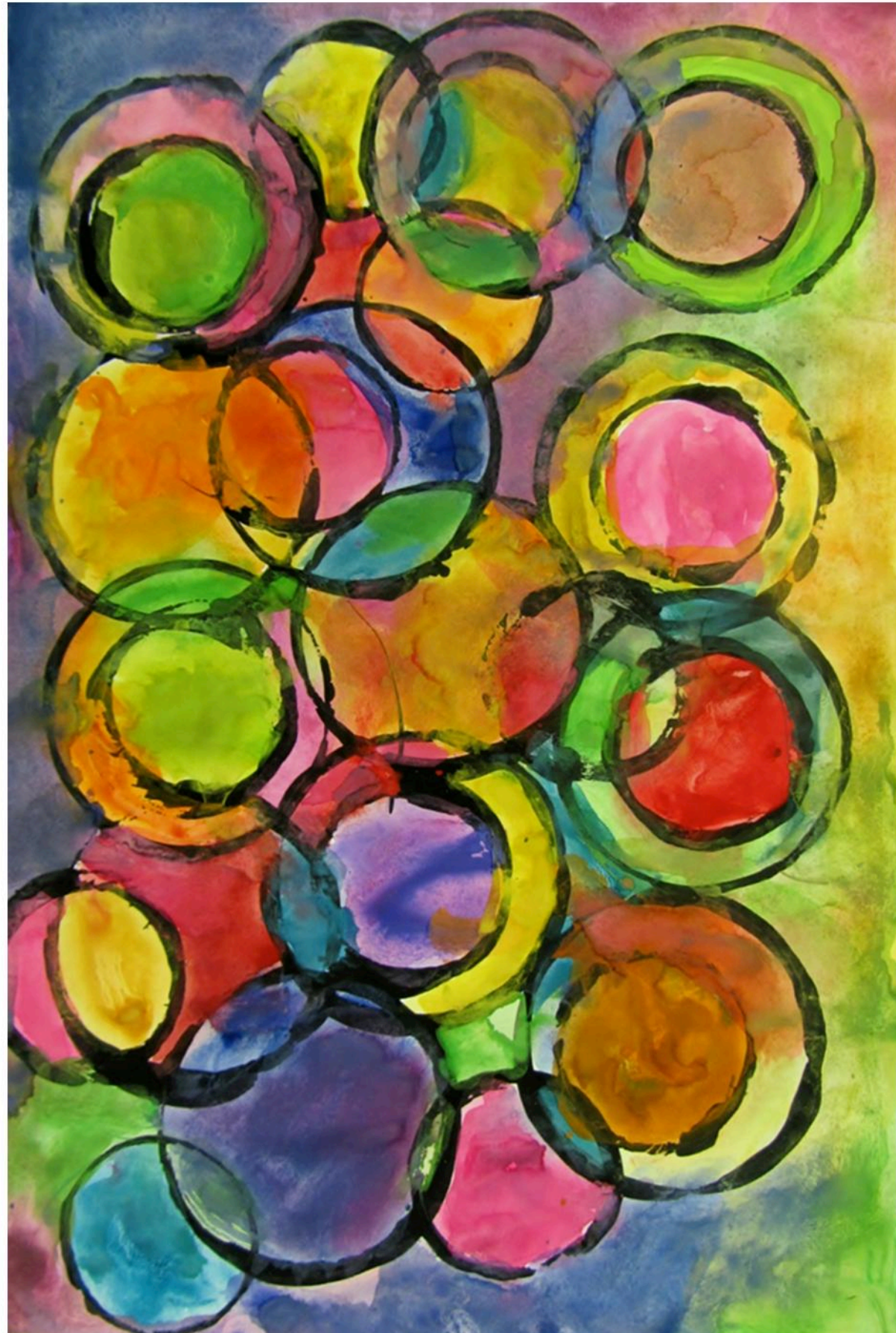


# Disability Inclusion Sunday 2014



**The Seasons of Life in the Family of Faith: Inclusion of people of all abilities.**

Artwork by Craig Woods

Student of FAR Conservatory and participant in the  
Rejoicing Spirits Community at  
First Presbyterian Church in Birmingham, MI



Presbyterians for Disability Concerns



For more information/resources use one of the two qr codes

<http://www.presbyterianmission.org/ministries/phewa/presbyterians-disability-concerns>

<http://www.phewacommunity.org/>



# PRESBYTERIANS FOR DISABILITY CONCERNS

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

## The Seasons of Life in the Family of Faith Resources for Worship and Inclusion Shortened (Introductory) Packet (For Full Packet go to: [pcusa.org/resource/disability-inclusion-sunday-2014](http://pcusa.org/resource/disability-inclusion-sunday-2014))

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## **PRESBYTERIANS FOR DISABILITY CONCERNS**

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

### **An Invitation to the Church**

You are invited to celebrate the gifts of people of all abilities on June 22, Disability Inclusion Sunday for 2014 across the Presbyterian Church (U.S.A.). Scripture tells us that all members of the Body of Christ have been given gifts by the Spirit to share with the community for the glory of God (I Cor 12:4-26). Disability Inclusion Sunday calls us to affirm these gifts and to make every Sunday – and every day of every week – a time for inclusion of all in the Seasons of Life in the Family of Faith

This resource is a sample of what you will find by going to <http://www.presbyterianmission.org/ministries/phewa/presbyterians-disability-concerns/> and to <http://www.phewacomunity.org>. You will find more ideas for worship, including calls to worship, prayers, children's sermons, scripture suggestions, sermon illustrations, affirmations of faith, hymn suggestions and benedictions. You will find practical articles to help you plan for inclusion (Stories from the Family of Faith) that move and challenge, and an annotated list of other PC(USA) resources, along with selected books, online articles, blogs, a documentary, YouTube videos, e-mail newsletters, websites, and web articles.

You can help us! When you have considered and used this packet, please complete the very short response form and return to the e-mail, fax, or U.S. postal service mail address on the form.

It is our hope and our prayer that, working together, we can make sure that no one is missing from the Lord's Table and that the gifts of all God's people are valued, affirmed, and put to good use, to the Glory of God.

*The Leadership Team of Presbyterians for Disability Concerns (PDC),  
a network of the Presbyterian Health, Education & Welfare Association (PHEWA)*



## **Circles Through the Seasons of Life: An Introduction**

Rev. Bebe Baldwin

Please join us in imagining that we are watching a group of children. They are playing a circle game – laughing, singing, holding hands. But look again. Who do you see in the circle? Is anyone outside, waiting to be welcomed in?

Circles can embrace, empower, include. Or they can shun, shut out, “tolerate.” What kind of circles are in your church?

Every time we baptize a child, we affirm our belief that she or he is created in the image of God and is loved by God. We promise to nurture the child in the faith and to support his family as he grows in discipleship. We encircle the family with our presence as the body of Christ.

If the child has a disability, is she included in the circle through all the seasons of life? As others in the congregation face the loss of abilities, do they know God’s all-embracing, all-inclusive love? Are they included in worship, education, fellowship, service, and leadership? Is anyone missing from the Lord’s table?

The 2014 resources developed by PHEWA’s Presbyterians for Disability Concerns (PDC) were designed to challenge churches to become circles of inclusion for persons with disabilities at all stages of life. Sometimes it takes courage to invite others into our circles, or we may not know how to be more welcoming. The PDC resources will help you think through the challenges and even take the risk of being more inclusive.

### Resources for Worship

These resources have been prepared by experienced worship leaders who are committed to including all persons in worship. Choose, mix, and match what fits your own setting. Use them all year long, not only on Disability Inclusion Sunday. Use them in a variety of settings: Sunday worship, church meetings, fellowship gatherings, worship at Presbytery.

### The Seasons of Life: Children and Youth

When parents receive a devastating diagnosis for a beloved child, they may ask, “Where is God?” In “Held by the Presence,” by Cathy Smith and “God Is With Us,” by Carol Brown, two mothers share moving personal stories of pain and faith. In “My Faith Journey,” by Cameron Scott, a teenager tells how his faith has changed and grown because of the simple but profound faith of Clayton, his twin brother, who lives with multiple disabilities. In “Be Kind, Be Kind, Be Kind: Inclusion and Belonging in a Summer Camp,” A.J. Pratt describes her church’s Creative Arts and Nature Camp where all children belong and none are excluded.

### The Seasons of Life: Gen X and Y (20-45 years)

How can the church support young adults with disabilities as they make decisions that will shape their futures? In “My Gen Y Perspective,” Sarah Nettleton issues an honest and direct challenge to church members to take inclusion seriously by doing more than saying a quick “Hi,” on Sunday morning. In “Good Employment as One Important Expression of Self, Vocation, and Contribution,” Milton Tyree explores the assumptions behind the question, “What do you do?” and calls the church to positive action in opening up employment opportunities for people with disabilities. In “Rebuilding the House – Students with Disabilities,” Noah Buchholz and Sarah VanderZee McKenney report on their experiences at Princeton Theological Seminary and Columbia Theological Seminary and tell how they invited people around them to fit into their culture. In “Still Part of the Whole,” the Rev. Dr. Rhonda Myers recounts “advice” that illustrates the barriers well-meaning people erect around people with disabilities – but also the way attitudes can change.

### The Seasons of Life: Baby Boomers (45-62 years)

What personal resources and support can we summon when we face radical life changes? In “Moments of Grace,” by Sara Johnston and the Rev. Bebe Baldwin, Sara shares the rich spiritual resources and the wholeness she has discovered, resources that have empowered her to live creatively on her journey through illness and disability. In “What I’ve Learned So Far,” Karen Casady approaches disability from a different perspective, that of baby-boomer parents who have faced the realities of life-long planning for adult children with disabilities.

### The Seasons of Life: Retired and Redirected (63 and older)

Can we make peace with aging and disability? In “Celebrate Life,” Steve Dietz tells of his struggle with his mother’s Alzheimer’s disease and the peace he found when his family gathered to celebrate her life. In “A Case of Ignored Identity,” the Rev. Bebe Baldwin introduces readers to a friend who, like many people with disabilities, was seen by a stranger only as disabled and needing to be “fixed,” not as a creative, active, competent person. In “Do You Know the Bells?” Amy Buhaug writes lovingly of her grandparents and the service-oriented, faithful, joyful life they lived even when they faced aging and disability.

### The Seasons of Life: Crossing the Generations

The Rev. Sue Montgomery, Team Leader for the PC(USA) Disability Consultants program, tackles tough issues that cross generational lines. In “Eavesdropping Opens the Door to a New Way of Thinking,” she discusses common concerns of family members who are planning funerals for loved ones with disabilities. In “A Question of Marriage,”



she argues for a new understanding of marriage. In both articles she draws upon her long experience as pastor and chaplain to list practical suggestions for pastoral care.

### Resources for the Family of Faith

In this section, Carol Brown offers a collection of carefully selected resources chosen by PDC members who have a broad understanding of disability issues and ministry with people who live with disabilities.

### A Concluding Note

It is the hope and prayer of the PDC Coordinating Team that you will use these resources, not only on Disability Inclusion Sunday, but every Sunday of the year ... and not only on Sunday. Inclusion happens, or does not happen, every day of every week. May the circles we form embrace, empower, and include all of God's precious children – wherever they are in the seasons of life.

### **PDC Leadership Team**

Carol Brown (Resource Packet Committee)  
Miguel Carlin  
Lynn Cox (Secretary and Resource Packet Coordinator)  
Rev. Ernest Krug, M.D.  
Cindy Merten (Co-moderator and Resource Packet Committee)  
Gary Pratt, Treasurer  
Cindy Ray, G.A. Committee on Representation (GACOR) Liaison  
Rev. David Young, Co-moderator

### **Past PDC Moderator and advisor to the PDC Leadership Team**

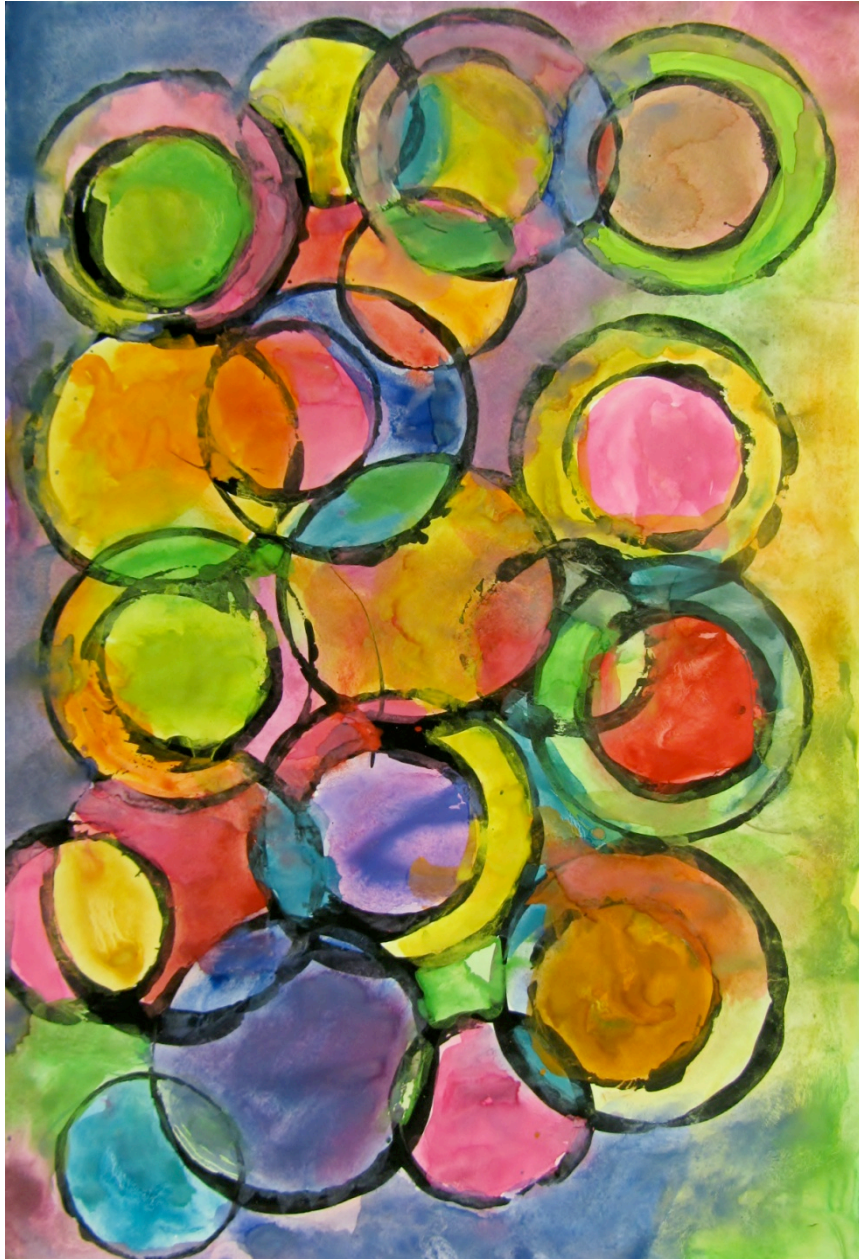
Rev. Bebe Baldwin

### **PC(USA) Consultants for Disability Concerns**

Rev. Sue Montgomery (Team Leader and Mobility/Accessibility Issues,  
Resource Packet Committee)  
Rev. Raymond Meester (Hearing Disabilities Issues)  
Rev. Rick Roderick (Visual Disabilities Issues)  
Elder Milton Tyree (Intellectual Disabilities Issues)

**Presbyterians for Disability Concerns**  
A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

**The Seasons of Life in the Family of Faith:  
Worship Resources**



**2014 Disability Inclusion Resource Packet**  
**Artwork by Craig Wood**

Student of FAR Conservatory and participant in the Rejoicing Spirits Community at  
First Presbyterian Church of Birmingham, Michigan

# Disability Inclusion Sunday 2014



## The Seasons of Life in the Family of Faith: Inclusion of People of all Abilities.

Artwork by Craig Woods

Student of FAR Conservatory and participant in the Rejoicing Spirits  
Community at First Presbyterian Church in Birmingham, MI



Presbyterians for Disability Concerns



**Presbyterians for Disability Concerns (PDC)** celebrates the gifts of all people and is committed to affirmation, support and advocacy for the rights and responsibilities of persons with disabilities in the total life of the church.



June 22, 2014 is designated on the Presbyterian Planning Calendar as **Disability Inclusion Sunday**. PHEWA's Presbyterians for Disability Concerns (PDC) has developed our annual Resource Packet to help in observing this day- on June 22 or whenever works best in the life of your worshipping community. This year's theme is "The Seasons of Life in the Family of Faith: Inclusion of People of all Abilities."



*Offering Our Gifts* is a PowerPoint presentation with pictures and audio that features the personal experiences of persons with disabilities. Included are "Access Your Heart," by poet Sarah Nettleton, and "Beatitudes for an Inclusive Church," by Bebe Baldwin. The resource celebrates the valuable gifts people with disabilities bring to the Body of Christ and offers practical suggestions for including people with disabilities in the church's life. Originally developed by the PDC Leadership Team for orientation of Commissioners to the 219th General Assembly (2010), the PowerPoint is appropriate and recommended for all church gatherings.



For more information/resources use the qr code.

<http://www.presbyterianmission.org/ministries/phewa/presbyterians-disability-concerns>

<http://www.phewacomunity.org/>





# **PRESBYTERIANS FOR DISABILITY CONCERNS**

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

## **Call to Worship**

Rev. Mary Austin

In all of life, the grace of God surrounds us.  
Before we speak, the image of God lives in us.

**God is alive  
in playful years, and in work,  
in growth and in limits.**

When we learn the swiftness of life,  
God's wisdom goes with us.

**God surrounds us,  
in health and in sickness,  
in joys, and in pain.**

As breath leaves us, God awaits.  
God's mercy is our home.

**Let us worship the God of all our years.**

*The Rev. Mary Austin is the Pastor of Westminster Church of Detroit, a church for all people in the city of Detroit, Michigan. She has also been a hospice chaplain. She tells stories at <http://stainedglassinthecity.com/>.*

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# PRESBYTERIANS FOR DISABILITY CONCERNS

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

## Prayer for Illumination

Rev. Ernest Krug

One: The Lord be with you

Many: And also with you.

All: Creator God, create in each of us an open mind that we might hear your Word truthfully; and hearing it, believe; and believing, commit to more faithful living as disciples of Jesus Christ. Amen

*The Rev. Ernest Krug, M.D. is professor of Biomedical Sciences and Pediatrics and course director for Medical Humanities and Clinical Bioethics at the Oakland University William Beaumont School of Medicine. He is also Parish Associate at First Presbyterian Church of Birmingham, Michigan.*



# PRESBYTERIANS FOR DISABILITY CONCERNS

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

## Prayer of Confession

Rev. Mary Austin

God, you call us in every chapter of life,  
and in the rush of our childhood,  
the self-absorption of youth,  
the pressures of our middle years  
the worries of later life,  
we miss your voice.  
Forgive us,  
for forgetting to listen  
failing to follow,  
and missing the mystery of your love.  
In every season of life,  
turn our hearts and our days again to you.  
Help us begin anew  
as your beloved ones.  
In Jesus' name,  
Amen.

*Mary Austin is the Pastor of Westminster Church of Detroit, a church for all people in the city of Detroit, Michigan. She has also been a hospice chaplain. She tells stories at <http://stainedglassinthecity.com/>.*

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## PRESBYTERIANS FOR DISABILITY CONCERNS

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

### Measuring God's Love

Children's sermon by the Rev. Joanne Blair

(Supplies: measuring cup, measuring tape, stopwatch)

This morning I was thinking about how big God's love is, and I was wondering how we can measure it. So I brought some "measuring supplies" with me, and thought we'd give it a try.

Do any of you cook? I use this measuring cup all of the time when I'm making cookies so they'll turn out just right. But the Bible says, "My cup runneth over" (Ps. 23), so I guess we can't measure God's love that way.

Do your parents measure you to see how much you've grown? I know my doctor measures me. But the Bible says, "God's love is higher than the heavens" (Ps. 108), so I guess we can't measure God's love that way.

Do any of you swim on a team, or run races, or try and hold your breath? We use timers and stopwatches to measure time. But the Bible says, "God's love is from everlasting to everlasting" (Ps. 103), so I guess we can't measure God's love that way either.

So how do we measure God's love?

Well, we can't. And we don't need to. God's love is so big that it is bigger than anything we have to measure it with. So rather than measure it, we just need to trust it and feel it.

*Prayer:*

Dear God,

We thank you for your love.

A love so big, we can never know all of it.

Help us to love others like you love us.

Amen.

*The Rev. Joanne Blair is Assistant Pastor for Inclusion & Pastoral Care at First Presbyterian Church of Birmingham, Michigan.*



# **PRESBYTERIANS FOR DISABILITY CONCERNS**

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

## **SCRIPTURE SUGGESTIONS**

### **The Seasons of Life in the Family of Faith**

#### **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 and members of PHEWA's Presbyterians for  
Disability Concerns (PDC) Network Leadership Team.*



# PRESBYTERIANS FOR DISABILITY CONCERNS

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

## **The Imperfect Perfect Solution**

A Sermon Illustration by the Rev. Bebe Baldwin

Bill and Mary worshipped regularly at the church where they had been members for many years. When Bill was diagnosed with Parkinson's, the couple faced many changes but looked to their church family for support and nurture.

Like most of us, Bill and Mary sat in their "chosen" pew every Sunday. One morning after worship, a woman who shared their pew complained to the pastor that Bill's tremor was causing the pew to shake so much that she could not worship.

The pastor offered the "perfect" solution. He told Bill and Mary that they should "attend" worship by sitting in the church library and watching the service online. He reasoned that they could continue to go to church, without Bill's tremor disturbing other worshippers.

Bill never again attended worship. Mary, who is now a widow, has continued to participate in worship and other church activities, but she grieves the fact that when Bill was having to face the loss of abilities, he also lost his relationship with his church family.

Bill and Mary are not the real names of the couple, but the story is true. It was told to this writer during a workshop she led on inclusion of people with disabilities in the life of the church.

*The Rev. Bebe Baldwin is a retired member of the Presbytery of the Twin Cities Area, a former moderator of the Presbyterians for Disability Concerns (PDC) Network of the Presbyterian Health, Education & Welfare Association (PHEWA), and the current moderator of the Presbytery Disability Concerns Ministry.*



## **PRESBYTERIANS FOR DISABILITY CONCERNS**

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

### **Affirmation of Faith**

Rev. Rick Roderick

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 is a graduate of the University of Illinois and Louisville Presbyterian Theological Seminary, with ordination in 1980. He is honorably retired from the Kentucky Office for the Blind, a state rehabilitation agency where he was a rehabilitation counselor and later an assistive technology specialist. He has served on the leadership team of PHEWA's Presbyterians for Disability Concerns (PDC) network and is now one of four PC(USA) Consultants for Disability Concerns, with focus on blindness and low vision.*



## PRESBYTERIANS FOR DISABILITY CONCERNS

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

### **Prayer of the People**

Rev. Dr. Timothy H. Little

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, DMin, BCC, ACPE Supervisor, has served in capacities as a hospital chaplain and CPE supervisor for over 45 years in Iowa, Georgia, and most recently at the University of California Davis Medical Center. Through an interest in end of life planning and 20 years of service on the UCDCMC bioethics committee, he has developed a sensitivity regarding the misrepresentation of justice issues within the current delivery of health care in this country.*

*Having been legally blind for all his life and totally blind for the past 20 years, he is especially concerned regarding the ways in which our churches respond to the inclusion of persons with disabling conditions. He has experience consulting with congregations regarding ways in which to eliminate barriers and providing authentic welcome to persons with disabling conditions.*





# PRESBYTERIANS FOR DISABILITY CONCERNS

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

## 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



# PRESBYTERIANS FOR DISABILITY CONCERNS

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

#692 Spirit, Open My Heart

Text: Ruth Duck, 1994

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

#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. Matthaus 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, who is the Director of Christian Education & All Abilities Inclusion Ministries for First Presbyterian Church of Birmingham, Michigan. Cindy serves as co-moderator of Presbyterians for Disability Concerns (PDC), one of ten volunteer ministry networks of the Presbyterian Health, Education & Welfare Association (PHEWA).*



## PRESBYTERIANS FOR DISABILITY CONCERNS

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

### **Benedictions**

Rev. Raymond Meester

May the Lord, who gave sight to the blind,  
enabled the lame to walk and the deaf to hear,  
bless you now and always. Amen.

May the God who created us as diverse persons,  
And Jesus Christ who brought sight to the blind, hearing to the deaf,  
and made the lame to walk,  
and the Spirit, who bestows gifts upon each and every one of us,  
and Jesus Christ who came to destroy barriers,  
bless you now and always with wholeness. Amen.

*The Rev. Raymond Meester is pastor of Heritage Presbyterian Church in Lincoln, Nebraska, which has a ministry with the deaf. Raymond's parents, as well as four uncles and aunts, were deaf. He has served on the board of the Nebraska Commission for the Deaf and Hard of Hearing and is one of four PC(USA) Consultants for Disability Concerns, with focus on ministries with the deaf and hard-of-hearing.*



**PRESBYTERIANS FOR  
DISABILITY CONCERNS**

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

## **Benediction**

Lisa Larges

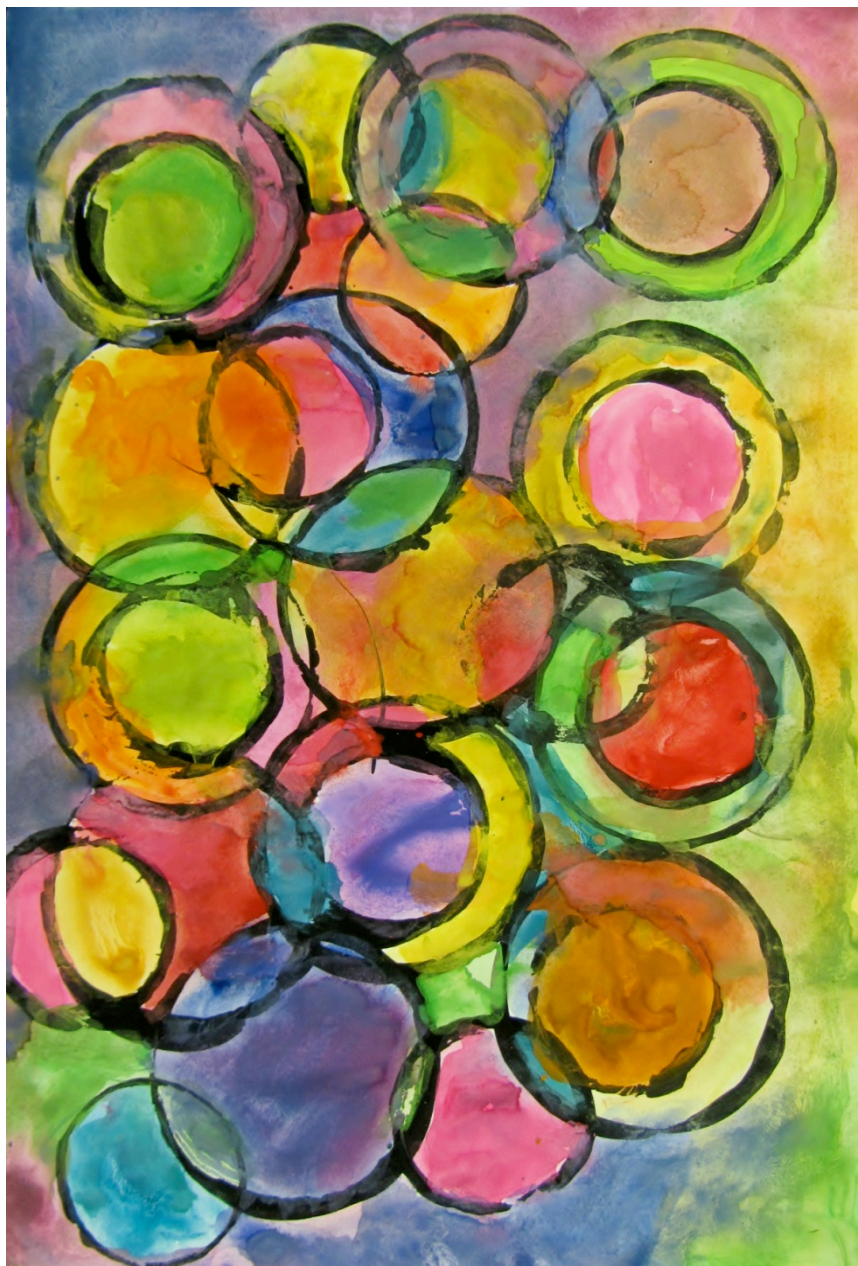
Now, by the power of the one who formed you from the dust of the stars,  
The source and wellspring of all that is,  
Who set a seal upon you,  
Who called your name from the beginning of time,  
Who knew you and knows you,  
Beautiful, beloved, in your whole embodied self,  
And by the grace of the 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 works at State Services for the Blind of Minnesota as their Outreach and Marketing Coordinator. She is a part of Lake Nokomis Presbyterian Church in Minneapolis, Minnesota, and a candidate for Ministry under the Presbytery of San Francisco.*

# Presbyterians for Disability Concerns

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

## The Seasons of Life in the Family of Faith: Stories from the Family of Faith



2014 Disability Inclusion Resource Packet  
Artwork by Craig Wood

Student of FAR Conservatory and participant in the Rejoicing Spirits Community at  
First Presbyterian Church of Birmingham, Michigan



## **Held by the Presence**

Cathy Smith

In 2004 my husband, Dave, and I decided to grow our family through adoption. We signed on with an adoption agency and shortly thereafter we were matched with a two year old boy in Ulan Ude, Russia. His pictures and medical report showed him to be a healthy, happy little boy. We brought Alek home in October. By December, we knew there was something wrong. He had difficulty running, climbing stairs, getting up off the floor. He just wasn't keeping up with his peers. Many people said, "It's just orphanage delay, he'll catch up." Our parent's intuition told us otherwise. We were finally referred to a neurologist who made the diagnosis of Duchenne Muscular Dystrophy. DMD is a progressive, degenerative muscle disorder. His muscles will continue to get weaker and weaker, eventually involving his heart and lungs. Most boys with this disease die in their late teens to early twenties.

The day we received the diagnosis we were devastated. All we could do after the doctor's appointment was to drive around crying and trying to console one another. We connected with one of the ministers from our church and he just held us saying, "My kids, my kids." It felt as if God was the one holding us, we could feel his presence with us in that moment. Words were not necessary for us to pray, God knew what was in our hearts and was surrounding us with love.

After that moment, we were faced with going on with our lives. To get through those days I found myself praying constantly. Every step was a prayer. I took the opportunity to intentionally pray, with words, several times a day, but in reality, my whole life was a prayer. I lifted up to God my fear, my helplessness, my grief, as well as gratefulness for my family, friends, church, and most of all a life partner who was on the same path. We prayed for Alek, for our family, for Alek's doctors, for the researchers trying to find a cure, and for the strength to walk through this dark time in our lives. In between these prayer times I would find myself singing hymns and songs to keep my faith alive. One of my favorites was from the Taize community, "Jesus remember me, when I come into your kingdom; Jesus remember me when I come into your kingdom." I was praying without ceasing.

God answers prayers. I have found the strength to move on with my life. I no longer feel consumed with this terrible disease. I still pray for my son and our family, but it is not as intense as it was during the time immediately following his diagnosis. The sadness is still there - when I need to help him up the stairs into the house, when he struggles to stand up from the floor, when he needs to go to the cardiologist, when it is difficult to maneuver his wheelchair. God is with me in all of those moments. I have learned that there are many ways to pray: with song, with breath, with words, with tears, and with hugs. God hears our prayers without ceasing.

*Cathy is a ruling elder at Westminster Presbyterian Church, Minneapolis, Minnesota, a member of the Presbytery of the Twin Cities Disability Ministry group, and a student at Luther Seminary in St. Paul, MN.*



## Good Employment As One Important Expression Of Self, Vocation, and Contribution

Milton Tyree

*"What do you do?"* It's a familiar, friendly, although mildly intrusive and vaguely judgmental question directed toward new neighbors, parents attending their kids' soccer games, and even visitors of our neighborhood Presbyterian churches. Most people reflexively translate and reply to the questions behind the question: "What kind of employment do you have and where do you work?"

Whether or not a person is employed, and *if* employed then the kind of work performed, influences the person's identity, including his or her sense of belonging and place in the world. In our hypercompetitive society, there's no doubt that employment and job status have become way too important. For example, stay-at-home moms and dads often experience certain levels of misapprehension because they're "not working."

While it's important to temper the seductiveness of competition and social status, as well as recognizing the virtue of all honest labor, it's equally necessary to acknowledge historical patterns of socially devalued people being relegated to low paying, low status jobs or chronic unemployment. For people with disabilities, this has traditionally meant few real work options, with estimates hovering around 80% unemployment. When work is offered, it's often the kind predetermined to be suitable for "people with disabilities." Others make these decisions prior to knowing anything about an actual person. Or sometimes what's given is an employment substitution called "work activities," grouping together people with disabilities, solely on the basis of having a disability. Even when such responses are rooted in good intentions, the results are overwhelmingly limiting, often leading people to wonder: *What can I do? Where do I belong? Do I belong?*

"For I know the plans I have for you," declares the Lord, "plans to prosper you and not to harm you, plans to give you hope and a future." (Jeremiah 29:11 NIV) Though captured by low expectations, rather than by the Babylonians, people with disabilities can draw from these words the promise that God knows everyone *personally*, offering hope and a future. ("I know the plans I have for **you**." *Not*, "I know the plans I have for y'all.")

*"Where there is no vision, the people perish."* (Proverbs 29:18 KJV) Fortunately, over the last several decades there's been an emerging vision of citizenship, *including* good employment for people with disabilities. Much has been learned about making this vision a reality. Countless books have been written, weeklong seminars delivered.... The following are a few of the principles that have helped move things along in a positive and hopeful way:

*The presumption of employability* - "Each person is given something to do that shows who God is: Everyone gets in on it, everyone benefits." (1 Corinthians 12:7 MSG)

It's a radical idea: (a) *Every* person has a God-given purpose, and its expression is good for everyone. (b) And every person's calling may be expressed through employment. The Apostle Paul is responsible for saying the first part, the understanding about the universality of personal vocation. The employment-for-all part came many centuries later. Historically, human service professionals have been granted authority to determine who's in and who's out, who's employable and who's not – effectively shutting down the collective imagination. The presumption of employability defies this deeply rooted historical way, offering a presumed employability firmly based in biblical truth. “Okay. Fine. But *surely* you don't mean Dan. Just look at him!” Yes. We mean Dan, at least until we've exhausted all available ideas. And even if we run out of ideas, then that still doesn't prove Dan can't work. It only means we've run out of ideas. Isn't this a more healthy, honest, and authentic way of thinking about God's people?

*Contribution versus competition* – The inherent need to contribute, doing something that matters, is especially important for those who so often find themselves on the receiving end of help. “From the fruit of their lips people are filled with good things, and the work of their hands brings them reward.” (Proverbs 12:14 NIV) Mike Callahan, one who's devoted much of his life to the presumption of employability, had the insight that *everyone* can contribute, but *not* everyone can compete. This awareness reframes rules and relationships about the work that needs to be done and the people performing the work. In what ways do personal gifts and talents intersect with employer needs? Often referred to as *customized employment*, competition is replaced with a voluntary negotiation of jobs that pairs employer needs with personal competence and contribution. It opens the door for the dignity of contribution, offering something personal, something that matters. This U.S. Department of Labor link provides additional information about the concept of customized employment: <http://www.dol.gov/odep/categories/workforce/CustomizedEmployment/deliverables/index.htm>

*Discovery* – “Each of you should use whatever gift you have received to serve others, as faithful stewards of God's grace in its various forms.” (1 Peter 4:10 NIV) Working is a common way of offering personal talents and gifts. However, people with disabilities have often grown up without work expectations, their lives void of the typical childhood questioning, “What do you want to be (when you grow up)?” What should people do when they've never explored their talents, perhaps to the point of being convinced they have nothing to offer? Discovery provides a way of discerning personal gifts and talents previously unrecognized and translating these into characteristics of fitting employment. It's a process of learning with people about fitting conditions for work – when and where people are at their best, finding a spark related to a particular interest, stirring a passion formerly unknown. Discovery offers hope and positive possibility through fitting employment, a way of answering those nagging questions: What can I do? Where do I belong? Do I belong?





***What are ways for a faith community to respond to its members with disabilities needing good employment?***

- 1- *Begin by reframing this question* by deleting two words. What are ways for a faith community to respond to its members ~~with disabilities~~ needing good employment? If any member needs a job, then what are the ordinary ways of responding? Begin with the typical and valued approaches, and then adapt these if needed. For instance, networking is a primary way that everyone finds work. Just think of the networking possibilities within groups, formal and informal, in your faith community, and then expand this to all of the connections and people known outside of the faith community. Jake has a real knack with things mechanical, and he's seeking work where he can contribute by using this talent. Perhaps Jake needs some consideration around job design. Promote ways for Jake to connect with an employer where what Jake has to offer meets the work demands of the employer. If your church already has an employment ministry, then be sure people with disabilities seeking work are involved.
- 2- *Sign-on to "The Statement of Solidarity by the Religious Community Around Employment of People with Disabilities"* drafted by the Interfaith Disability Advocacy Coalition (IDAC): <http://www.aapd.com/what-we-do/interfaith/idac-statement-of-solidarity.html> The name of the statement says it all. Faith communities have an essential role to fill.
- 3- *Learn about things others are doing.* "Putting Faith to Work" is the name of a Kessler Foundation two-year initiative just beginning (at the time of writing this article) involving a partnership of universities in Tennessee, Kentucky, Minnesota, and Texas -- all studying, learning about and exploring ways that faith communities can further good jobs for members with disabilities. (You may contact Milton Tyree, through contact information at the end of this article, if you're interested in learning about the initiative.)

"Each of us should please our neighbors for their good, to build them up." (Romans 15:2 NIV) Be an ally. Explore with people their interests and talents. Presume employability. Engage your imagination. It's possible that supporting others to learn and express their God-given vocations through employment turns out to be an important expression of your own vocation.

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

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## **Eavesdropping Opens the Door For a New Way of Thinking**

Rev. Sue S. Montgomery

Imagine yourself listening in on the following conversations:

One, a family is meeting with the pastor to plan the funeral for their father. The father was deaf, and was proud of being a member of the deaf community, a linguistic minority. His deafness was not a disability; it was a gift from God. The children explain to the pastor their father's life long wishes, that when he died the officiating pastor would not say anything about him hearing in heaven. There would be no comments that in death he could finally hear the birds, music, laughter, rain or thunder. In heaven, he would be not only a Son of God in the family of God, but he would be as deaf in heaven as he was on earth. The children tell the pastor their father warned them, "If anything is said against my will, I'll wake from the dead, sit up in the casket and correct the pastor."

Two, a young teenager with multiple disabilities has just lost his grandfather in death. He is asking many questions about heaven. He asks, "When I get to heaven will I be able to walk, talk, run, and do everything everyone else does?" The pastor with whom he was speaking was cautious and responded, "I don't know, but this I do know: you will be you, those who love you will recognize you and God will embrace you with eternal love." The young man lowered his head and then looked up and said, "Thanks. I am me and sometimes I think people want me to die so I can meet their expectations of being healed and whole. Although I'd like to be like everyone else, I like being loved for who I am, just as I am. Why is it that people feel free to tell me that I will be like them when I get to heaven? It hurts. I want to be loved for who I am. I want to be me now and in heaven. I want to be loved as I am in life not as what someone wants me to be in death."

Three, a chaplain who was retiring after 45 years of ministry with people who have intellectual/developmental disabilities was discussing his funeral plans with some colleagues over coffee at McDonalds. Here is what he said: "When I die, I don't want anyone preaching at my funeral to call me a saint for working with men and women with intellectual/developmental disabilities. I am no saint! My work is doing what God has called me to do; there is nothing saintly or special in it, nothing out of the ordinary, nothing honorable or elevated to a special status. I have always done what God called me to do; I have been who I am. My daughter and the funeral home director have received these instructions, and so, too, have you. Ministry with persons with disabilities is not something reserved for saints. Ministry is being a brother or sister in Christ to those around us. It is nothing more. Whenever people say that I am a saint for working with people with disabilities, it demeans the people I love and care for with all my heart."



Three conversations—three insights into the profound thoughts and unique identities of people who live with disabilities, their families, advocates, and friends. People who live with disabilities want their funeral services to be a celebration of the resurrection and a celebration of their faith and life. Here are some suggestions pastors can consider when writing funeral services for people who have lived with disabilities or who have been pastors with people who live with disabilities.

Do not focus on the disability unless it is absolutely necessary. The person was far more than the disability.

Speak of the spiritual gifts the person shared. Share stories of the person's faith. The gifts and stories can include the disability, but usually the stories of faith don't need the disability framework.

The person is more than their smile. Although a person can have a smile that lights up a room, speak about why the smile is so important and what the smile gave to those who saw it. Persons living with disabilities often are frustrated and demeaned by always being known only for their smiles, as if that's all they could ever do. Being expected to smile all the time further reduces and destroys their humanness. People with disabilities, as people of faith, know how to walk through the valleys of the shadow of death and despair. Expect faithfulness, questioning, and profound faith—don't lower the life of a person with a disability to the role of always smiling.

Don't be afraid to share the struggles the person endured. Don't turn them into moments of inspiration or heroic acts. Share how the person addressed adversity, just like everyone else, through faith, mutual ministry, and through the communal support of family and the worshipping community.

Don't speak of the person with a disability as being one of God's angels or state that as one of God's angels, forgiveness and entrance into God's kingdom is guaranteed. Such language perpetuates the image of the eternal child. People with disabilities, including cognitive disabilities, can and do make decisions of faith and professions of faith. Share how the person came to know Christ and chose to live their faith in Christ. People who are called to serve God in specialized ministries with people with disabilities ask that their ministries not be elevated above other ministries. Such thinking makes the statement that ministry with people with disabilities is more difficult and further demeans the lives and gifts people living with disabilities bring to their communities.

Unless you know where the person living with the disability stood on the theological issues of heaven and the heavenly body, do not speak of the perfect body in heaven where eyes see, ears hear, legs walk, hands move, and people dance with God. People living with disabilities already dance on earth, walk in the Lord, see and hear in different ways. No one knows what the heavenly body will be like. What we do know is this: when



the disabled earthly body is replaced with a perfect body in heaven, the message becomes quite clear—the body of a person with a disability is never acceptable except in death. Only the heavenly body is whole, complete, and honorable. A person living with a disability will never be accepted until they are dead and their body is made whole in heaven. This is a powerfully painful statement to those who live with bodies that are disabled. Many people with disabilities will say that they don't want a healed or perfect body, they want to be who they are, loved for who they are; there is pride and gratitude to be found in the bodies God has given them.

Make sure the service is held in an accessible venue. When the friends and colleagues of people with disabilities cannot participate or share in the funeral service it is a disservice to all. Seek to meet the ministry needs of those who need sign interpretation, hearing amplification, Braille bulletins or larger print, architectural access—including restrooms— emotional support, and/or an environment that enables those with autism or other cognitive disabilities to participate fully. Extend this to the traditional dinner held following funerals. People with disabilities also enjoy sharing and creating new memories around tables where bread is broken.

As the meditation and service is written, review it and ask, am I doing this differently than I would for anyone else? Go back and review the content—how can it be rewritten to affirm the person's life and faith without a heavy focus on the disability? People living with disabilities simply want to be just like everyone else, the person, the son or daughter of God whom God created —nothing else.

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## **A Question of Marriage**

Rev. Sue S. Montgomery

In 1980, when first introduced to a large group of men and women who lived with intellectual and developmental disabilities, there were several who said to me, “I’m going to marry Cindy, I’m going to marry Henry.” The staff members who were introducing me to the young, excited people talking about marriage, looked at me, winked, and moved on to other tasks. The dreams of the young men and women were basically perceived by the staff as foolish, unrealistic; therefore, the staff needed to “protect” them from such foolish thoughts. Then, as well as now, many perceive young people who live with intellectual/developmental disabilities as eternal, perpetual children who will never mature into responsible adults.

Over the last 44 years, I’ve looked into the history of the men and women who live with intellectual/developmental disabilities, with particular attention to how relationships have shaped lives, family, and faith. Due to the extended history of people with intellectual/developmental disabilities being placed in institutional settings, the early history is not positive. Institutional abuse led to documented cases of sexual abuse between staff and peers. When a female became pregnant, both she and her child were then institutionalized, as no one would adopt the child of a parent with a history of disability. Sadly, many women were forcibly sterilized, a strategy to keep women “safe” from pregnancy.

Fortunately, times have changed. Institutionalism is no longer the primary accepted practice for parents and medical professionals. Yet at the same time, the vision of allowing people who live with intellectual or developmental disabilities to marry is discouraged. Actually, marriage is frequently discouraged for all people who live with disabilities. The level of disability is often used as a factor to determine capability. Pastors are now being approached by parents, who are accompanied by their sons and daughters with intellectual/developmental disabilities, asking the pastor to guide them in their marriage plans. Parents have always been advocates for their sons and daughters. The journey into marriage is a new one and raises many questions. Should there be an actual “marriage covenant?” Would a Blessing of the Union suffice? These questions are real, in that there are multiple ramifications of a marriage license. Legal marriage affects medical insurance, Social Security Disability, and/or Social Security Supplemental Income benefits. If either partner is the recipient of death benefits of a parent, legal marriage can affect the continuation of those benefits, as well.

The good news is that young couples with disabilities are fulfilling their dream of marriage and living within a loving relationship. Group home and community placement services are being challenged by this new development. Pastors, sessions, and

congregations are being challenged in their understandings of traditional marriage by these emerging dreams. With support, married couples can live as husband and wife; with mentors and guidance, young couples can even take the journey into home ownership, responsible employment, and becoming parents. There's a whole new world opening up the frontiers of maturity and adulthood to people who live with intellectual or developmental disabilities.

This is the story of one young couple. Mary lives with Down Syndrome, Tom lives with Cerebral Palsy. Following several years of dating and living in two different group home settings, their care staff found an apartment for them and arranged for support staff to enable them to live safely in the apartment. Tom and Mary shared several happy and fulfilling years. Due to her Down Syndrome, Mary began to experience a rapid decline in her heart and respiratory health. Mary's abilities to care for herself began to decline. Tom did all that he could, but Mary needed more care. Mary was moved to a skilled nursing center where Tom now visits her every day after work. Throughout their journey, Tom and Mary have done what every other married couple does, love and care for one another. And as Tom would say, again and again, as he visited Mary, "I'm just doing what everybody does, I love my wife."

The question of marriage among people living with disabilities, especially significant disabilities, is often left unanswered or answered with an unequivocal "no," simply because of the debilitating image of the eternal child placed on youth when they reach the age of dating and marriage. The difficulty is, each relationship and setting is unique and has to be woven into all that it can be, with creativity of thought, openness to the Spirit moving in the relationship, understanding of state laws and guidelines relating to marriage, medicare/medicaid, Social Security assistance programs, and a willingness to work with what could or might happen with social service providers, community living support staff, and family. The good news is that marriages or blessed unions are no longer a dream, they are realities that are coming true for couples that have dared to dream and have rooted their futures in the love, trust, and hopes of someone they love.

The question of marriage extends beyond persons who live with disabilities. It also extends to older adults or the survivors of spouses who lived with disabilities. Spouses of Vietnam veterans who have died find that they cannot remarry until they are a certain age—usually 57 or older. If they remarry, they lose the death benefits their spouse's service-related death provided for him or her. For the same reasons, persons living with disabilities face barriers to marriage, as do older adults. The serious and life threatening risks that accompany the loss of medical and other financial benefits are hefty and frightening. Persons with disabilities who receive community support services to maintain their independence also face the risks of losing health and home care benefits. Legal marriage can nullify or significantly reduce benefits. Blessings of Unions are one of many solutions some churches and pastors are choosing. Many older couples seeking



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to live together, affirming their love in faith and in a covenantal relationship, often don't have time for civil laws and guidelines to change.

The church—and pastors, along with the couples who are seeking to be married, and those who love and care for one another, are facing moral and ethical dilemmas. Spiritual and religious understandings of marriage are being examined. The time has come to move beyond what can't, mustn't, or shouldn't be, and move into a time of asking what is God doing? Certainly, just as with all couples, God is at work in bringing two people together to love one another. And so, with the guidance of God, scripture, our creeds, traditions, the time is now to ask the questions, find the solutions, and even though every situation will be uniquely different, how can the love of God flow through those who love one another? It isn't just a dream, it is God's good gift to those who dare to dream and even more so, dare to love.

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# **PRESBYTERIANS FOR DISABILITY CONCERNS**

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## ***RESPONSE FORM***

### ***The Seasons of Life in the Family of Faith: Resources for Worship and Inclusion***

*Presbyterians for Disability Concerns (PDC), a network of the Presbyterian Health, Education & Welfare Association (PHEWA) creates a Resource Packet of this type each year that can be used in conjunction with the designated Presbyterian Disability Inclusion Sunday in June (or whatever Sunday your congregation or worshiping community chooses). Your answers to the following questions will assist in the creating of future Resource Packets.*

*Thank you so much for your input.*

**How were the materials in the packet used by you or your congregation?**

**Which was the most useful part(s) of this packet for your use/ministry?**

**Do you have any suggestions for themes/content/writers for future packets?  
Other input?**

**How may we contact you?**

Name \_\_\_\_\_

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