

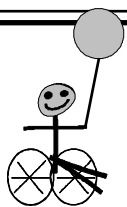


...Those who wait upon the LORD shall renew their strength, they shall mount up with wings like eagles, they shall run and not be weary, they shall walk and not faint. Isaiah 40:31

Wings

A FAITHLETTER FOR, BY AND ABOUT
UNITED METHODISTS WITH DISABILITIES

Spring 1999 — Vol. 9 Issue 4 No. 36



FROM WHERE I SIT By Jo D'Archangelis



We recognize and affirm the full humanity and personhood of all individuals with disabilities as full members of the family of God.

From the Book of Discipline of the United Methodist Church, "Social Principles," ¶ 66, § G (Rights of Persons With Disabilities)

Recently I was helping the young son of my live-in PCA (personal care attendant) with his homework. Gaby is 7-years-old, and although he's been around me his whole life, only in the last year or so has he shown much curiosity about my being in the wheelchair. Just as he had done many times before, he asked me why I was in a wheelchair, and, just as I had done many times before, I told him I couldn't walk because my muscles were very weak.

He then reminded me that I had once told him I could walk when I was a child. "Maybe you didn't exercise or eat the right food when you were a little girl," he suggested, apparently thinking of his mother's admonitions to exercise and eat healthy food so that he would grow up "big and strong."

I assured him that wasn't the cause of my problem. But realizing he wanted some kind of explanation and figuring a lecture on defective recessive genes would kind of go over his head at this point, I added, "It's because there is something..." I paused, not wanting to use the word "wrong" because that sounded too negative, "...something not quite right inside my body."

Gaby nodded as though that made perfect sense. Then he solemnly stated, "But you're still a human being." Ha! This was so unexpected that I laughed and, not knowing exactly how to respond, blurted out, "Thank you, I certainly am." No argument there, I thought, but, gee, he's so PC and at

such a young age too!

His pronouncement brought to my mind the paragraph in the *Book of Discipline* which, with a solemnity equal to that of Gaby's, duly notes the "humanity" of people with disabilities. The rights of many people, including the aged, women, homosexuals, and persons of differing races and ethnicities, are also spelled out in the same passage, but, interestingly enough, only people with disabilities—and children—are specifically acknowledged to be human beings (as opposed to, perhaps, chimpanzees?).

Isn't it odd that what comes out of the mouths of children as simple and yet endearingly factual can come out of the mouths of adults as condescending and yet irritatingly pompous? I wonder what would have been the reaction if we women had

had our "full humanity and personhood" officially recognized by the United Methodist Church. One trembles to speculate.

The other night Gaby was reading to me from a book about a little kid who wanted to be an astronaut. After he finished, he asked, "Jo, what would you like to be?" Again the unexpected, and certainly not a question frequently asked of a woman in a wheelchair teetering on the brink of senior citizenship.

I paused before answering (I pause a lot when conversing with Gaby, having the weird idea that anything I say to him is going to be indelibly etched on his brain for the rest of his life and so it had better be a "good" answer—whatever that is). If I honestly tell him what I would like to be, it's going to sound like a real crip cliché, all sad and pathetic, and that's not the way I want to sound. Still, it's important to be honest with him.

"Well, I'd like to be a dancer, but..." I replied and waited for the reality of this whole disability business to sink into him and to hear his words of commiseration. But I had forgotten he wasn't an adult with an adult's standardized and circumscribed view of reality. "You can still dance—you can dance in your wheelchair," he said pointing to the joystick control of my powerchair and then circling his hands in the air. And, yes, I could see myself through the eyes of his imagination do -si-doeing back and forth and pirouetting round and round in my wheelchair.

Of course, I was talking about being a dancer as in Prima Ballerina With The Bolshoi Ballet. But he was right. I could dance in my wheelchair and, in fact, *have* danced in my wheelchair many times over the past years (although not, I must admit, in front of other people). Yet again I was reminded how easily sclerotic minds can create barriers and how just as easily youthful minds can knock them over. Hey, I thought, this kid really gets it; there's hope for us yet.

Then [Gaby] solemnly stated, "But you're still a human being."

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Book REVIEWS

Strong At The Broken Places

By Stewart D. Govig

Westminster/John Knox Press [1989]

Where is the balance between hope and reality for those of us who are differently-abled? Who defines the parameters of this balance? Who is left out as a result of those definitions which lead to attitudinal barriers and a sense of hopelessness for those who want to be included in the life of community?

Stewart D. Govig, who at the time this book was published was serving as Professor of Religion at Pacific Lutheran University, is a Lutheran minister. The Western Jurisdiction United Methodist Congress of the Deaf is very much involved with the same vision that Govig articulates for the whole of the church in opening the doors for the differently-abled. His invitation throughout the book is one which calls for confronting barriers, recognizing resources, risking change, making innovative experiments, and striving for both short- and long-range objectives.

The book is integrative in that it links biblical teaching in a way that dignifies the experience of persons with disabilities. Though the book is a little dated, it is a wonderful resource to have in the church library for lay persons to read as an educational tool.

There is much emphasis in the church today on accessibility.

However, there is also a need for emphasis in the church on the prophetic vision of scripture and what this means to the lives of persons with disabilities.

Govig points to the prophetic vision of a new heaven and a new earth. He articulates the idea that the church and society are called to be accessible but that accessibility is not enough: "God banishes the marks, the pain, and the tears." This is the prophetic vision the church is called to revere—that a new heaven and a new earth shall appear for all persons, and in particular for persons with disabilities that they might participate with liveliness and wholeness in the communities in which they live!

— Sharon K. Cooper —

Cooper is Treasurer of the Western Jurisdiction of the United Methodist Congress of the Deaf. This review is reprinted, with editing, by permission of the author from the *United Methodist Congress of the Deaf Western Jurisdiction Newsletter* [February 1999].

Avoiding Attendants From Hell: A Practical Guide To Finding, Hiring And Keeping Personal Care Attendants

By June Price

Science & Humanities Press [1999]

As someone who has had numerous PCAs (personal care attendants) over the years—family members, friends, strangers, full-time, part-time,

permanent, temporary, old, young, wise, foolish, kind, insensitive—I wish I had had something like Price's handy -dandy guidebook long before this. It would have saved a lot of heartache and frustration for many of us, caregivers and care-receivers alike.

Editor of a newsletter for people with spinal muscular atrophy and a wheelchair-user who has employed PCA's for many years, Price knows whereof she speaks, and she speaks with clarity, humor, and common sense. Comprehensive as all get-out, her book first helps us to decide if we are ready for "independent living" and to determine exactly what our needs are. Subsequent chapters cover screening, interviewing, training and hiring.

The key to a successful arrangement? Communication! Let a prospective PCA know what you expect in care, and when, and what you can tolerate and what you absolutely will not tolerate (the last is particularly important in a live-in situation). The same holds true from the perspective of the PCA.

Included are sample want ads, job applications, live-in contracts, medical emergency data sheets, and resource listings. Although not every contingency can be covered in regard to such a sensitive and fallibly human relationship as that of caregiver and care-receiver, this book comes darned close.

— J. D. —

Available in either spiral-bound (ISBN 1-888725-18-4) or perfect-bound paper (ISBN 1-888725-19-2), this 110-page guide can be obtained by contacting: Science and Humanities Press, P.O. Box 7151, Chesterfield, MO 63006-7151; phone: 314-394-4950; website: www.banis-associates.com/books/attend.htm; e-mail: banis@banis-associates.com. The cost of each book is \$16.95 plus \$3 shipping.



A non-official, non-profit quarterly newsletter published for, by and about United Methodist adults with disabling conditions

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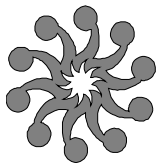
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RONNIE AND THE DANCE

By Minta McDavid

Ronnie is a 54-year-old child of God with Down's syndrome who is part of our congregation. He loves to come to church, most often late, since he lives alone now following his mother's death. The minister may be preaching, the choir may be singing, or someone may be reading scripture as Ronnie enters worship. But he has a way of bringing a presence with him as he enters. He usually comes in talking and then greets various people as he makes his way down the aisle to the front pew.

Once there, he proceeds through a ritual of removing his backpack, his glasses on a chain, and his sweater, and hanging them on the end of his pew.

Ronnie's passionate singing of the hymns and his reciting of the creeds in a piercing voice, several words behind the congregation, sometimes irritate or embarrass members. His bear hugs and kisses on the cheek during the greeting make others feel uncomfortable. There are times when it would be easier if Ronnie would not come to "our" well-designed, rehearsed worship services, which are comfortable and do not require much energy, thought, or change.

During worship on Palm Sunday, I was prepared to offer an interpretive

dance. I sat in the second pew, expectantly awaiting the procession of children waving palm branches at the beginning of the service. When the music began, I looked back and saw Ronnie in the midst of the children, making his entrance as usual but today waving his palm branch, lost in the celebration of Palm Sunday

...It would be easier if Ronnie would not come to "our" well-designed, rehearsed worship services, which are comfortable and do not require much energy, thought, or change.

worship. He came down, sat in front of me, and went through his usual ritual. To be honest, my first thought was to ask Nancy, who usually sat with him, to hold onto him when I began my dance because I knew he might want to dance, too. But Nancy left with the children after children's time, and then it was time for the dance.

As I walked up to the front of the altar, the minister's words from that morning rang in my ears: "Have you ever lost yourself in something like the followers of Jesus did on that first Palm Sunday?" Yes, I thought to myself, *when I dance*. In my dancing, I combine some signing with interpretive movement to express the

meaning of the message.

The music began and I started to dance to the song, "The Rose," which describes love as a flower and us as the seed. As I interpreted a verse about the fears that keep us from loving, I noticed that Ronnie was signing the same thing I was signing while he was seated in his pew.

The next thing I knew, he was standing beside me, facing the congregation, making every move I made, in sync, in rhythm, as if we had rehearsed it. We were moving together to the music within us.

The final verse of song reminds people that when it feels like winter in life, the seed of love lies on the ground and "in the spring becomes the rose." As the words ended, the piano continued. Our closed right hands, symbolizing the seed, were extended in front of us. With each beat of the piano, we opened our hands more and more until they were completely open, blooming like a rose.

After the song was over, we sat down. But this time I sat on the front pew next to Ronnie, and he leaned over and kissed me on the cheek. We had lost ourselves in the music, like the disciples had that first Palm Sunday. And I knew we had been visited by Jesus, the Lord of the Dance.

From *Alive Now* under the title "The Dance" [July/August 1998]

DIVERSITY COSTS

There's a lot of talk about diversity, but I don't think we have ever prepared ourselves for dealing with how diverse diversity is. Diversity may be a catch word for wanting to get everybody in, but my question is, "What will you do with us once you get us in?" When diversity starts to get lived out, however well or poorly, folk in the church begin to see how demanding it is. Diversity costs. It costs spiritually, it costs emotionally, it costs economically. And everyone has to deal with it. Not just a few. I don't see us there. Many of us want to be, but I don't see the groundswell.

— Emilie Townes —

From "A Conversation With Tex Sample and Emilie Townes," *Alive Now* [September/October 1995]



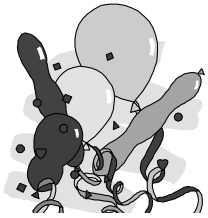
LET THE CHILDREN COME!

Let the children come —
Halting, faulting, limping, wheeling, crying,
Laughing, listening, watching, mute . . .
Not hearing voices of unseen surroundings.
Don't we all thus come?
Let the children come —
Children of God, even as we
Strive in our differences to be
Exceptional in God's sight
Surrounded within divine love as we are!
"Let the children come —"
Aren't just words.
God said, "I AM . . ." If God is,
Then you are — God's child!
The same as I am — God's child!
Who dares to say:
"Let the children come, all God's children!"
And leaves you out, or me, or any child,
In our differences?

— Tom Lane —

From *Alive Now* (January/February 1997)





INSPIRATION, FELLOWSHIP, AND FOOD HIGHLIGHT UMWD/FUMWD GET-TOGETHER

On Saturday, February 27, a group of nineteen UMWDs (United Methodists With Disabilities) and FUMWDs (Families and Friends of United Methodists With Disabilities) met in the Bender Fellowship Room of the United Methodist Church in Fallbrook, Calif., for inspiration, fellowship, and food. The gathering also served as a reunion of past attendees of the Earl Miller Spiritual Life Disability Retreat.

Inspiration was offered by the Rev. Wilbur Johnson, a retired United Methodist minister and post-polio survivor. He spoke on the topic of spiritual growth, assuring us that even as his body grows weaker his spirit grows stronger in the knowledge of unconditional love.

Unlike that of many ministers, Rev. Johnson's spellbinding talk was way too brief, leaving his audience asking for more. He then graciously obliged by offering an impromptu exhortation to stand up (figuratively speaking of course) for what we believed in as God's inclusive church.

Another retired United Methodist minister, the Rev. Don Locher, gave a presentation on the "Podium of Access," an adjustable lectern for use by clergy and laypersons who must give sermons or read scripture while seated. An accomplished woodworker, Rev. Locher brought along a prototype of the lectern for the group to "try out" and offer comments and suggestions.

Rev. Locher said that since introducing the lectern last year the

response has been phenomenal and that he was prepared to send a "kit" including general guidelines and diagrams to any church requesting it. He pointed out that many churches have people skilled in woodworking who could easily fashion the lectern to accommodate each church's individual design.*

Chef Mel Tennyson, assisted by Donna Tennyson and Les Fulcher, all members of the Fallbrook United Methodist Church, prepared and served a delicious luncheon. Our deep appreciation to them and to all who made the get-together a success.

(And special praise to those intrepid UMWDs and FUMWDs who managed to find their way to what is possibly one of the more disability accessible, but geographically inaccessible, UM churches in southern California. *Ed.*)



***Anyone interested in the "Podium of Access" (*Wings*, Fall 1998) is asked to contact Don Locher (who currently serves as Special Assistant to the President of Claremont School of Theology) at:**

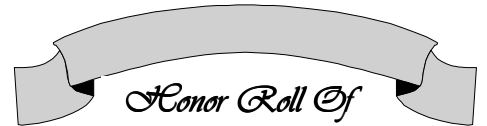
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