



# Wings

...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 [NRSV]

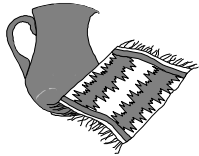
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For, By and About PHUMPS  
(Physically Handicapped United Methodist Persons)



Summer  
1997



## FROM WHERE I SIT By Jo D'Archangelis

She was talking about her husband, a music teacher in his 40s, who had recently died with a rare genetic disease, Fatal Familial Insomnia, a condition characterized by the inability to sleep—at all. “It was an insult to his dignity,” she said.

What was? The progressive deterioration of his body? The degeneration of his mind? His dying in a hospital bed tethered to tubes and hoses? No. “I had to put him in the shower, bathe him, dry him, and dress him,” she said.

A disabled man ends a letter of frustration and bitterness to the editor of a disability publication by asking, “Do you know what it’s like not to be able to take a shower by yourself?”

It’s not too hard to understand such feelings. From the time we are born, we are encouraged to stand up by ourselves, walk by ourselves, go to the bathroom by ourselves, dress ourselves, brush our teeth ourselves, and feed ourselves. Each step in our “normal” development from dependent infant to self-sufficient youth is treated with praise and applause.

An able-bodied child who fails to meet these criteria after a certain period of time is often looked upon as spoiled or lazy or emotionally stunted—like a mini-slacker overstaying his/her welcome at the maternal breast.

No wonder then that a disabled teenager or adult can feel humiliated at staying at, or regressing to, an infantile stage of dependence. No wonder we cling tenaciously to those things we are still able to do with a certain fierce pride (“Yes, I can still

**“Nothing is normal. Everyday I live with humiliation, complete dependency on others, the chronic turnover of personal care attendants and the loss of freedom.”**

*From a letter written by a quadriplegic to Jack Kevorkian (quoted in “Paging Dr. Death” by Jean Dobbs, New Mobility, April 1997).*

dress myself; I don’t need help; I don’t want help.”).

It used to be that having others assist you in your personal needs was a positive indication of your standing in the community, not an affront to your dignity. It showed you were rich or powerful enough to hire servants or coerce slaves into handling the diddley but necessary things of life, like bathing or grooming your hair or disposing of your...waste products.

More than that, having others do for you what might be considered something of an intimate or personal nature was often a sign of hospitality or even of honor.

In Jesus’ time, one showed respect and welcome by washing the feet of guests at dinner, removing the dust of travel and refreshing the spirits at the same time. Actually, one usually had servants or slaves do it, but the idea was the same.

Jesus, as was his custom, turns that idea on its ear in John’s Gospel. During his last Passover meal with his disciples, he suddenly gets up from the table, pours water into a basin, and, removing his robe, wraps a towel around his waist. He kneels down in front of each disciple and proceeds to undo his sandals and wash his feet.

Peter is embarrassed—not humiliated, mind you, just embarrassed—and when Jesus gets to him, he draws back his feet, protesting that Jesus, his Lord, shouldn’t be acting

like...like a servant.

Jesus gently tells him that unless he washes Peter’s feet, Peter can have no “share” in him. And Peter, as was his custom, impulsively reacts—not just his feet then, he declares, but his face and hands as well!

Jesus, presumably with a smile (I suspect that Jesus often smiled at Peter’s over-the-top words and gestures), assures him that washing the feet alone

is sufficient as a symbol of cleansing.

He then reminds all his disciples that just as he, their master, can serve them, they in turn can serve each other. No one is to be either elevated or degraded in their intimate care for each other.

Recently someone suggested that a foot-washing ritual be part of an upcoming disability retreat. Someone else remarked that it sounded kind of “creepy” to her—not degrading, mind you, just “creepy.”

Well, maybe there is something a little “creepy” about turning one’s feet over to others in some kind of sacramental doing. And maybe there is something a little more than “creepy” about turning one’s whole body—exposed, vulnerable, messy, and disabled—over to others, whether relatives, friends, or strangers, in some decidedly non-sacramental doing.

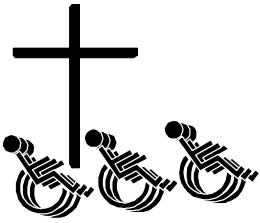
But there is nothing essentially degrading in being physically cared for. Feelings of humiliation and shame only lie in culturally-conditioned attitudes and responses (and men, for some reason, seem to have a harder time than women with this whole thing).

Once you get past the embarrassment and the shame—if you can get past the embarrassment and the shame—and if you’re really blessed, the transcendent promise may be fulfilled: that the banal but needful ministrations of others will be transformed into a sharing...for everyone concerned.

If we are accepted with our limitations as well as our abilities, community gradually becomes a place of liberation. Discovering that we are accepted and loved by others, we are better able to accept and love ourselves. So community is the place where we can be ourselves without fear or constraint. Community life deepens through mutual trust among all its members.

—Jean Vanier—

From *Community and Growth: Our Pilgrimage Together*, copyright (c) 1979 by Jean Vanier, Paulist Press.



## DANCING WITH DISABILITIES: A BOOK REVIEW By Ken Tittle

**R**eaders who have read Brett Webb-Mitchell's first book, *God Plays Piano, Too: The Spiritual Lives of Disabled Children*, know him as a fine storyteller and essayist, showing how mentally disabled children experience and express their relationships with God in poignant and often insightful and evocative images. They may be startled to read *Dancing with Disabilities: Opening the Church to All God's Children* (United Church Press. 176 pages. Paperback, \$15.95.), as the real Webb-Mitchell steps forth as a radical, even a revolutionary, and a social thinker of uncommon scope and grasp.

The title is somewhat deceptive: the book is not at all about dancing, except in a tenuous metaphorical sense mentioned only in the introduction. It is not about persons with mobility impairments except marginally and by extension. Most importantly, it is not about "opening the church."

Webb-Mitchell's vision is a far more bracing two-fold vision of people with disabilities transforming, reforming, and renewing the church, and then of the transformed church existing as the kingdom of God over and against both the secular nation-state *and* the civic religion of North American Christian churches.

The radical heart of his argument is embodied in Christ's call to let the little children come onto him as lived out sacramentally by the church baptizing a mentally disabled child into Christ *and* into the church.

In broad, deft strokes Webb-Mitchell outlines how the Enlightenment glorification of the mind and of independent thought was reified in the post-Reformation church to the impoverishment of liturgy, sacrament, and ritual and to the glorification of the sermon and

**...Webb-Mitchell argues persuasively that for the church to step into the breach, it will have to reject its idolatry of "family values"....**

right doctrine.

The Enlightenment so influenced the church that a right understanding of God became more important than the experience of God, he argues. The post-Enlightenment secular view of persons valued according to what they know and what they can do has corrupted the church, and this is glaringly evident when persons with disabilities are excluded because they "cannot understand" or will "distract" the "normal" worshippers.

Webb-Mitchell writes, "The Church is not bound by the surrounding world's definitions of what is or isn't normal in light of the Enlightenment. The church is in itself a culture unique among other cultures, a culture where people are welcomed not because of what they can or cannot do, but because of whose they are--God's children." (page 40)

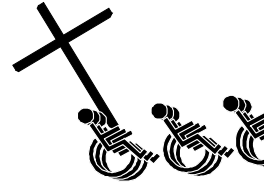
He also discusses how the industrial revolution intensified the fragmenting impact of the Enlightenment, redefining the "family" in nuclear terms and leading to the rise of the nation-states while vitiating the middle ground of tribe and clan and community and even culture.

This brings families of disabled children (and persons with disabilities) into crisis, forced back upon their individual resources and dependent on the support of a nation-state that is increasingly unwilling to support those

members of society who are deemed less valuable according to Enlightenment ideals of what you can produce and what you know.

Webb-Mitchell argues persuasively that for the church to stand into the breach, it will have to reject its idolatry of "family values" and reclaim the Christian biblical primacy of the church, rather than the family, as the household of God.

The good news for the families of children with disabilities is that when we baptize a child, it is both into Christ and into the church. The child becomes then, not "your child" but "our child." This is not a vision that the church in the United States will rush to embrace, but this is a call, I believe, to the faithful remnant to respond with the prophetic word lived out sacramentally in community. And the disabled shall lead them.



Dr. Ken Tittle is founder/co-director of Mariposa Ministry, Calexico, Calif.

**Keep yourselves  
in the love of God.**

—Jude 21—



is a non-profit quarterly newsletter published by and for United Methodist adults with disabling conditions.

**Founder/Editor • Computer Layout/Graphic Design**  
Jo D'Archangelis

### Wings Needs The Following From You

Ideas and suggestions for articles  
Original stories, poetry, cartoons  
Personal essays and anecdotes  
Appropriate items from another source  
The name and address of someone dying to be on our mailing list  
A change-of-address notice if you are moving

**Send All Correspondence To**  
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## BEYOND THE SPOKEN WORD

By Leah Hager Cohen

When I was four and five years old, I was one of a few hearing children who attended Lexington's preschool [Lexington School for the Deaf, Queens, NY] as part of an experiment with integration.

In many ways I seemed no different from any of my classmates, making doll cakes in the

sandbox, playing chase outside on the patio, eating just the middles of my bread-and-butter snack, as was our fashion. But I was not the same.

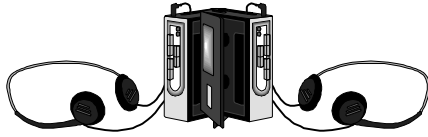
One afternoon, while playing with my classmates outside, I sought to remedy my most blatant difference. I selected two pebbles—urban pebbles, rough bits of dark gravel—from the ground and set them in the shallow cups of cartilage above my earlobes.

When the teacher spied my improvised hearing aids, I was thoroughly scolded. "Never put anything smaller than your elbow in

your ear!" was her mystifying admonishment. Puzzling over this helped deflect some of my embarrassment and hurt, but it did nothing to help me fit in with the others.

I sorely envied my classmates their speech lessons. Whenever I had occasion to peek into one of the closet-sized speech rooms along the hall, I drank in the scenery, the exotic paraphernalia—mirrors and flash cards, balloons and balls, feathers and tongue depressors—with a lustful, wondering eye. I didn't know then that many deaf children loathe speech lessons, experience them as something designed for humiliation and failure.

(Once, when I was six and attending public school, I faked a lisp for the speech therapist who visited our class so that I could finally discover what really went on during speech lessons. They turned out to be crushingly dull;



the therapist—a beige, squarish woman—presented me with an entire box of plastic drinking straws and directed me to practice saying my s's around them at home.)

But the time I remember being most alienated as a student at Lexington was during story hour. The other children and I would pull our little wooden chairs up to the table, and each of them would plug a special hearing aid into the metal box that sat on top, an FM unit that amplified the teacher's voice as she read the story into a wireless microphone.

With their regular hearing aid receivers strapped around their chests on white harnesses and their heads crowned with large blue earphones, the other children leaned together, tightly connected, all joined to the same circuit.

I never felt so apart. The privilege of being able to hear paled in comparison to the privilege of being close, of sharing that common experience with the other children.

From *Train Go Sorry: Inside a Deaf World*, copyright (c) 1994 by Leah Hager Cohen, published by Houghton Mifflin Company.

## HELEN KELLER'S LEGACY

By Robert J. Smithdas

Always the small beginnings of great things:  
always the pioneer who breaks a trail  
across uncharted regions of the mind  
or through a trackless wilderness those  
unknown.

But it takes more than courage to subdue  
a world that's gray and silent and obscure;  
there has to be a passion to explore  
the hidden corners of the universe.

This is our legacy from one who walked  
the distance of a lifetime without fear:  
that darkness is a challenge to the soul,  
and silence has a language we must learn;  
That we are tested in the crucible of  
circumstances to know our inner strengths,  
to break our own paths that will mark the  
way from small beginnings to still greater  
things.

I only know that when I touch a flower,  
or feel the sun and wind upon my face,  
or hold your hand in mine,  
there is a brightness within my soul that  
words can never trace.

I call it Life, and laugh with its delight,  
though Life itself be out of sound and sight.

From *Shared Beauty*  
by Robert J. Smithdas.

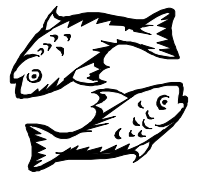
## A MESS OF FISH

By Thomas P. Chandler

Having become disabled, I often receive gifts from my friends, the local commercial fishermen, presented to me as an expression of their care. Caring that I've become crippled, concerned about my misfortune, they stop me on the road or turn up at my front door with weathered faces and callused hands and in their local accent say, "A mess of fish for you, Tom."

What is "a mess of fish" worth? One could purchase these anywhere in the world at a reasonable price, but what are they really worth when we receive them as a gift?

"A mess of fish for you, Tom." What beautiful words, as I allow them to sink into my heart. Beautiful men in their unsophisticated ways, their rough exterior cannot hide the manifestation of a tender heart that shows through in the giving of their gifts. Christ saw such hearts in Peter, James, and John, and I see such hearts in these men. No gold or jewel could buy the love I receive, nor all the monies of the world the dearness of those words: "A mess of fish for you, Tom."



Reprinted from *The Upper Room* (Sept./Oct. 1993).

*The only answer in this life,  
to the loneliness we are all  
bound to feel, is community.*

—Dorothy Day—  
*The Long Loneliness*

## RETREAT LEADER CANCELS, HOLY SPIRIT COMES THROUGH



The theme of the 1997 Earl Miller Spiritual Life Retreat for Persons with Orthopedic and/or Visual Disabilities was set as "Embracing the World: The Ark of the Covenant at Our Side." It could just as easily have been "Let the Holy Spirit Do the Leading."

At the last moment, the scheduled retreat leader, the Rev. Dr. Harold Wilke— noted pastor, author, and disability and religious activist—had to cancel due to an emergency. In his place, a few retreat-experienced and resourceful people—Zelle Hammond, Bill and Gigi Tell, and Ken Tittle—got together and improvised a program, several class sessions, and a Sunday morning worship service for the retreat held on May 30-June 1 at Camp Cedar Glen.

What appeared at first to be uncertainty, if not chaos, quickly evolved into a spirit-energized weekend filled with spontaneous outpourings of talk, song, prayer, praise, and personal testimony, not only from the newly-ordained leaders but from all those attending. We learned, not for the first time perhaps but certainly with greater clarity, that we as disabled people can affirm our differentness from those who are able-bodied and at the same time recognize our equality with each other as children of God and as brothers and sisters of Christ in the Holy Spirit.

The weather, incidentally, was perfect, the cedars tall, and the laughter and tears highly contagious. Our thanks to Zelle (retired special-ed teacher and United Methodist deaconess) for her (unflapp-)ability to enthrall adults with children's stories; to Bill and Gigi (he—full-time high school teacher; he and she—part-time preachers and evangelists) for their gifts of music and ministry; to Ken (founder and co-director of Mariposa Ministry) for his imaginative, witty, and poignant take on *Job* (otherwise known as "James Oscar Brown"); and to Lupita Alonso-Redondo and Lola Ruvalcaba (members of Mariposa) for demonstrating most vividly how God does indeed lift us up on eagle's wings.

Tom Simmons served as retreat dean (for the 8th year in a row!), and registrars Norm and Helen Stockwell assisted with logistics. Other participants were Tammy Simmons; Abby Vincent and guide dog, General Mills; Alma Enyeart; Tiffany Genzer; Jo D'Archangelis; Elizabeth Medina; Ana Maria Mendez; Jill Halley; Chris Halley; Cathy Halley; and Ruth Owen.

The 1998 disability retreat is scheduled for the first weekend after Memorial Day, again at Camp Cedar Glen near Julian, Calif.



### Prayer Notes:

For the Rev. Dr. Harold Wilke, who at this writing is reported to be recuperating well from oral surgery, and for past "retreaters"— *Phyllis-Anne Church*, recently diagnosed with ALS or Lou Gehrig's Disease, *Dick Martin*, with a fractured arm which stubbornly refuses to heal, and *Tyler Nakashima*, undergoing chemotherapy.

### Honor Roll Of Appreciation

*We thank the following persons or organizations whose gifts of time and/or money have made possible the publication and mailing of Wings:*

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### CHANGES AND CORRECTIONS

The disability special-projects group based in Minnesota is called **Made in the Image**, not **In His Image** as reported in the Spring issue. Updated URL for **Made in the Image** is: <http://www.hamline.edu/~gritner/mimage.html>  
Updated URL for **Disability Awareness Ministries, Inc.**, is: <http://www.hamline.edu/~gritner/dami.html>



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