

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

***Inclusion from the Inside Out:
Welcoming God's Children of All Abilities***



2011 Disability Inclusion Resource Packet

Artwork by Nick, age 16
Student of FAR Conservatory for Therapeutic Performing Arts
and member of First Presbyterian Church of Birmingham, Michigan



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Disability Consultants of Presbyterian Church (U.S.A.)

Introduction

Inclusion From the Inside Out: Welcoming God's Children of All Abilities

“Let the children come to me.” These words are from what is often the first story our children learn about Jesus. If you are reading this article, however, you know and are concerned about the painful reality that children and youth with disabilities do not always find a welcoming and inclusive community in the church.

Presbyterians for Disability Concerns (PDC) is offering our 2011 Inclusion Sunday resources to equip churches for inclusive ministry. The ideas and suggestions for worship and theology, confirmation, and models of ministry come from actual experiences of writers who are committed to inclusion of children and youth of all abilities. It is our prayer that this packet will assist you in your ministry with all of God's children.

Thomas Reynolds' article, “**Vulnerable Humanity: Disability and Community Beyond 'Normalcy,'**” from *Welcoming All God's Children: Worship Resources*, lays a theological foundation for inclusion. He calls us to move beyond the “assumption that value is based upon power and ability” and toward an acceptance of our common humanity, our vulnerability. He calls us to a new vision of community in which all can flourish. Reynolds is no stranger to what he calls the “tyranny of normalcy.” In his book, [Vulnerable Communion: A Theology of Disability and Hospitality](#), he tells his own family's story of a church's rejection of his son because of his disability.

Poetry and readings by Kathleen Deyer Bolduc, Thom Schuman, Ann Weems, and Sarah Nettleton will enrich worship on Inclusion Sunday but will call the church to faithfulness throughout the year. Sarah Nettleton's “**God in Us**” is a powerful reminder that God is present in each of us and that all have gifts to share with the body of Christ. “**Multisensory Worship Ideas**” by Chaplain Margot Hausmann lists practical suggestions for using all the senses in worship, for incorporating motion, and for using sound and sight in creative ways.

Welcoming All God's Children: Confirmation is a feature offered this year in response to concerns shared with us by many families. The articles challenge us to think in new ways about what confirmation means and about how we “do” confirmation. (Is confirmation more than “cramming” facts into the heads of young people?) Sue Montgomery, in “**Reflections on Communicant Membership for Youth and Adults with Pervasive Disabilities,**” reminds readers to explore the ministry needs of each person. She argues that adapting curriculum is not always the best way and she urges readers to get to know the individual and discover how she or he communicates.

In “**Confirmation: Tools for Inclusion,**” Cindy Merten introduces us to Clay and Elizabeth, two confirmands at First [Presbyterian Church in Birmingham, Michigan](#). In planning their two-year confirmation program for youth of all abilities, leaders have defined six major concepts upon which to focus and have sought ways to make them real in the lives of young people. The article lists tools for inclusion, including talking photo albums. A video of the talking photo album is embedded in this article.

Welcoming All God's Children: Models of Ministry includes a range of strategies for inclusion. In “**Radical Wholeness: All Children, All Youth, and the Complete Faith Community,**” Milton Tyree calls the church to become “counter cultural” and to move beyond “special.”

His focus is “congregational belonging for children and youth who have intellectual disabilities.” He urges the church to break the habit of exclusion - the separation of persons with “special needs.” He goes on to suggest ways to create community for all.

This section gathers together articles that address specific issues. Bebe Baldwin suggests ways to involve children with vision and hearing impairment and offers ways to help children learn self-advocacy. Ellen Notbohm lists ways to provide supportive settings for children with autism. Catherine Smith describes steps [Westminster Presbyterian Church in Minneapolis, Minnesota](#) has taken to accommodate her son, including a plan for emergency evacuation. Kathie Snow reminds us of the importance - and pitfalls - of language. Lynn Cox, a teacher who believes in addressing behavior instead of labeling children, gives practical suggestions for including children who have difficulty paying attention. Sarah Nettleton urges churches to choose alternative formats that meet individual needs when presenting gifts (Bibles, story books, etc.) to children or youth. David A. VanderMeer and Rachael C. Stewart introduce us to young musicians with disabilities and the gifts they share through the ministry of music at [Central Presbyterian Church in Atlanta, Georgia](#). Deborah V. Blair describes inclusive worship at [First Presbyterian Church in Birmingham, Michigan](#) and includes graphic representation as a strategy.

In *Welcoming God’s Children: Resource List*, Mary Anona Stoops has gathered and organized resources too numerous or lengthy to be included in this packet. All resources were suggested by members of Presbyterians for Disability Concerns (PDC).

Members of the PDC Leadership Team would like to express our deep gratitude to all who so generously contributed their wisdom and experience for this packet. We would like to offer a special “Thank you” for the art and photos that have enriched our resources and our lives. God’s children at First Presbyterian Church in Birmingham, remind us that as we work for inclusion, we are doing more than planning programs. We are ministering with and learning from real people of all abilities.

Finally, let us remember that Inclusion Sunday, June 26, 2011 is only a glimpse into what every Sunday - and every other day - can be in our churches. Let us truly welcome all of God’s children and youth!

Rev. Bebe Baldwin, for the PDC Leadership Team
Lynn Cox - packet coordinator
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Welcoming All God's Children: Theology and Worship Resources



Artwork by Rusty, age 16
Student of FAR Conservatory for Therapeutic Performing Arts
and member of First Presbyterian Church of Birmingham, MI

1 | Prologue

The Invitation **A Poem for Two Voices**

A party!
The Church is throwing a party!
Prepare the guest list.
Pen the invitations.
Send them to every Christian in the neighborhood,
regardless of denomination.
Hand-deliver to those with wealth and prestige . . .
the ones with the means to help us to grow!

Go, buy the food and wine!
the finest fruit . . .
the freshest vegetables . . .
the best cuts of meat . . .
the most expensive vintages of wine.

Ready the table!
Lay it with fine linens,
Set it with silver, crystal and china.
Call the florist.
Summon the musicians.
Stringed instruments and trained soloists,
music to praise our Lord
for all that the Lord has done for us!

A sumptuous feast!
A celebration of the senses!

A commemoration of Christ's presence among us!

What's that you say?
Invite the . . . who?

Invite the outcasts

The poor
The maimed
The lame
The blind

You must be kidding!
We're talking first class here . . .
Why . . . they wouldn't know how to act!
They couldn't appreciate the excellence!
Only the best for . . . our Lord, is that you?

Oh no, we would never forget you, Lord!

When you put it like that . . .
I suppose we could re-think our guest list . . .
Perhaps we could re-word our invitations . . .
but I insist on calligraphy!
Only the best . . .

I don't know as I remember that Scripture.
Could you refresh our memories?

Forget the mailing list!
Scrap the formal invitations!
Go into the streets,
the prisons,
the group homes,
the hospitals and psychiatric wards,
the parks where the homeless sleep,
where the least of these are languishing for love . . .

Yes. Did you forget?

*I know that, dear ones.
But did you forget that if one member suffers, all suffer?
If one member is honored, all rejoice?
Weakness in strength
Strength in weakness*

*Isaiah 61 would make
the perfect invitation*

*The spirit of the Lord God
is upon me because the Lord
has anointed me to bring
good tidings to the afflicted,
to bind up the brokenhearted,
to proclaim liberty to the
captives and the opening of the
prison to those who are bound*

The body of Christ is throwing a party!

This is used by permission of the author, **Kathleen Deyer Bolduc**, from her book *A Place Called Acceptance*. She is also the author of *His Name is Joel: Searching for God in a Son's Disability* and *Autism & Alleluias*. <http://www.kathleenbolduc.com/>

Being Whole in the Eyes of God Conference at Stony Point Center, NY

Call to Worship

Leader: God calls us to this place:

People: creating a safe haven for all of God's people.

Leader: Jesus calls us to this place:

People: inviting us to seek all that he longs to do for us.

Leader: Spirit calls us to this place:

**People: her arms embracing each of us,
her heart cradling everyone.**

Unison Prayer of Confession

You stand, quietly calling to us, Heart of Hope, but we find it easy to ignore you. The least stand by the side of our lives, but our gaze slides quickly by them. Your Word challenges us to serve the lost, but we are unable to hear them over the seductive tunes of temptation. You invite us to your feast, but we find ourselves gorged on fear and doubt.

Forgive us for our foolishness, Safe Haven. You hold out your heart to us, broken and bleeding, so we will know how much you love us, and how you want to heal us through your Child, Jesus Christ, our Lord and Savior, who comes calling us to your side.

Assurance of God's Pardon

Leader: Take heart, dear friends. God hears our prayers and heals our lives. Get up, for God calls to you with words of hope, of grace, of forgiveness.

**People: Now we see, now we know, now we can follow
set on the path to God's inclusive kingdom, we
will call all we know to travel with us. Thanks be to
God. Amen**

Great Prayer of Thanksgiving

Leader: The Lord be with you.

People: And also with you.
Leader: Lift up your hearts.
People: We lift them to the Lord.
Leader: Let us give thanks to the Lord our God.
People: It is right to give God thanks and praise.

Leader: You stood by the side of chaos.....
.... who forever sing your glory:

We sang something called Evening Mass: Sanctus by Deanne Witkowski

Leader: Remembering his faithfulness to you,
celebrating the gift of resurrection to new life,
we speak of that mystery we call faith:

People: Jesus come to us,
Jesus hears us calling out:
Jesus will offer us healing.

Leader: Pour out your Spirit.....
.... God in Community, Holy in One. Amen

Unison Prayer After Communion

Our Creator God
has called us to this safe haven,
and called us Beloved.
Jesus, who redeems us,
has called us by name: Sister, Brother
and has given us this joyful feast.
Spirit, who sustains and empowers us,
has called us to embrace,
and cradles us in her heart.
For these gifts we praise you, Holy in One,
and claim your power
to live in freedom, justice and wholeness. Amen

Thom M. Shuman currently serves as Interim Pastor at First Presbyterian Church in Glendale, Ohio. He is the author of "*The Jesse Tree*" (Advent devotions) and "*Cradled in God's Grace*," liturgies for Year A in the Revised Common Lectionary. He offers prayers, lectionary liturgies and more at the following web addresses:

www.occasionalsightings.blogspot.com

www.lectionaryliturgies.blogspot.com

www.prayersfortoday.blogspot.com

TO TOM McCALL, WHEREVER YOU ARE

From *Reaching For Rainbows*, by Ann Weems

A few years ago there was a little boy in my church school class who was perpetual motion. He never sat down and the teachers could not guess what he would do next. He moved away and I've lost track of the family, but I've always had a soft spot in my heart for Tom McCall.

Reader:

I've always loved you, Tom McCall,
Of spirit large and figure small,
Since first we met in the church's hall
And you stuck your tongue out, Tom McCall.

Individual Voices

1: Tom McCall, all legs and feet,
2: Tom McCall never sits on the seat.
3: Tom McCall, your shirttail's out.
1: Tom McCall, do you always shout?
2: Tom McCall, paint on your face,
3: Did you have to paint the rest of the place?

Reader:

The choir children are in single file,
Looking angelic all the while.
Here comes one with a great big smile:
Tom is backing down the aisle.

1: Tom, your choir robe's askew.
2: Tom, did it ever occur to you,
3: If you don't watch out you're going to fall.....
1: Now you've done it, Tom McCall!
2: Tom McCall, grin on your face,
3: You've melted hearts all over the place!

Reader

And then in church school late in fall,
We spoke of a child who had nothing at all.
Tom took his feet from the church school wall,
Emptied his pockets and gave his all.
Here's to you, dear Tom McCall!

1: Tom McCall, all legs and feet.
2: Tom McCall, never sits on the seat.
3: Tom McCall, your shirttail's out.
1: Tom McCall, do you always shout?
2: Tom McCall, paint on your face,

Reader

Tom McCall, child of grace.

Excerpt from *Reaching for Rainbows*. Ann Weems, Westminster Press, Philadelphia, 1980

Ann Weems is a Presbyterian elder, a lecturer, and a popular poet. She is the author of *Family Faith Stories*, *Reaching for Rainbows*, *Searching for Shalom*, *Kneeling in Bethlehem*, *Kneeling in Jerusalem*, *Psalms of Lament*, and *Putting the Amazing Back in Grace*, all available from Westminster John Knox Press.

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 the Presbyterians for Disability Concerns (PDC) Leadership Team. 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.).

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 the Presbyterians for Disability Concerns (PDC) Leadership Team. 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.

TACTILE ELEMENTS

GREETING AND GENTLY TOUCHING each person as service begins
WIND from a fan as a reminder of Spirit's presence, hand-held or electric
ANOINTING of hand/forehead with oil
LOTION can be rubbed on hands
ASPERSION blessing by sprinkling water with an evergreen branch as benediction
MISTING gently from a water bottle
WARM WASHCLOTH touched to forehead as a sign of cleansing
HOT STEAM TOWEL service as a sign of cleansing
TOUCHING of object involved in the lesson, such as water, rock, etc.
LAYING ON OF HANDS as participants receive a prayerful blessing. Depending on comfort level: gentle touch on arm, hand on head, shoulders, or embracing sides of head with hands
PLACING A ROBE on the newly baptized, symbol of being clothed with Christ
HAND WASHING OR FOOT WASHING ceremony [John 13], washing of hands for what you've done, washing of feet for where you've been, washing of face for how you're known
SIGN OF THE CROSS MADE WITH WATER on forehead as a reminder of baptism
SIGN OF THE CROSS MADE WITH ASHES on forehead as a reminder of mortality, repentance

OLFACTORY ELEMENTS

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SCENTED ANOINTING OIL on hand/forehead
INCENSE as a reminder of God's presence in the temple
SCENTED CANDLE for God's presence
BAKING BREAD from portable bread-making machine
WINE brought to participants to smell
LOTION which can be rubbed on hands
PERFUME to signify our fragrant praise offering
SCENT OF FLAVORS (found in baking section) on cotton ball, kept airtight

GUSTATORY ELEMENTS

EUCHARIST, receive bread, juice; can be served to all as a taste of pabulum with grape juice, or in the Russian Orthodox tradition of breaking the bread into the cup and spooning it into mouth
TASTES of honey, bitter herbs, and other illustrative flavors

Please send other ideas to:
Chaplain Margot Hausmann
Eastern Christian Children's Retreat
700 Mountain Ave.
Wyckoff, NJ 07481

Include a self-addressed stamped envelope to receive an updated list including new suggestions!

SIGNS OF THE SACRAMENTS including font, table, cup, plate
BIBLE, visible when read
BOLD GESTURES AND SIGNS which will illuminate the text as it is read
ASH CROSS on forehead for repentance
STAINED-GLASS WINDOW (*where available*) as the object of instruction
A PROCESSION with banner at the front on appropriate days: Palm Sunday, All Saints, Good Friday. May include balloons, sunflowers, sparklers, trumpets, cross, etc.
AN ADVENT TREE to which an appropriate symbol/ornament is added each week
RAISED HANDS of the worship leader as the closing blessing is announced
DRAWN SIGNS such as a 'happy face' or a 'sad face' to be worn as worshipers participate in a liturgical drama
WRITTEN SIGNS to be worn as worshipers participate in a liturgical drama as various 'characters: Hope, Sorrow, Promise, Rejection, etc.
PARTICIPANTS LEAD FROM THEIR WEAKNESS, leader explains that I.V. treatment is a metaphor for how the LORD feeds and strengthens; leader may explain the spiritual significance of humility behind a "bowed" posture if someone is bent over, etc.

MULTISENSORY WORSHIP IDEAS

KINESTHETIC ELEMENTS

CLAPPING, with hands, feet, and eyes!
DANCE and expressive dance movements with arms or legs as able
PROCESSIONS to site of worship with banners, placards, wheelchairs, music, etc.
TRIPUDION step of humility, taking 3 forward and 1 back; also appropriate for wheelchairs
ORANS, uplifted hands as a gesture of prayer
RAISING OF THE EYES as praise or to ask for God's help
FOLDING OF HANDS symbolizes submission to God's will [Imagine God's hands around your own]
FOURFOLD MOVEMENT, when a four word response is required (i.e. "Lord hear our prayer") those gathered may participate with four claps, four stomps
GESTURAL LEADERSHIP, as congregation follows the leader's gestures (posture, arms, etc.)
PASSING THE PEACE with a handshake or hug as a sign of reconciliation
BREATHING "in" the Holy Spirit and breathing "out" the old stale air
STRIKING of the breast in penitence
KNEELING in humility or penitence
PROSTRATION, laying face-down in humility, depravity (as some disabled folks demonstrate on their positioning equipment!)
MARKING the sign of the cross on one's body symbolizes belonging to God
OFFERING gifts by bringing them forward
POSITION wheelchairs or other chairs as in DaVinci's *Last Supper*, or other meaningful ways
CONGREGATIONAL DANCE by clasping arms at shoulder level and swaying, stepping
DRAMATIZING the "feeling" of a word by worshipers, such as "love" or "praise"
PREPARING THE WAY, participants may clear away clutter and obstacles from worship space to make the way to our hearts "accessible" for Christ
APPROACHING table to receive eucharist
WRITING of prayer requests, if able

AUDITORY ELEMENTS

GREETING each person by name
SACRING BELL calling those gathered to worship, or rung before scripture is read
SPEAKING THE NAMES of participants often (i.e. "God so loved the world, Helen, that he gave his only son, Richard...")
TAPED MUSIC to which participants can join in song or with instruments
SUNG MUSIC, choruses or simple songs
HAND-HELD INSTRUMENTS, maracas, tambourine, bells, etc.
HEAD-HELD INSTRUMENTS, bells attached to a baseball cap
CLAPPING with hands or feet!
PASSING THE PEACE by name, "The peace of the Lord be with you, Nicky, and with your spirit."
READING of the word
RESPONSIVE READINGS which allow a congregation or assistant leader to participate with a simple response, "God's love lasts forever" (Psalm 136)
TAPED OR PHONE-LED LEADERSHIP by someone not able to get out to worship, such as the scripture reading
ANTHEMS which proclaim the word
INVITING SPOKEN PRAYER REQUESTS while also listening for the meaning behind non-verbal vocalizations to include in prayer (a cry, laugh, shout, etc.)
SYMPHONY/CACOPHONY OF PRAYER, inviting all to speak their prayers simultaneously
BIDDING PRAYER, short petitions which may conclude with the leader saying, "Lord in your mercy" to which all respond "Hear our prayer."
MUSICAL ACCOMPANIMENT in the background of pastoral prayer if lengthy
SING 5-FOLD "AMEN" to conclude prayers
INTERPRETATION WITH VOICE of a service which is first signed
SILENCE of being still before God
GRACE for people who are deaf or hearing impaired to interpret our prayers

VISUAL ELEMENTS

COLORFUL BANNERS appropriate to the message, also use of simple symbols such as arrows pointing up or down
COLORFUL FLAGS to wave, or a tall pole bearing an inverted hanger strung with long ribbons
CLOTH DRAPED IN WORSHIP SPACE, red for Pentecost, etc.
STOLE AND PARAMENTS of season's liturgical color, also point out others present wearing color. When celebrating the priesthood of all believers, crepe paper stoles for all!
WORSHIP PENDANTS, leader may wear large symbols such as bread, grapes, rock, fish, lightbulb, etc., explaining meaning
COLOR BANDANAS for all, worn around the neck, purple for Advent, etc.
SIGN LANGUAGE, sign a greeting, simple songs, prayers, Lord's prayer, benediction, etc. All participants may be invited to sign even a simple "Thank you", "I'm sorry", "Please", or "I love you" to God in prayer
GESTURAL LORD'S PRAYER with fewer and more simple gestures than American Sign
BRIGHT SATIN RIBBONS may be attached to hand-held instruments
COLORFUL SCARVES to wave during music
BALLOONS to celebrate baptism, or in color of liturgical season
BUBBLES blown in celebration!
FLOWERS as a sign of life
A DOVE hanging from the ceiling as reminder of the Spirit's presence
A CANDLE (when safe) as reminder of God's presence
SLIDES PROJECTED onto screen corresponding to each part of the service (i.e. bible, offering plate, praying hands)
LITURGICAL DANCE which illuminates text
SIGN OF THE CROSS which marks an individual as belonging to God
OBJECTS which lend themselves to the teaching: i.e. crown, wrapped gift, rock, etc.

Vulnerable Humanity: Disability and Community Beyond 'Normalcy'

By Thomas E. Reynolds

I cringed as he told his story. Speaking to a group of about 20 attentive listeners was an articulate, compassionate, and successful businessman in his early 60's, quietly recalling his public rejection by a priest. Some years ago, as he approached a church altar for communion during worship, a priest singled him out, exclaiming loudly and with disgust, "We don't serve drunks here!" True, this man talks with slurred speech and moves with a jolted gait. Yet he does not drink. He has cerebral palsy.

This story unsettles easy assurances. It exemplifies how we can misunderstand someone and exclude him or her on the basis of that misunderstanding. While the implications extend far beyond disability, in the case of this man, the rejection began there, ironically in the very place where one would expect inclusion and acceptance to prevail. Of all places, Jennie Weiss Block notes, the church should be a model of the "accessible community," a point of entry into God's love radiating through the lives of its participants. Ideally, "the Body of Christ presumes a place for everyone."¹ However, "place" is difficult for persons with disabilities. Too often they encounter a threshold that signals "access denied"—whether physical, behavioral, or attitudinal. This is tragic for both those with and those without disabilities, for specific kinds of people are rendered "helpless" or "deficient" in some way(s) by others. On this basis they are excluded from participation, which diminishes their genuine humanity. Also diminished are church communities themselves, as disabling principalities and powers come to obscure how people with disabilities can and do make real contributions to their communities, which thwarts the redemptive work of God. So it becomes important to reflect theologically on how Christians might think about and act differently toward persons with disabilities.

It does not take much to recognize that serious problems accompany Christian language about God and God's love when applied to disability. After all, encountering disability challenges the assumptions by which non-disabled people find order and meaning in the world. In order to uphold these assumptions, believers almost automatically defer to notions that imply that God somehow "causes" disability — for example, as a curse or punishment, a "cross to bear," an opportunity for God to "heal," a way for non-disabled people to demonstrate charity, a kind of moral lesson for non-disabled people ("there but for the grace of God go I"), or a spiritual lesson ("those people are so childlike and open to God").² Even though these kinds of responses can be found in biblical texts, they trade upon a bogus way of representing disability. Namely, that disability is not "normal" (abnormal), that it displays something different than what the "standard" human body should, a stigma marking a deviance considered deficient. But what is normal? And what constitutes a disability?

Nancy Eiesland describes disability as the consequence of impairment, that is, an inability to perform some task or activity considered necessary within a social environment.³ This makes disability, to a large degree, a social construct. Disability represents a diminishment relative to a context of valuation and its conventions, a lack of ability to function in ways considered valuable to a group. In this way, as disability theorist Lennard Davis describes, disability and normalcy are part of the same system.⁴ Impairment does not necessarily mean disability. For example, visual impairment in today's world is not considered a disabling condition, but

needing a wheelchair or medication for bipolar disorder is. Why the difference? Because certain conventions have become status quo, constructing what is “normal” and thereby creating the difference between bodies that are “able” and those that are “disabled.” There is more at stake, then, in the matter of disability than an impairment that someone happens to have. For society disables people by representing impairment as a flaw. But if we grant that the “normal” is a standard that is socially constructed, we are brought to recognize that it can also be critiqued and de-constructed. The basis for this, I believe, lies in something all human beings share: vulnerability. It is an inescapable fact that we are born, live our lives, and then die as vulnerable creatures needing each other, not just to survive as helpless infants, but also to grow and come to flourish as subjects of our own experience, eventually dying in the care of others, helpless before our mortality. Such vulnerability binds us together with those who accompany us. Highlighting this theme, therefore, is essential because it provides a way into more vigorously acknowledging and experiencing our deep connecting points with one another, points that indicate a basic web of mutual dependence, but which all too often become cloaked by the exchange values that animate human communities under the sway of what Stanley Hauerwas calls “the tyranny of normality.”⁵

So rather than ability – for example, the capacity to think rationally, act autonomously, look healthy, or produce and purchase things as self-interested consumers – it is human vulnerability that is a starting point for discovering what we share in our differences, a source bearing the precious and fragile grace of solidarity with one another. Jean Vanier, founder of L’Arche, a network of communities for intellectually disabled people, sums it up eloquently: “We do not discover who we are, we do not reach true humanness, in a solitary state; we discover it through mutual dependency, in weakness, in learning through belonging.”⁶

Viewed through the lens of basic vulnerability, neediness or lack of ability is not a flaw detracting from an otherwise pure and complete human nature. Rather, it is testimony to the fact that we receive our existence from each other. And recognizing this is a source of relational openness to others, who are in turn similarly constituted. Genuine wholeness is found not through ability but through an acknowledgment of vulnerability that is made concrete in relations of mutual giving to and receiving from others.

This notion is difficult and painful to process under the sway of dominant social conventions; it runs counter to the common assumption that value is based upon power and ability. We suppose that our identity, our worth, derives from the power of completeness, a capacity to be independent and self-initiating, able to control our bodies in the face of others and thus be recognized as contributing to the group. The irony is, in the words of Stanley Hauerwas, “our neediness is also the source of our greatest strength, for our need requires the cooperation and love of others from which derives our ability not only to live but to flourish.”⁷ Living out of this reality is a source of genuine good, for it entails helping others—in their “disability” – as essential not only to our own flourishing but also to the common good of the community in which we flourish.

Yet neediness is a difficult reality to accept. For it means recognizing that we are at the core exposed to imperilment and suffering, contingent and incomplete beings who need to belong to become ourselves.⁸ Indeed, we do suffer. Vanier observes: “Weakness is at the heart of the need to belong; weakness that we may fear, because we have been hurt.”⁹ Fearful of being wounded, we often attempt to cover our vulnerability, protecting it by denying our dependence upon others. The irony in this, however, is that belonging is inescapable. We

become who we are through community. But in the modality of fear, belonging becomes a false means to assure ourselves of strength and completeness. For we presume that security entails conforming to the projected strength of others, bolstered by the conventions of society and its power mechanisms. It is as though acquiescing to the status quo offers protection by rendering us immune to contingency and its perils.

Such pretense is what fuels efforts to build protective walls around the "normal" and classify certain anomalies as "abnormal." We thereby come to judge the different and strange – that which does not fit into the ordered scheme of things – according to our fears. In a state of insecurity, we hunt for a scapegoat for our fear, someone or something to turn into the object of fear, and then contempt.¹⁰ The different is frightening because it mirrors our own weakness and vulnerability. It ruptures conventions of normalcy and forces us to acknowledge that which we shun and seek immunity against: inability, incompleteness, and neediness. Hence, disability is considered a weakness because it concretely reveals to us what we shun in ourselves: weakness.¹¹ Often the cement that binds a group together is cast over the sense of vulnerability that preoccupies its constituents. And this is a moral failure. Not only does it lead to representing vulnerability as a flaw, it also seeks to objectify such flaws as an attribute of the other who is different. By projecting our own fear of vulnerability onto another, we become cut off from the wellspring of our own flourishing: mutual dependence. We deny the other, and so, ourselves.

Our efforts to suppress it notwithstanding, mutual dependence is primary. It is the fulcrum from which we emerge as persons. It elicits a fundamental sense of wholeness that, even as we conceal it, rises here and there like grass through asphalt, captivating our attention. Vanier explains why: "Weakness carries within it a secret power. The cry and the trust that flow from weakness can open up hearts."¹² The vulnerability of another is a window into our own vulnerability, evoking a sympathetic relation that eludes the tyranny of the normal, sweeping under the radar of conventional economies of value exchange. In this way, Vanier suggests that those who embody weakness and are considered "nobodies" in a society – i.e., people who exhibit disabilities – "have profound lessons to teach us."¹³ They invite us to move out from behind closed walls of false security and exclusion to acknowledge and accept our vulnerability. Theologian Jürgen Moltmann confirms the point in stating, "A person with disabilities gives others the precious insight into the woundedness and weakness of human life."¹⁴ Disability is a profound symbol of human brokenness, not as a flaw but as a pervasive condition.¹⁵ Of course, we can suppress or deny our weakness, fleeing from it by pushing away those others whose difference overtly exhibits it as something we deem ugly or dirty or deficient. But by doing this we shun what is perhaps most human about us – the need to belong and be recognized as of value.

There is, in the end, no hard and fast line between ability and disability, but rather a nexus of reciprocity that is based in our vulnerable humanity. All of life comes to us as a gift, an endowment that is received in countless ways from others throughout our lifetime. When we acknowledge this, the line between giving and receiving, ability and disability, begins to blur. Moltmann goes so far as to state: "There is no differentiation between the healthy and those with disabilities. For every human life has its limitations, vulnerabilities, and weaknesses. We are born needy, and we die helpless. It is only the ideals of health of a society of the strong which condemn a part of humanity to being 'disabled.'"¹⁶ Conversely, having a disability is not equivalent to being ill or sick, needing a cure. Disability does not define a person.

Full personhood is neither diminished by disability nor confirmed by ability. Instead, it is a factor of the interdependent relationships we share with one another as creatures loved into being by God and in the image of God. There is a wider horizon in which all persons in their uniqueness and vulnerability coexist within the enfolding presence of a gracious God. Again, Moltmann notes, a "person with disabilities gives others the precious insight into the woundedness and weakness of human life. But a person with disabilities also gives insight into the humanity of his own world. Through persons with disabilities, other people can come to know the real, suffering, living God, who also loves them infinitely."¹⁷ Reflecting on his own work, Vanier suggests something similar, namely, that those with disabilities call us into acknowledging our own human weaknesses and thus open us up more radically to God's grace.¹⁸

To exist as a finite creature is to be vulnerable. And, speaking theologically, it is precisely such vulnerability that God embraces in Christ, entering fully into the frailty of the human condition, even unto a tragic death. Jesus is Emmanuel, God with us. Sharing the divine self in this way sends a distinct message: God is in solidarity with humanity at its most fundamental level, in weakness and brokenness. Here, God reveals the divine nature as compassion not only by "undergoing" or "suffering with" human vulnerability, but also by raising it up into God's own being. Redemption, then, is a welcoming, a divine act of hospitality. It does not negate vulnerability by making humans invulnerable and perfectly whole. Nancy Eiesland notes this by calling our attention to the fact that Jesus' body remains scarred after his resurrection.¹⁹ So instead of doing away with the capacity to suffer, redemption transforms vulnerability into a communion with God, prefiguring the final horizon to come when all things will become so transformed.

So I come to the conclusion that disability is tragically but redemptively fundamental. It is tragic because it entails real suffering, which in many cases is caused by society – even by our churches, to recall the case of the man who was rejected at the communion table. Disability is redemptive because it opens up our human vulnerability and dependence upon each other and God. This gets to the heart of Paul's proclamation in 2 Corinthians 12 that God's power is made "complete" and perfected in weakness. And it has dramatic implications for living together, for wholeness is not self-sufficiency. Rather, it is the genuinely inclusive communion that results from sharing our vulnerable humanity with one another in light of the grace of God. Would it not be appropriate, then, to open the table fellowship of communion to all God's children, sharing the inclusive love of God without representing some people as "abled" and others as "disabled"? Of course, this would mean taking a hard look at the humanity we all share, and adopting a radically new understanding of what it means for us to be truly human.

1. Jennie Weiss Block, *Copious Hosting: A Theology of Access from People with Disabilities* (New York and London: Continuum, 2002) 131.
2. For an excellent survey and critique of such responses, see Kathy Black, *A Healing Homiletic: Preaching and Disability* (Nashville: Abingdon Press, 1996).
3. Nancy L. Eiesland, *The Disabled God: Toward a Liberation Theology of Disability* (Nashville: Abingdon Press, 1994) 27. Eiesland refers to S.Z. Nagi's definition, from "The Concept and Measurement of Disability in Disability Policies and Government Programs," in E.D. Berkowitz (ed.), *Disability Policies and Government Programs* (New York: Praeger, 1979) 3.

4. Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (London and New York: Verso, 1995) 2. See also pp. 48-49.
5. Stanley Hauerwas, "Community and Diversity: The Tyranny of Normality," in *Critical Reflections on Stanley Hauerwas' Theology of Disability: Disabling Society, Enabling Theology*, ed. John Swinton (Binghamton, NY: The Haworth Pastoral Press, 2004) 37-43.
6. Jean Vanier, *Becoming Human* (Mahwah, NJ: Paulist Press, 1998) 41.
7. Hauerwas, "Suffering the Retarded," in *Critical Reflections* 97.
8. Hauerwas, "Suffering the Retarded" 100-4.
9. Vanier 46.
10. Vanier 73.
11. See Vanier 74-81.
12. Vanier 40.
13. Vanier 45.
14. Jürgen Moltmann, "Liberate Yourselves by Accepting One Another," in *Human Disability and the Service of God*, eds. Nancy L. Eiesland and Don E. Saliers (Nashville: Abingdon, 1998) 105-122, 121.
15. See Stuart Govig, *Strong at the Broken Places: Persons with Disabilities and the Church* (Louisville: Westminster/John Knox, 1989).
16. Moltmann 110.
17. Moltmann 121.
18. Vanier 39-41.
19. Eiesland 98-105.

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Welcoming All God's Children: Confirmation



Artwork by student of FAR Conservatory for Therapeutic Performing Arts, Birmingham, MI

Reflections on Confirmed Church Membership For Youth and Adults with Pervasive Disabilities

By Rev. Sue Montgomery

Introduction: This article was written in response to a parent's search for guidance in enabling her young adult son who is medically fragile and lives with pervasive disabilities to become a communicant member of the church. The family belonged and participated regularly in the life and mission of their church.

These words introduce the vision of the Presbyterian Church that is presented in the 2006 [*Living into the Body of Christ: Towards the Full Inclusion of People with Disabilities*](#), a social witness policy of the Presbyterian Church (U.S.A.):

“As the Body of Christ, we are open to welcome everyone to the banquet Feast of God's Love in this world. The Feast of God's love is open to all and fully inclusive of people from all pathways of life. We envision a church in which the designation or naming of a person's disability is less important than who that person is as one of God's people.” (*Living Into the Body of Christ: Towards the Full Inclusion of People with Disabilities*, p. 1.)

These words become the background and the guide for today's church as she seeks to answer the big question of how the church can meet the ministry needs of our youth and young adults living with pervasive disabilities to become active confirmed members. Many times because the young adults and adults cannot speak for themselves, their families are the ones who approach the pastor and seek ways for them to become communicant members of Christ's church. This is a valid question for both the parents, the persons living with the disability, the session of the church, and the pastor. How should a session and pastor respond to this question? How could today's church respond to the question, maintain the integrity of church membership, and at the same time be inclusive and nurturing of people with severe intellectual or cognitive disabilities?

Over the years the church has answered this question in a variety of ways. For some parents, and their pastors, the question of church membership has never been important. The belief was that since the child or young adult could not speak for him/herself, church membership wasn't necessary. The underlying theological message was that persons with intellectual disabilities were “eternal children,” or “eternal angels.” Therefore, confirmation and the act of making a personal statement of faith were unnecessary. This theological viewpoint remains alive and well today and it is as gravely wrong now as it was years ago. During the 1950's the parents of children born with disabilities began to embrace with a renewed commitment and understanding the concept of the family. For the first time parents began to say an emphatic and resounding “no” to the medical professionals whose recommendations were to institutionalize the children who were born with disabilities.

When today's church is asked the question about confirmation, the church is being asked to do what parents chose to do years ago, and that is to affirm and embrace what it means to be the family of God. Youth and young adults do want to be a part of the church, God's family. Youth and young adults can make faith decisions. The church simply needs to learn how to listen to the youth and to their families. Today's church needs to learn how to perceive faith

in new ways. These new ways may include learning how to understand non-verbal communication, communication expressed through facial and hand gestures, or to embrace creative use of symbols that reflect the meaning of faith. Today's church needs to learn how to embrace compassionate caring, even when it simply means embracing the presence of a non-verbal youth or young adult in the activities and ministries. One family said: "Our son is included in all our family activities. To the outsider he appears to be just sitting there, yet we know he is listening, watching, and sensing that he is loved and he is family. I wish the church could learn this gift that he has taught us." Today's church, like our academic institutions, is so focused on product outcomes, that the person is often forgotten.

When a teacher gets to know a person with pervasive disabilities, it becomes evident rather quickly that the typical approach to adapting a confirmation class curriculum to match the abilities and comprehension level of the class members with profound disabilities will not always be an effective approach. Here is where it is vital for the teachers to get to know the confirmand and his/her parents or caregivers. By including the confirmand in all the discussions, a team is developed to nurture the youth or young adult through the learning process. Because all of us have been given the gift of life, we have all been given the gift of being able to perceive God, faith, and to express that faith. It is imperative for the church to explore the ministry needs of the person with the disability and the family in their desire to secure church membership. As the support team gets to know the confirmand and how he/she communicates, the doors to learning and sharing lives for everyone will be opened. This is important not only for the teacher of the class, but the young adult's peers as well.

One way to seek to meet the ministry needs of the persons involved is to approach the question of how the confirmand learns from the perspective of the parents and caregivers. The parents or caregivers can provide wisdom and understanding on how to communicate with the youth or young adult with the disability. It's always difficult to gauge or measure how much a person is grasping the information around them. The church is good at asking these types of questions. For decades the church has required a certain level of comprehension and understanding to validate church membership. However, when a child is born with disabilities within a family, the family does not place any criteria on the child for acceptance and love. This is the gift of being a family. The church, as the family of God, is being called on now to embrace that profound definition and gift of being God's family. People with profound disabilities do have faith needs and gifts of faith. It is the task of the church to learn how to enter into a relationship with the persons with the disabilities and their families.

The next question often asked, then, is, where do we go from here? The typical statements of faith, recitations of creeds, memorization of prayers and scripture may be outside the realm of what is possible for those with profound disabilities, in terms of class product outcome and expectations. Does this mean that persons with pervasive disabilities should never become members of the congregation? What's to be gained and what's to be lost in the development of an alternative statement of faith, perhaps one where the entire class of confirmands work together? This is the moral and ethical dilemma that pastors and sessions are charged with as they bear the responsibility of maintaining the integrity of church membership and affirmations of faith. Again, when we understand that we are all a part of God's creation and as such are the family of God, disability cannot ever be an acceptable exclusionary clause to church membership.

Here is where pastors and sessions are faced with the real questions of their ministry—does the church as the family of God exist solely to maintain structure and order, or does the

church as the family of God exist to meet the ministry needs of her people? For persons living with disabilities and their families, the call to meet the ministry needs of the family takes priority. When a parent requests church membership for their son or daughter with a disability, the session, pastor, parents, and the confirmand, can enter into a covenant agreement to nurture, mentor, and support one another in church membership. It also means that within this covenant relationship the confirmand is a full member of the church, just like everybody else. He/she has made their statement of faith and is a part of the ministry and mission of the church. Such a covenantal relationship signifies that, although the confirmand due to disability cannot function without supportive assistance, the church family is ready and willing to meet his/her ministry needs. This may lead to new understandings of ministry in how communion is served, how people are included through making transportation available, making buildings accessible, and the language a congregation uses to describe people living with disabilities. Such a ministry might bring new dimensions to how the congregation worships and brings in visual and sensory elements to enhance worship's traditional verbal context.

Church membership needs to be understood as much more than one's cognitive ability to make a statement of faith. Parents who are speaking on behalf of their youth and young adults understand that their sons and daughters want to live—and die—within a church family and community. When members of the church die, their obituaries state that they were members of a specific church. Parents and guardians along with the youth and young adults they care for, seek that same identity and relationship with God's family and with the church.

Even more important is to develop relationships with the young person or young adult with the disability and with his or her family. This is where the church meets its greatest challenge. The traditional church ministries that are designed for people who are homebound or experiencing a crisis need to be re-examined in light of chronic and life threatening disabilities. Church families can be supportive in ways that expand the traditional understanding of church. Families with long term care needs often need someone who can just come, sit with them, listen, and offer prayer. The person with the disability longs for someone to touch them who is not a salaried care giver or family member. Having a church member care enough to visit, to extend the right hand of fellowship is what is longed for and cherished by people living with disabilities.

Recently at a large residential facility for persons with developmental disabilities a family came searching for a long lost relative. During a genealogical search the family discovered they had an uncle who had been placed at the facility when he was a baby. Eighty years had passed; no one in the family knew he existed. His birth, at that time, was a tragic secret to be hidden. This family was Jewish. During his eighty years of life within the institution their uncle had been raised as a Protestant. When they were reunited with their uncle, he immediately received all the religious rites and special services of a lifetime as a Jew. No questions were asked about his intellectual ability to understand. He was a son of God and as a son of God was a member of the Jewish family—there was NO question. The faith of this family said that in creation all God's children belong to the family. The diversity of God's creation includes disability. Disability does not exclude anyone from the family of God. As their uncle received his yarmulke, his prayer shawl, the blessings of his faith and family, it was a moving witness of acceptance and profound love. Although the family respected his history of nurture in the Christian faith, they wanted him to receive the unconditional love, and the gift of his roots in the Jewish traditions. Our Christian covenant of baptism has no exclusionary clauses for disability. Although it is undeniable that there are no easy answers, disability is not a valid exclusionary clause to church membership. Despite the many

questions there is one imperative guiding all the works of the church and that imperative is to meet the ministry needs of the family of God. The social witness policy of the Presbyterian Church (U.S.A.) also seeks to:

“Encourage the self-advocacy and self-determination, and full participation of people with disabilities in congregational life, spiritually, physically, and programmatically.” (p.4.)

As the church seeks to meet the ministry needs of persons with pervasive disabilities and their families, the words of the parable of the workers in the vineyards found in of the Gospel of Matthew 20: 1-16 guide us. In the parable of the vineyard laborers, despite the length and quality of their work, all are treated equally. The covenant agreement to work in the vineyard is more important than what the laborers receive in return. Is it not the same in the church? And who is to say that persons with pervasive disabilities don't have gifts to offer? “The first shall be last and the last shall be first.” It is in that humble ministry that we stand and with faith embrace and celebrate the presence and the gifts of persons with pervasive disabilities into full active membership in the church of Jesus Christ.

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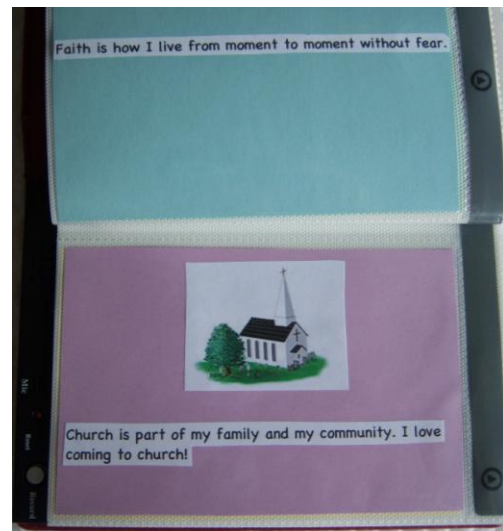
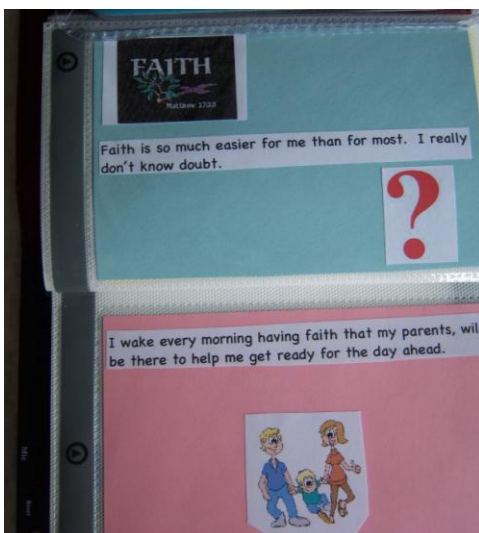
Confirmation: Tools for Inclusion

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/christian-education/disability-inclusion-ministry/>. 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) Leadership Team.

Welcoming All God's Children: Models of Ministry



The Gifts of God for the People of God

Artwork by Nicholas, Age 9
First Presbyterian Church
Birmingham, MI

Radical Wholeness: All Children, All Youth and the Complete Faith Community

By Milton Tyree

Children are always learning something: Who gets invited and who's left out? Who belongs and who doesn't? Who belongs with whom? Who's important and who's not? *And why?* Belonging and un-belonging messages are relentlessly sent – purposely or not; consciously or unconsciously received.

Young children are like sponges for social messages, often responding innocently to the world's prejudice. Given positive introductions, their natural curiosity readily accepts differences in people rejected by the larger society. Likely this openness played a role in Jesus' defense of little ones. "Truly I tell you, unless you change and become like little children, you will never enter the kingdom of heaven." (Matthew 18:3)

Our teens are more easily captured by the world and its ways, acutely aware of what it takes to belong. And fitting in, somewhere, somehow, is exceedingly important.

So this business of belonging for children and youth is complicated stuff. The focus of this article is congregational belonging for children and youth who have intellectual disabilities – those historically kept apart and away from children and youth who do not have disabilities. If the church is called to break this cycle of exclusion, then where can we begin? How can we start to understand and address the needs of children and youth who have intellectual disabilities?

Clearly, we need a radical way. Not militant, not aggressive, but decidedly counter-cultural. We need a peaceful, thoughtful, loving, gentle, caring and deliberate recalling of the roots of our faith. Setting the stage for positive possibilities. Involving and including children all too often rejected. Understanding those so often misunderstood. Discovering and using gifts and talents of the children and youth believed by many to have nothing to offer. Building up the very people the larger society has a way of keeping down. "Do not let any unwholesome talk come out of your mouths, but only what is helpful for building others up according to their needs, that it may benefit those who listen." (Ephesians 4:29)

So what do children and youth with disabilities need? To be loved, included, involved, understood, to have their gifts and talents recognized and used. To be known and valued individually, as a child of God, and as an essential congregational member. There you have it. Children and youth with disabilities actually need what all of us need. If anything, they need it more.

The good news is that there are positive ways to move forward – approaches that are tried and true, deriving from or aligning perfectly with our Christian tenets, and with potential for energizing a congregation as it seeks to become more complete:

Valuing those that the world devalues. Jesus dealt quite directly with social devaluation, turning upside-down our human tendency to rank order people and their perceived social significance. All children were part of a socially devalued class in Jesus' day. "Therefore, whoever takes the lowly position of this child is the greatest in the kingdom of heaven. And whoever welcomes one such child in my name welcomes me." (Matthew 18:4-5) The synoptic gospels are full of instances where Jesus reminds, "... those who are last who will be first, and first who will be last." (Luke 13:30)

Moving beyond "special." Avoid starting special entities or special ministries that group children or youth with disabilities together. There's no doubt about it, "special" is deeply embedded in our society. The good intentions and benefits of special groups are so widely promoted, that the costs are rarely considered. It's time to get radical! Special groupings represent one of the primary obstacles to knowing an individual and can even represent the loss of individuality for a child or teen. Instead of a child or teen's disability being seen as part of his or her identity, it can become *the* defining characteristic. After all, it's the reason she's in the special group. Very easily and unconsciously, we start to believe that everyone in the group is really the same, needs the same things, or learns in the same way. Furthermore, all of a faith community's time, energy, and resources used for *special* congregational life are not available for promoting *typical/valued* congregational life. "Special" takes on a life of its own – a separate and distinct life. We need a *community* of faith, not a *collection* of groups of people, especially not people grouped because of a commonly held socially devalued characteristic.

Devoting time to know one child or one teen at a time. Here's a question a congregational member recently told me she poses to parents of children with disabilities: "What gives your child joy?" What a wonderful way to begin a conversation! Welcome the child or teen with a disability and you'll welcome the entire family. Request time with parents to learn everything they have the desire and energy to share. What are Nick's gifts? What needs to be in place to help things go well? When and where is he at his best? What kinds of personalities fit? What activities does he enjoy? How does he learn best? Are there teachers who could help us plan for his successful involvement? What are things that create difficulties, things we should take care to avoid? How would you suggest I spend time with Nick to know him better?

Feeding the hunger to belong – discovering personal talents and interests. Even for those who can't express it, just about everyone wants to fit in. Especially teenagers. Since our human construct of "disability" requires us to name ways people are deficient when compared to the norm, all too often we forget to mine for people's gifts, talents and interests. Asking isn't enough. The child or teen may not speak, and even if she does, she may not know an answer. This is one of the most essential facets of building a complete congregation. Who are the people who have the standing, the high expectations and the insight to see things in children and youth that have gone previously unrecognized? How do these personal gifts translate within the everyday rhythms of congregational life?

Seeking typical and valued congregational roles and ways of fitting in. Every congregation has its distinctive culture and norms. Here's the central question: What do people of the same age and gender do within your faith community, and what will it take for Jane to be involved? You don't have to do everything to do something. Orchestrate a positive beginning for the child or teen, teacher and classmates, and build from there. Even if it's five minutes in the beginning, just do what's possible to lay a positive foundation. Alternatives to involvement in typical happenings such as Sunday School or worship can be used for the other time, perhaps teaming with a peer or youth (e.g., assisting with clerical tasks in the church office, going for a walk, helping with another Sunday School class...).

Asking peers to help. Despite their many differences, one thing children and youth will have in common is their desire to be asked, to be heard, and to help. They can have pretty good answers if we'll only inquire. Inviting children and teens to help think about ways Michael can be involved in our class can build a solid basis for wholeness. Teens, who come naturally equipped with a healthy skepticism for grownup ideas, can be especially good at coming up with creative and respectful ways of inclusion.

Leading, not following. Opening the door. Offering the invitation. Children will always be learning something. We have the opportunity to model complete community. Valuing children and youth devalued by the larger society. Honoring Jesus' example. Embracing a radical wholeness. It's an imperative and a privilege.

[Milton Tyree is the PC\(USA\) consultant for people having developmental or intellectual disabilities.](#)
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No Outsiders: Welcoming Children With Vision or Hearing Loss

Rev. Bebe Baldwin

Including children with disabilities in the life of the church invites us to discover and enjoy the unique giftedness of each child. Children who have vision or hearing impairments are, first of all, children, not problems to be “fixed.” When we recognize each child as a person created in the image of God, we affirm that she or he is more than a pair of eyes or a pair of ears.

Words are important! [Using person-first language](#) reminds us that “Susie” is a girl who is blind or has vision impairment. She is not a blind or visually impaired girl. “Jason” is a boy who is deaf, is hard of hearing, or has a hearing impairment. He is not a deaf or hearing impaired boy. Naming the person first and not the disability affirms that the child is more important than her limitations. We are not defined by our disabilities!

Parents can help you create an inclusive setting for their child. Talk with them and learn what the child can and cannot do. Don’t end the conversation with the child’s limitation. Take the time to begin to discover his strengths and abilities. Knowing her gifts and interests will help you connect with the child and plan for inclusion.

You may be able to engage the child in finding ways to become inclusive. You might ask a question like, “What will work for you?” Having this conversation can help the child to learn self-advocacy.

Suggestions for Inclusion of Children with Vision Loss

- Learn about the child’s vision. Most people with vision loss have some sight. Fewer than ten percent have no sight. The kind and degree of vision loss varies so greatly that it is important to learn what the child can and cannot see.
- Offer the child the opportunity to visit and explore the classroom before the first gathering.
- Be aware of safety. Keep pathways clear.
- Use tactile resources when helpful and available.
- Use specific language. Describe what sighted children are seeing. Avoid terms like “here” or “over there.”
- If you are showing projected materials, read the print aloud and describe what is on the screen.
- Partnering is sometimes helpful but partnering should be mutual, giving each child the opportunity to use his gifts.
- Encourage the child to be as independent as possible. Ask before you try to assist. Don’t assume that he wants help!
- Talk with the parents or with the child about accommodations. Is the curriculum available in Braille or in an electronic format? If not, can it be made available electronically or on cassette tape or CD? Expanding the print is

helpful for some children, but the degree of magnification will depend on the child's vision. Remember, type needs to be not only large, but also dark and heavy.

- Practice courtesy. Identify yourself when you approach the child. Let her know if you are leaving. Encourage others to follow your example. Tell the child who else is in the room.

Suggestions for Inclusion of Children with Hearing Loss

- Learn what the child can and cannot hear and what are her particular needs. Most persons with hearing loss have some hearing.
- If the child uses sign language, always speak to the child and not to the interpreter. Teach his peers to follow your example.
- Minimize background noise.
- Offer older students the opportunity to read lessons before the class meets.
- Always face the child and maintain eye contact when speaking to the child. Keep hands or objects away from your lips.
- Encourage children who read lips to sit where they have the best view of other children. Use a circle for discussion time.
- Encourage the child to sit where she can hear the best and where she is away from background noise.
- Use a microphone in a large space.
- Speak clearly but do not shout! Shouting is not helpful and is demeaning.
- Use visual resources when they can be helpful and are available. Keep the sight lines clear for children with hearing impairment.

Finally: Celebrate the gifts each child brings to the life of the church. Take time to expand your own awareness and that of others. Enjoy each child for the unique person she is and is in the process of becoming. Celebrate, take time, and enjoy!

Rev. Bebe Baldwin was moderator of the PDC Leadership team in 2009-2011 and is the co-moderator of the [Disability Concerns Ministry of the Presbytery of the Twin Cities Area](#).

Ten Things

Your Student with Autism Wishes You Knew

These ideas make sense for other kids too

by Ellen Notbohm

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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, overstimulated, 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.

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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.

A Plan for Alek

By Catherine Smith

My family and I belong to the same church where I grew up. However, our church today is far different than the one I attended as a child. It is more diverse and inclusive than I remember as a child. I am now seeing the church through my children's eyes and advocating for them to ensure full inclusion in the life of the church.

My husband, Dave, and I have two children; Jocelyn, 11, and Alek, 8. We adopted Alek from Russia when he was two years old. Upon arriving in the U.S., we learned that he had Duchenne Muscular Dystrophy (DMD). DMD is a progressive, degenerative muscle disorder that robs him of his ability to use his muscles. As his muscles fail, his mind will remain intact. At this point Alek uses a wheelchair for longer distances but can move around a classroom independently.

The church has been very responsive and proactive in addressing our special needs. This attitude toward full inclusion has begun with the clergy and flows through the layers of staff, teachers, other families, and the children of the church. The ministers have been with us through all of the struggles with Alek's health and are aware of some of his needs. The Christian education director has looked at how we can include him in the larger gatherings of the church school.

The most important people we have connected with about Alek's needs have been the church school teachers. The teachers have created the environment and set the example for how to treat Alek in the classroom. At the beginning of the school year, our church school distributes a questionnaire for parents to fill out regarding their children, asking about their learning style, personality, and needs to have a successful experience. Alek's needs are communicated using the same means that all children's needs are; there is not a separate form for the "special needs child."

We have met in person with Alek's teachers to talk about the specifics of his needs for the class year. We demonstrated how to use his wheelchair and have created evacuation plans in case of emergency. Our church has installed several evacuation chairs on church stair wells, including one in the education wing. We have identified one of the church school teachers either in his class or in one near by that would be able to carry Alek, should that be necessary. We have discussed how to include Alek in the class activities so that he does not stand out due to his special needs. If the class is moving around the church, perhaps to another level, the whole class can move together using the elevator to travel between floors.

There is a commitment on the part of the church to make all children, youth, and family activities accessible. For example, the committee in charge of our church's camp facility is exploring how to make it fully accessible, utilizing a disability

consultant who understands that true accessibility goes far beyond just meeting standards mandated by the Americans with Disabilities Act.

Accommodating the special needs of children with disabilities is a natural extension of being an inclusive community of faith. The cooperation between clergy, staff, teachers, parents, and children creates an environment where our child with a disability feels welcome in his church school community.

Catherine Smith is an Elder, [Westminster Presbyterian Church](#), Minneapolis, MN and a member of the [Presbytery of the Twin Cities Area Disability Concerns Ministry](#).

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 nauseum!*

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.

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

Mark Twain

—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

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.*

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

Alternative Formats

For Children and Youth With Disabilities

By Sarah R. Nettleton

Remember children and youth with disabilities when you think about alternative formats. Does your church give bibles to new second graders, a youth bible to confirmation graduates or a devotional book to graduating Seniors? These are all opportunities to ask parents and youth with disabilities about whether your traditional gift is appropriate or whether an alternative format would best meet the student's needs.

Understanding the student's needs will help insure the bible or devotional guide will be used as you intend. Some things to consider are print size, the contrast of the print on the page, reading level or whether an audio version would be best. Talking with parents and students with disabilities will help answer these questions. Remember to make sure the gift will be age appropriate. A graduating Senior with a third grade reading level might love to receive a large print bible that he could read himself but not one that has pictures designed for seven year olds.

While it is important to give everyone the same gift; it is equally important to make sure the gift is useful for everyone. When a congregation gives bibles to new second graders, the goal is to foster the growth of the child's Christian education. Why not foster that education in an appropriate format? No church wants their gift sitting on a shelf gathering dust. They want bibles and devotional guides being used, worn out and enjoyed.

Alternative formats aren't just for adults. Children and youth with disabilities will benefit from your congregation's consideration of alternative formats to meet their needs.

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

Gifts Shared Through Music: A Model of Inclusion in Music Ministries

Article Contributors: David A. VanderMeer and Rachael C. Stewart

Introduction: [Central Presbyterian Church in Atlanta, Georgia](#) is a vibrant downtown congregation which truly celebrates its children and youth. Its music ministry supports three vocal choirs (grades K-2, 3-5, 6-12), a youth handbell choir, and a drumming choir of children, youth and adults. Staff music directors, David VanderMeer and Rachael Stewart share experiences and their reflections about inclusion of all children in their music programs.

Reflections from David A. VanderMeer:

This spirit of inclusiveness is consistent with our belief that we sing to the glory of God, who honors all of our gifts. Nevertheless, we have found that using this approach has not in any way negatively impacted the quality of what we do: our music programs are of the highest quality. We are committed to bringing our best to God - and in fact we have found that the gifts we receive through our policy of inclusiveness are far greater than any accommodation we might make for any particular individual lives.

Having had the privilege of serving the church as a full time director of Music for over thirty years, I have always included everyone who wished to sing, ring, play instruments, dance, drum, create art for our worship services, or participate in choir rehearsals. Some of my music director peers audition singers and ringers, but it is my philosophy to be inclusive of all people who want to offer their gifts to God through these programs. Members of my current Chancel Choir include singers with advanced vocal music degrees and those who have learned to read music by singing with us. Because we are an urban church surrounded by a significant homeless population, we have even had persons who are homeless sing with us, and one particular man, homeless at the time, played his recorder in worship.

I have also had the opportunity and privilege to work with many young people with learning disabilities, ADHD, autism, and physical disabilities. I have always found that these individuals brought many, many gifts to the ensembles I have conducted.

In my youth handbell choir in Houston, Texas I had the joy of working with two wonderfully gifted youth with autism. Although both boys were challenged with some physical limitations and one with his eyesight, it was amazing to watch these boys improve in their ringing skill as their eye hand coordination developed. It gave me great joy to watch the development of their inherent musical gifts through their participation in the handbell choir. A key factor in their development was the encouragement of their fellow ringers and adult sponsors that assisted in rehearsals. A musical ensemble is team work. These boys grew as they developed their skill and their confidence, but so did the other ringers. My philosophy of including all children of God in the ministry of music program is reinforced over and over again.

At the present time I have a Youth Handbell Choir with over 20 ringers. Most of the young people in this choir have been in our graded choir program from the time they were in kindergarten. They enter the Youth Handbell Choir in sixth grade. Some are quite advanced in their musical training, having had private lessons or experience in school groups. Others are new to the notion of musical ensembles. Ensemble is really the key word here, because in a handbell choir, the ensemble is key. Any one ringer plays only a narrow range of the notes in a composition. It is only as an ensemble that we can make music.

One of our ringers is a young man who progressed through our children's choir program and began ringing when he entered sixth grade. He is now 18 years old, and is still in Exceptional Education programs at school. He has the use of only one of his hands, and has other physical and intellectual disabilities. He cannot read music, but loves ringing in the bell choir. He is paired with an adult assistant, who has learned to anticipate his notes and lead in such a way that he can ring half of his part with his functional hand.

He is a participating member of the ensemble in every way including making the decision to travel with the group on our latest Music and Mission Trip last summer to Jacksonville, Florida. We spent a week singing, ringing, and doing work projects with inner-city programs. He had never been on a youth mission trip before, and it took some courage on his part, and the part of his parents, for him to travel as a part of this group. One day we were assigned to clean up and organize a day school for underprivileged children and youth. Kurt and I volunteered to mow the playground grass that was nearly a foot tall. There were some types of work on this trip the Kurt was not able to do, but it turned out mowing grass was something he was very good at. It took the two of us all day in the hot Florida sun to mow the grass, but we ended the day with big smiles on our faces for the accomplishment we had achieved. I truly had tears falling down my face because I was so proud of Kurt for the gifts he brings to our church community life. Through his participation in this group, his life has been enhanced, but all of our lives are enhanced as we become more and more aware that every one of us has gifts to offer to God and to each other.

My greatest hope is that all the youth in our music program are shaped by the presence of each member of the choirs and ensembles they are part of, and that the gifts they receive from members who might have been excluded in some other settings create a model for them that will impact them throughout their lives.

Soli Deo Gloria!
David A. VanderMeer

Reflections from Rachel Stewart:

At Central Presbyterian I direct the older elementary children's choir and the youth choir, and we work on all the fundamentals of singing together in a choir: matching pitch, learning rhythms, keeping a steady beat, sounding out consonants and vowels, memorizing lyrics, learning hymns, understanding the meaning of what we sing, communicating the text, learning to sing in two parts (for children) and four parts (youth) - the "mechanics" of singing. In addition, and perhaps more importantly, church choir is one of those places in life where we can be part of a "team,"

something bigger than ourselves. Each member is important to the whole and valued for the gifts each brings to the team. Those gifts will inevitably vary with each person, but each is valued as a child of God. There are opportunities for solo singing, of course, but my hope is that each choir member feels a connection to the choir, realizing their part in making it whole. Choir participation also gives children and youth a meaningful way to participate in leading worship regularly.

I'm a firm believer that very few people in this world are "tone-deaf," and that we are ALL called to *make a joyful noise to the Lord*. If a child or youth says to me, "but I can't be in choir because I can't sing" ... my response is something along the lines of "that's really ok with me; you don't have to be able to sing to join the choir ... I won't ask you to sing a solo, but you can be a part of the group, and we'll be a better choir if you are there."

Until Kurt joined choir, I hadn't worked with anyone living with disabilities, and hadn't really thought about what challenges that might present. Kurt and his family have been long-time Central members, and I've known him since he was born, 18 years ago. Kurt has a warm personality, a little twinkle in his eye, and through music, we've been able to form a wonderful bond. Though Kurt sang in children's choir for several years, he wasn't able to consistently match pitch. Nonetheless, with some one-on-one attention, he learned to move from his "basement" voice into his "2nd floor" head voice. Later, when he advanced into middle school, Kurt became more aware and self-conscious of his singing limitations. He decided to try the Youth Handbell Choir. With one strong hand and a helper hand, Kurt is limited to playing one bell. To help him be successful, he is partnered with an adult who gives a big prep when it's time to ring his bell. After ringing for several years with his partner, Kurt has become a great ringer! He doesn't read music, but he *feels* it and has a part in making it beautiful.

As David VanderMeer shared in the reflections above, last summer, our youth vocal and handbell choirs combined for a week-long "Music and Mission Trip." Though Kurt wasn't active in Youth Fellowship and didn't really have connections with the other youth, he still wanted to go on the trip. I wasn't sure how it would all work out, but to my delight, Kurt enthusiastically participated in every activity - ringing with the bell choir, playing percussion on several of the songs we sang, doing the service work for four days, and enjoying the recreation. After the trip, Kurt said it was the best trip of his life. He could hardly wait until the next one! Music was the bond that brought us together!

I've gotten to know Martha more recently, when her family moved to Atlanta three years ago and joined our congregation. Martha, (with Down's Syndrome) has an excitement about life that is wonderfully contagious. What Martha lacks in vocal ability, she more than makes up in her enthusiasm for all things musical! She doesn't often sing the "right" notes, but she effectively communicates her joyous spirit! She never fails to memorize the words to any anthem the choir is singing. I've also noticed that she already knows many of the hymns that we choose as a part of our "hymn of the month" activity. As her father explained to me when she joined choir, "Martha LOVES to sing ... only problem is she has a vocal range of about three notes!" (I've since learned that is not a matter of hearing the pitch but a physical limitation in her vocal cords to produce the pitch).

Our rehearsals start with warm-ups, often singing a unison pitch (treble A) on the syllable 'noo.' Many, but certainly not all children can match that pitch fairly quickly. In a recent rehearsal, after 2+ years in my choir, Martha matched pitch for the first time!! Wow, I can't describe the excitement of that moment, not just for me, but for the whole choir! What a celebration! Martha was so proud. And yet, despite her accomplishment and as hard as she might try, Martha still has trouble singing the "right" notes. So as a result, the other choristers are more aware of how we all must work extra hard to fit our individual voices into the "sleeve of the sound." In the final analysis, I know that all of us, especially me, wouldn't trade the experience with Martha in our choir for anything!

Including children and youth with special needs into a choir program, and indeed, the life of the church affects not only the child, but also the choir and the congregation, often in surprising ways. It gives the congregation a way to connect with the children and youth, to know who they are. An older member of our congregation shared a precious moment he had with Martha. On his first Sunday back in church after his wife of 60+ years had died, Martha ran up to him, gave him a big bear hug and said, "I'm sorry," and "I love you." The member was deeply touched, and upon hearing the story, so was the entire congregation.

Music touches something deep inside us, whether we can sing well or not. Including those with special needs in our music ministry provides a learning experience for all of us to see and model Christ's acceptance of each one of us - with all of our abilities and disabilities. We work hard at learning and preparing music to lead worship because we want to give our very best to God. In the end, it's not about a perfect performance (is there any such thing?). It's about joining our voices with all others in our midst to offer our praise - indeed, our very lives, to God!

Rachael C. Stewart

David A. VanderMeer has been serving the church as a full time Director of Music Ministries for over 30 years at Central Presbyterian Church in Atlanta, Georgia. central@cpatlanta.org

Rachael C. Stewart is the Director of the Jerusalem and Nazareth Choirs at Central Presbyterian Church in Atlanta. central@cpatlanta.org

Musical Tools for Worship Inclusion

By Dr. Deborah V. Blair

Graphic representation is commonly used in music classrooms and curriculum resources to enable students a way to understand melody (pitch and duration) in a multi-sensory experience that combines seeing, hearing, enacting (singing) and movement (tracing of the contour). As with many classroom strategies, graphic representation enables musical engagement for all learners confirmed by the many adults in our services that appreciate the notation provided this way. Our music leader is a music educator who provides the graphic representation for services including song sheets for families to use at home, as multiple repetitions foster familiarity with the music for our participants.

Throughout the service, all participants are encouraged to play a musical instrument and a wide variety of instruments are offered to families as they enter the service. We have begun a drumming ensemble for youth. At each service, drummers attend and play drums with our songs and are joined by children attending the service. Tambourines, egg shakers, and other hand instruments are distributed. For our closing song, “Go Now in Peace,” we use resonator bells in the chord C-E-G which can be played throughout the song as it is sung in a round. Our inclusive and participatory musical experience has become a highlight of the *Rejoicing Spirits* service at First Presbyterian Church in Birmingham. For more information on *Rejoicing Spirits*, see <http://www.fpcbirmingham.org/worship/worship-schedule/saturday-evening-worship-services/>.

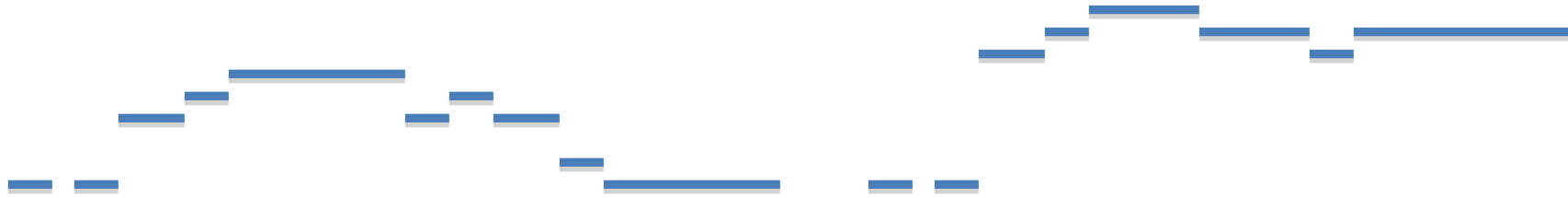


Dr. Deborah V. Blair is assistant Professor of Music Education in the Department of Music, Theatre and Dance at Oakland University, Rochester, MI. She also serves on the music staff at First Presbyterian Church, Birmingham, MI.

Bles-sed be the name!

Blessed be the name!

Blessed be the name of the Lord!



Bles-sed be the name!

Blessed be the name!

Blessed be the name of the Lord!



Blessed be the name of the Lord!

Welcoming All God's Children: Resource List



Artwork by a student of FAR Conservatory for Therapeutic Performing Arts
Birmingham, Michigan

Inclusion from the Inside Out: Welcoming God's Children of All Abilities 2011 Presbyterians for Disability Concerns (PDC) Resources List

Books

Souls Beneath and Beyond Autism

By Thomas Balsamo

McGraw Hill, New York, NY: 2004

<http://www.portraitsbythomas.com/souls.html>

A Healing Homiletic

By Kathy Black

Abingdon Press, Nashville, TN: 1996

Creating an Inclusive Worship Community: Accommodating All People at God's Table

By Elizabeth Browne

Liguori Publications, Liguori, MO: 2004

Autism Alleluias

By Kathleen Deyer Bolduc

Judson Press, Valley Forge, PA: 2010

A Place Called Acceptance: Ministry with Families of Children with Disabilities

By Kathleen Deyer Bolduc

Bridge Resources, Louisville, KY: 2001

His Name is Joel: Searching for God in a Son's Disability

By Kathleen Deyer Bolduc

Bridge Resources, Louisville, KY: 1999

Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families, and Congregations

By Erik W. Carter

Brookes, Baltimore, MD: 2007

You're Going to Love this Kid! Teaching Students with Autism in the Inclusive Classroom

By Paula Kluth

Brookes, Baltimore, MD: 2003

Helping Kids Include Kids with Disabilities

By Barbara Newman

Faith Alive Christian Resources, Grand Rapids, MI: 2001

Autism and Your Church

By Barbara Newman

Faith Alive Christian Resources, Grand Rapids, MI: 2006

Vulnerable Communion: A Theology of Disability and Hospitality

By Thomas E. Reynolds

Brazos Press, Grand Rapids, MI: 2008

What Adults with Disabilities Wish All Parents Knew: Reflections from a Different Journey

Edited by Stanley D. Klein and John D. Kemp

McGraw Hill, New York, NY: 2004

Expressing Faith in Jesus Resource Kit: Church Membership for People with Intellectual Disabilities

By Ronald C. Vredevelde

Faith Alive Resources, Grand Rapids, MI: 2005

Theology and Down Syndrome: Reimagining Disability in Late Modernity

By Amos Yong

Baylor University Press, Waco, TX: 2006

Creating an Inclusive Worship Community: Accommodating All People at God's Table

By Elizabeth Browne

Liguori Publications, Liguori, MO: 2004

Children's Books

Don't Laugh at Me (a Reading Rainbow Book)

By Steve Seskin

Tricycle Press, Berkeley, CA: 2002

Have You Filled a Bucket Today?

By Carol McCloud

Ferne Press (an imprint of Nelson Publishing & Marketing), Northville, MI: 2006

Ian's Walk: A Story about Autism

By Laurie Lears

Albert Whitman and Co., Morton Grove, IL 1998

Special People, Special Ways

By Sheila Bailey

Portunus Publishing Co., Santa Monica, CA: 1999

My Friend Isabelle (A companion Teacher's Guide is available)

By Eliza Woloson

Woodbine House, Bethesda, MD: 2003

The View from Under the Pew

By Diane Winters Johnson

Abingdon Press, Nashville, TN: 2004

The View from Under the Pew

By Diane Winters Johnson

Abingdon Press, Nashville, TN: 2004

Braille version from National Braille Press Inc.

88 St. Stephen Street

Boston, MA 02115

(800) 548-7323

www.nbp.org

DVD's

Intricate Minds I: Understanding Classmates with Asperger Syndrome.

Coulter Video, www.coultervideo.com,

Intricate Minds II: Understanding Elementary School Classmates with Asperger Syndrome. Coulter Video, www.coultervideo.com: 2006

Autism and Your Church

Published by CLC Network <http://www.clcnetwork.org/clc-store/church-services/dvds>

Believing, Belonging, BECOMING: Building Welcoming Faith Communities

Now available from the Wisconsin Board for People with Developmental Disabilities (2002)

http://www.wi-bpdd.org/publications/pub_by_category.cfm?catid=24

Organizations and Web Resources:

Christian Learning Center (CLC) Network

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

The CLC Network helps individuals, both young and old, who have unique challenges and gifts. Their staff and resources empower congregations and other organizations to become inclusive communities.

Disabilities and Faith.org

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

Training Faith-based Organizations on How to be More Welcoming and Accessible. This website has links to free fact sheets, handouts and guide books to resource congregations seeking to be inclusive.

Information on Autism for Religious Education Teachers

<http://new.gbgm-umc.org/umcor/media/pdfs%20health/autism_spirituality042007.pdf>

A series of helpful handouts by Mary Beth Walsh (Mary Beth Walsh teaches in the Pastoral Ministry program at Caldwell College and has a son with autism) and Bill Gaventa (Director of Community and Congregational Supports at the Elizabeth M. Boggs Center on Developmental Disabilities, and Associate Professor, UMDNJ-Robert Wood Johnson Medical School).

Interfaith Disability Network

<http://www.interfaithdisability.org/worshiplink.php>

Interfaith Disability Network educates and engages faith communities in cultivating mutually beneficial relationships with people with disabilities.

Living Into the Body of Christ; Towards Full Inclusion of People with Disabilities

<http://oga.pcusa.org/publications/living-into-the-body-of-christ.pdf>

A social witness policy approved by the 217th General Assembly of the Presbyterian Church (U.S.A.) in 2006; includes a study guide.

Offering Our Gifts

<http://oga.pcusa.org/ga219/home/offering-our-gifts/player.html>

A PowerPoint presentation, originally developed by Presbyterians for Disability Concerns (PDC) for orientation of commissioners to the 219th General Assembly (2010). It features personal experiences of persons with disabilities, poetry, and readings that celebrate the diversity of gifts people with disabilities offer the church.

Parent to Parent

<http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx>

A nationwide network providing emotional & informational support for families of children who have special needs.

Presbyterians for Disability Concerns (PDC)

www.pcusa.org/phewa/pdc

A volunteer ministry network of the Presbyterian Health, Education and Welfare Association (PHEWA) that affirms, supports and advocates for the gifts, rights and responsibilities of persons with disabilities in the total life of the church. Links to the PC (USA)'s disability consultants who are available to resource congregations as they seek to be welcoming of members of all abilities can be found on this site, as well as information about staying connected through membership in PDC and PHEWA.

The Children's Corner

http://www.nationalministries.org/children/docs/Childrens_Corner_2008fallwinter.pdf

A newsletter from National Ministries of the American Baptist Church, this issue is devoted to including children with special needs and features articles by Barbara Newman, Bill Gaventa, Kathleen Deyer Bolduc and others.

Vanderbilt Kennedy Center's Disabilities, Religion and Spirituality Program

<http://kc.vanderbilt.edu/site/services/disabilityservices/page.aspx?id=20>

Local and national programmatic resources are shared here including many free articles by Bill Gaventa and a host of tip sheets for parents, educators, faith communities and more.

I Have a Voice

http://www.youtube.com/watch?v=t_0K-gPlyb0

<http://www.gigisplayhouse.org>

This is an upcoming Traveling Gallery, promoting Down Syndrome awareness. Portrait photography by renowned photographer Thomas Balsamo. A coffee table book is soon to follow designed by legendary Advertising Agency Bagby & Company. This film promotes awareness and the organization that brought this project to life, GiGi's Playhouse, a National Down Syndrome Awareness, non-for-profit organization. For more information, go to www.gigisplayhouse.org. All photographic images on this film are Copyright(c)2008 by Thomas Balsamo. This film Copyright(c)2008 by Mark Phillip Raff.

Disability Concerns Consultants

2011 Disability Inclusion Resource Packet

HEARING ~ MOBILITY ~ VISUAL ~ DEVELOPMENTAL

Help! I need a curriculum for children and adults with developmental disabilities.

Can you give me information about accessibility audits/checklists/surveys?

My Presbytery meets in a church that's not accessible. Don't they get it?

How can our church begin a ministry with persons who are deaf?

What do I say to a child who asks, "Why me?"

Rev. Raymond Meester,
Consultant for hearing
Heritage Presbyterian Church
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Raymond@HeritagePres.org



Ray is the pastor of Heritage Presbyterian Church where they have an active deaf ministry that includes an interpreted worship service and Sunday School classes for adults and children who are deaf. One adult, who is deaf, currently serves on the session. Ray's parents and four uncles and aunts were deaf, enabling him to be conversant in American Sign Language. In 2000, the Louisville Institute awarded him a 12-week sabbatical grant to study deaf ministry from a deaf cultural perspective. He has served on the board of the Nebraska Commission for the Deaf and Hard of Hearing, was a founding member of Presbyterians for Disability Concerns (PDC) and is a past moderator of the PDC, a network of PHEWA.

Rev. Sue Montgomery, Team Leader
Consultant for mobility/accessibility
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Sue Sterling Montgomery is the pastor of the Nickleville Presbyterian Church, Emlenton, Pa. She has also served as a chaplain at Polk Center, a residential facility for persons with mental retardation, since 1983. Sue has served on local and national boards addressing advocacy issues for persons with disabilities. She's no stranger to the barriers persons with mobility disabilities face. To

address more than just the architectural barriers, Sue has done extensive study in the areas of theology, language and philosophical approaches to life with a disability. Sue is an avid handcyclist who enjoys riding her 27 speed handcycle on the many rails to trails systems along the rivers of Pennsylvania. She received the Women of Faith Award from the Women's Ministries Program Area, PC(USA) for her work with persons with disabilities.

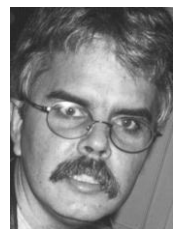
Rev. Rick Roderick,
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Rick has been working in the blindness field for 23 years. He began as a rehabilitation counselor and is now an assistive technology specialist. He teaches primarily Internet and Braille note-taking devices. He also does Internet research in the blindness field and is active on several mailing lists dealing with these issues.

Rick produces Braille for the PC(USA), primarily for the Office of the General Assembly. He has served on the Leadership Team for Presbyterians for Disability Concerns (PDC) and consults with the church on accessible technology. He enjoys leading worship when requested and participated in the leadership of the 213th General Assembly. He lives with his wife, Carol, their daughter, Marissa, and his current Seeing Eye dog, Randy.

Mr. Milton Tyree, Consultant
for developmental disabilities
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Milton Tyree is a member of Springdale Presbyterian Church in Louisville, KY. He has had numerous opportunities through the years to develop personal relationships with people who have disabilities and their family members. Milton has more than 25 years of experience in the design, development and provision of supports and services that promote participation of people with disabilities with valued aspects of everyday life.

He has worked in a number of capacities including teaching, curriculum development, consulting and program administration. His real passion is in the area of personal advocacy. Milton currently works for the Human Development Institute at the University of Kentucky.

As you can see, the PC(USA)
Disability Concerns Consultants
are busy persons working in a
variety of professional capacities.

**If you contact them directly, please leave
a detailed message concerning your
question or concern and how they might
contact you.**

Questions can also go through
**PresbyTel – the General Information Service
(1-800-872-3283)** of the PC(USA), or the toll-free
number for the office of the **Presbyterian Health,
Education & Welfare Association (PHEWA):
1-888-728-7228, ext. 5800.**

For information on **incentive loans** as well as
low-cost loans for expansions, renovations and
site purchase, call the PC(USA) **Investment &
Loan Program, Inc.** at **800-903-7457** and ask for
Ben Blake (ext. 5865).

For more information visit:
www.pcusa.org/phewa/pdc

Mav 2011