be addressed in the early stages of the Circle.

- Tell us about your life, when and where you were born, and where you have lived.
- What are some of your memories (highlights/milestones/turning points)?
- Who are the important people in your life? Family? Friends? Paid people?
- Who do you spend time with? How often do you see them?

- Is there someone in your past that you would like to reconnect with?
- Where in the community do you work, live, play, and visit?
- Where do you go on a typical weekday? Weekend?
- What are your hobbies and interests?
- What choices do you make? What choices are made by others?
- What creates a lot of excitement for you? When are you the happiest?
- What doesn't work in your life right now?
- When are you the most bored, frustrated, and unhappy?
- What are some of the unique gifts, capacities, and interests that you have?
- Describe some dreams or hopes you have for the future.
- What kind of movement would you like to make in your life? How can your friends help with that? Who do you feel comfortable asking for support or help?

From these early conversations with the individual, the facilitator can get a picture of the general nature of what a Circle would look like for this individual. This will help with the recruitment of members.

Calling the Circle

- The facilitator and focus person (and perhaps a pastoral staff person) brainstorm ideas on who might be invited to be in the Circle. It is important that the focus person feel comfortable with those who are to be invited. Think of people who have already shown friendship or who share common interests with the focus person. Persons from outside the faith community should also be considered. Other friends with disabilities may be a part of the group as well. If a group is comprised entirely of persons with mobility issues, however, some activities may be precluded due to transportation.
- Discuss together the invitations. Include date, time, and location for the first exploratory gathering.
- The facilitator contacts potential Circle members so that the focus person does not receive rejections personally.
- The facilitator hosts a social gathering. The facilitator and the focus person share their hopes and dreams for the formation of a Circle and describe what it will look like. The leader should encourage questions. Ask guests to consider prayerfully becoming part of the Circle. Sometimes guests are not asked to commit to being in the Circle until after several gatherings.
- After the gathering, the facilitator calls guests to encourage involvement and to answer questions. If a guest indicates that they don't have the time to participate regularly but wishes to be involved on occasion, the facilitator makes note of that for future reference.
- A Circle can be formed with as few as 3 people. The typical size of a group is 6-8.

The Circle Begins

- The facilitator meets with the focus person to plan the first several gatherings. The questions above may help the group get better acquainted with the focus person and determine together the direction of the Circle. It is advisable, however, that there be some degree of sharing by each Circle member. While the Circle is focused around the person with the disability, the gathering times should promote mutual sharing and fellowship. Sometimes a sharing question answered by all the group members can actually assist the focus person in reflecting and communicating about their life.
- Hospitality should be a regular feature of each Circle gathering.
- The group should agree upon ground rules for discussions and participation. This might include confidentiality, setting of boundaries, non-fixing approaches, and keeping cost of activities to a minimum. Except for special occasions, the focus person should pay for his own way.
- Circle members get acquainted and deepen their knowledge of the focus person. The facilitator helps the focus person talk about their history to the extent they feel comfortable. The focus person shares their current situation, using some of the questions above. The group shares possible ways of helping the focus person meet their hopes and dreams.

Continuing the Circle

- After the first several meetings, it is recommended that other Circle members share the facilitation and planning for the gatherings. Sometimes the focus person will also share in making arrangements for a gathering.
- A Circle should periodically review its time together and make adjustments as appropriate.
- New Circle members can be added at any time.
- The Circle may eventually evolve into one of more mutuality among members and not just focus on the person for whom the Circle has been called.
- As a focus person's dreams are met, other goals will surface that may reshape the type of activities the Circle does together
- Fellowship and celebration should always be at the center of the Circle's life together.

Continuing Support for facilitators and Circle members

The primary support for the facilitator and group members is given by a member of the pastoral staff who may already have a relationship with the focus person. Facilitators should also have access to training and ongoing support provided to groups like Stephen's Ministries and Deacons.

Dementia as Disability

The Rev. Mary Austin

Dementia, with its troubling progress and ever-increasing symptoms, is generally considered an illness, rather than a disability. For the people who struggle with it, however, it functions like a disability in daily life. Like a disability, it can limit independence and activities, and require new life skills and changed relationships – both for the person who has the memory loss, and the people around him or her. Like a disability, it can be isolating, if people don't know how to react to changed capabilities. Like a disability, memory loss changes our sense of self, and brings both new challenges and new gifts.

Memory loss, or dementia, has different sources, including events like stroke or head injury, or diseases like Alzheimer's or Parkinson's. Forgetfulness is one of the early symptoms, and the one you may notice first in a friend or member of your congregation. Other symptoms develop over time, including trouble with language and finding words, altered perceptions, difficulty making decisions, and struggles with directions and finding familiar places. A person may grow irritable as the world becomes unfamiliar and frightening, or she or he may act more aggressively, seeming more paranoid at times. Other people may forget social engagements, or you may notice their personality flattening out.

In the early stages of dementia, people may still live at home, with help from family or friends, and may still attend church regularly. For these people, congregations might consider:

- value community more than perfection. If someone talks during church, or sings the wrong verse of a hymn, be glad they're still present. Maintain a posture of hospitality, instead of dismay.
- if the person has always done a particular job at church, allow them to keep doing it, with some added help. Serving the church by ushering, or helping with funeral luncheons, or being in the nursery, are all still possible, with some help. Singing in the choir may not sound perfect, but the community is invaluable to the person with dementia. Also, a family caregiver who is on duty all the time may benefit from a break, during the time the person with dementia is with other people.

In the middle stages of dementia, everything is shifting for the person and their family. This may be the time when the family needs to consider additional help, or finding residential care. We, as congregation members and leaders, can support them best by being non-judgmental about their choices. No one knows what it's like inside anyone

else's home. None of us knows the stresses other people face, and so their choices belong only to them. Wise friends can make observations about the need for more help, as we see things change. Also, we can offer to sit with the person who has dementia, so the family caregiver can take a break.

People may stop coming to church at this time, feeling embarrassed or ashamed about the changes they see in themselves, or a loved one. The church can reach out and strongly encourage people to come to worship on Sundays, and to church activities. Don't wait, or hesitate. People can always say no, but they don't always realize they're still welcome. People with dementia benefit from seeing friends, hearing familiar music, and being in a familiar place. The more recognizable the elements of the service, the more at home people will feel. Again, hospitality is more important than perfection.

In the last stages of dementia, people may not recognize family or friends any more, and may eventually subside into silence. Even in this chapter of life, when it seems that there's no meaningful interaction, deep and powerful connections are possible. Visitors from the church should continue to go, even if the person is no longer able to converse. When you visit:

- Sit next to the person, so you don't seem threatening.
- Use more statements than questions, so the person isn't pressured to answer.
- Take the person's hand in your hands. Touch is powerful.
- Read familiar Psalms or Bible passages, or sing familiar hymns. At this point, the quality of the singing won't matter a bit, and the music may touch a place words can't reach.
- If you visit someone in a care facility, leave a note or card so the family knows that you were there. It will mean a great deal to the family to know that the connection with the church still continues.

This is a time of great grief for the family, and it involves them in a complicated dance of mourning, grieving for the loved one who is now gone, but also still challenged by the work of attending to the person who is still present. Again, true support will come without judgment about their choices, or how often they seem to visit. It's hard to understand this kind of pain until we experience it.

Gradually, the person will forget how to speak, how to eat and eventually how to breathe, and they will slip from this world into the life to come. Until that time, we can bring the grace of God to them with our presence, prayers and hospitality. We can continue to keep them part of the community of faith, first by welcoming them to church, and then by bringing the church to them with our presence. Even as human memory fades, God remembers us all. As followers of a loving God, we are called to remember each other in God's name, and to enfold people with memory loss in community.

The Rev. Mary Austin *is the pastor of Westminster Church, a church for all people, located in the City of Detroit, Michigan and is a former hospice chaplain. She can be reached at: Maryaustin520@yahoo.com*

Created in the image of God

By Cathy Smith

I am a member and an elder at Westminster Presbyterian Church in Minneapolis, Minnesota. I serve on the Task Force on Disability for the Presbytery of the Twin Cities Area. I also have Bipolar I with psychotic features, obsessive-compulsive disorder and post-traumatic stress disorder.

I was hospitalized for the first time in the spring of 2005. The church was very supportive and a minister visited me often. But I did not feel comfortable having others know about my mental illness. I did not want prayers from the congregation or from the prayer chain. My attitude has changed dramatically regarding letting others in on what is happening in my life.

Since that time, I have been hospitalized several more times. My disease progressed to having more delusions and hallucinations. It has taken considerable time to find the right mixture of medications to stabilize me.

My attitude toward letting others, especially those at church, know of my struggles changed during this intense time of turmoil. I have come to a place of comfort where I believe that we are all made in the Image of God, and part of our purpose in this life is to walk alongside one another, especially those who are hurting or marginalized. By sharing my struggle and challenges with others, I am allowing God to enter into our relationship and the grace of God becomes evident in all of our lives.

My church has responded to my illness with compassion and support. Westminster is a multi-staff church and every pastor shows an interest and concern for my life. They regularly remind me that they are praying for my family and me. They seem to have designated one minister to be the main pastor for me, both in times of struggle and when I seem to be doing fairly well. We stay in touch by getting together every once in a while and by calling on the phone every week or so. When my symptoms flare up, we talk more often, even several times a day, depending on what's going on. When my day treatment program suggested that I connect with someone I trust outside of my family, it seemed natural to turn to a minister. He said "yes" immediately. All of the ministers have been fantastic and whenever I see one of them, I get a big hug and usually, "I'm praying for you," whispered in my ear.

When I am in the hospital, I get a visit from a minister at least every other day, and quite often someone from the church comes every day. When I am in the psych ward, I feel extremely isolated from God and the world outside. There is nothing therapeutic about being there. It is just a place to keep people safe for a short time and then send

them back out to the streets. Every visit I get from a minister makes such a huge difference in my time there. When a pastor comes, we talk about how things are going for me and we talk about what's going on at church. We read scripture and we pray together.

These visits can penetrate the hopelessness that I feel and remind me that God is with me, especially in my darkest moments.

I now ask the church to pray for me from the pulpit when I am in the hospital. I know I have been on the prayer chain many times and one group of women knitted me a beautiful prayer shawl. One of the ministers remembered me in prayer throughout Lent by praying for the mentally ill during the Wednesday evening Taize services when I was unable to be present. During difficult months, people made meals and put them in the church's freezer for us to pick up and take home. The church organized babysitting so that my husband could visit me in the hospital in the evenings. We had many people willing to drive me to and from appointments when I was unable to drive. I have also had the love and support of our Thursday morning Mom's Book Discussion Group. They sent me cards every couple of weeks with personal notes telling me they were thinking and praying for me. They were instrumental in organizing my rides to aftercare.

I still have a hard time sitting through the Sunday morning service, especially when my symptoms are evident. I am afraid that I will start talking out loud to my hallucinations or that I will get too over-stimulated and overwhelmed (which sometimes causes me to have erratic behavior). On Sundays when I am not able to be in church because my symptoms are too high, I am able to listen to the sermon on the internet as well as download a printed copy. Westminster also has a daily devotional phone message that I often call, especially when I am in the hospital or am feeling especially isolated and alone. It is a great way to feel connected with the church without having to take the risk of reaching out to a live person.

I am now seeing how God may help me to use my gifts and my experiences to be a voice for those living with mental illness. I hope to have a part in guiding the church to a better understanding and inclusion of those who suffer with these diseases. I hope that this article can provide some ideas on how the church can respond to mental illness in a way that will help both the individual and the congregation to deepen their relationship with God and with each other.



No Room in the Inn: Ellen's Story

As told to Bebe Baldwin

It was 10:30 at night and Ellen had been waiting in the emergency room of a large city hospital for five hours. She was waiting to see whether she would be admitted to the hospital. She lives with schizophrenia and, in the past, had made several attempts on her life.

Ellen's parents had brought her to the hospital from an adult crisis center. There, a social worker had probed every detail of Ellen's illness. "Are you hearing sounds or voices no one else can hear? ... Have you ever tried to harm yourself? ... Do you feel like hurting yourself now?" Ellen was confused and, at times unresponsive, but she answered as well as she was able.

The social worker determined that she needed to be hospitalized. He called the social worker in the hospital who agreed to interview Ellen. However, she could not promise that she would be admitted.

After arriving at the hospital, Ellen began the five-hour wait – for a mental health interview room, for an administrator who checked her insurance, for a nurse to take her vital signs. An emergency room doctor quizzed her again. "Do you hear sounds or voices no one else can hear? ... Have you tried to harm yourself? ... Do you feel like hurting yourself now?" Again, Ellen, who by now was exhausted and frustrated, answered the questions as well as she could, given the gaps in her memory.

Finally, the hospital social worker entered the interview room. She was a no-nonsense woman who must have interviewed hundreds of patients but who did so with kindness, even when she needed to be firm and direct. Again – the same questions.

The social worker left Ellen and her parents alone while she consulted with the doctor. As the minutes crept by, Ellen grew more frustrated and exhausted. Her parents had to ask themselves the same terrifying questions they faced with each visit to the emergency room. If Ellen were not admitted, would they be able to keep her safe, no matter how vigilant they were? Ellen was working with a psychiatrist and a therapist, but where, outside the hospital, was the intensive treatment she needed in order to survive this crisis?

Finally, the social worker returned. There was a bed for Ellen. She would receive the care she needed.

By this time, most of the doors to the parking ramp had been locked, so the social worker walked to the exit with Ellen's parents. She told them the "inside" story. For patients with mental illness, there remained one available bed in the hospital. It was the only one in that health care system, which included several large area hospitals. Two patients, Ellen and one other person, had both needed that one bed. There was no more room in the inn.

As they left the hospital, Ellen's parents felt an overwhelming sense of relief and gratitude. Their daughter was safe and would be receiving excellent care. They could hope and pray for her return to stability.

Ellen's parents returned home to a restless sleep, haunted by questions the larger society must face. What of the other patient, the one for whom there was no bed? Did she have a loving family to surround and support her? Would she be sent to a hospital in another city, far from her support system? Would she be sent home to cope alone? Or, what if she was one of the many people with mental illness who are homeless, who live in shelters or on the streets?

Questions to think about

- How much do you know about the availability of mental health care and emergency service in your area?

Lack of treatment is a social justice issue. One in four families is affected by mental illness, but an appalling lack of services exists. The community services that were to have replaced hospitals are not adequate in many parts of this wealthy nation. There is a critical shortage of hospital beds for patients who are in crisis. To discover the facts about your state, go to <http://www.tacreports.org/bedstudy>

- How can you get your church involved? How can you begin to break the silence and stereotypes about mental illness?
 - Create safe places where people with mental illness and their families can share their concerns. This may include support groups for families.

- Plan programs to raise awareness in the congregation. Give “permission” to persons who live with mental illness to speak about their illness. Invite them to help plan education events.
 - Include people who live with mental illness in service, leadership, and fellowship opportunities. They have unique gifts to bring to the congregation.
- How can the church influence the larger society? How can we put our faith into action?
 - Form a connection with the [National Alliance on Mental Illness. \(NAMI\)](#) or another organization that lobbies for legislation. Mental health care is more than an individual issue. It is systemic and needs to become a priority in setting policies and budgets so that no one will be sent away because there is no room in the inn.