

Those who wait upon the LORD shall  
renew their strength, they shall mount up with  
wings like eagles.... Isaiah 40:31 (NRSV)



**A FAITHLETTER FOR UNITED METHODISTS WITH  
DISABILITIES AND THOSE WHO CARE ABOUT THEM**  
Summer 2006 — Vol. 17 Issue 1 No. 65



## FROM WHERE I SIT: DISABLED OR JUST DIFFERENT? By Jo D'Archangelis

**A**re those of us with physical, sensory, or mental limitation/loss “disabled” or just “different”? And who cares?

To take the second question first, apparently the U.S. government cares. The U.S. Census Bureau periodically surveys Americans to find out how many report having a “disability” as defined by the Bureau (see article p. 5 this issue of *Wings*). The government cares because it grants benefits on how “disabled” you are, not on how “different” you think you are.

And apparently certain groups care—strongly. Among such groups are Little People, those who are born of very small stature. They regard themselves not as “disabled” but as “different,” i.e., as merely exhibiting variations within a wide-ranging spectrum of human development. They often reject medical treatments such as leg-lengthening. The problem, they say, is not in themselves but in society’s misguided attempts to fix something that “ain’t broke.”

Another group that regards itself as “different” rather than “disabled” are the Deaf, mainly composed of those born without the capacity to hear who consider sign language as their primary language. They maintain you cannot be

“disabled” by the lack of something if you have no idea what that something is. (Describing hearing to someone born deaf must be like describing sex to an angel.) And whatever that something may be, they (the Deaf, not angels) can and do get along perfectly well without it and reject auditory devices such as cochlear implants. Like Little People, the Deaf feel that society should be able to adjust to and respect their differences instead of trying to “correct” them.

As for the first question—Are those of us with physical, sensory, or mental limitation/loss “disabled” or just “different”?—any answer, of course, depends on what what you mean by “disability” and “difference.” But then it also seems to depend on how well you can get past all the negative baggage attached to having a disability in our able-bodied culture. The stigma associated with disability is so prevalent—e.g., being infantile, only “half a man,” “not all there,” useless, unproductive, “a drain on society”—that it comes as a surprise, at least to me, that in a 2002 Census Bureau survey over 51-million Americans actually admitted to being “disabled” (see p. 5).

Because I can’t, and shouldn’t, speak

for anyone but myself, I’m rephrasing the question to: Am I disabled or just different? To go about answering it, I like to make use of three common, if overlapping, ways to define “disability”: one, as a noticeable limitation or loss of function; two, as difficulty in performing an everyday activity (see the government’s definition, p. 5); and, three, as having a specific “disabling condition.” Yes, the last “definition” begs the question, but it can be very informative if someone asks you, for instance online, what your disability is and you reply, “Oh, I have Spinal Muscular Atrophy,” and they know immediately what’s going on with you (or not, depending on how often we wonderful people with SMA are featured on Oprah).

As for “difference,” I define it very precisely as something that’s not quite the same as what people are...well...used to.

Under the above “disability” definitions I am *disabled*. I am severely limited in the function of mobility. I cannot walk and must use a wheelchair. I cannot dress myself and so must have a personal assistant. Having a neuromuscular condition like SMA that progressively destroys neurons and weakens muscles is—and in my opinion no other single word describes it more accurately—*disabling*.

But no matter how disabled I may be, I don’t (except for those occasional “dark moments” I’ve written about before) consider myself “broken” or “defective” in any medical, moral, or theological sense. I don’t need to be “fixed” or “healed” to be more of a “whole” person than I am now. Still, I wouldn’t turn up my nose if some medical cure or treatment were to come my way if for no

(*FWIS* continued on page 2)

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## DISABILITY MINISTRY NEWS & NOTES

### AUDIO LOOP SYSTEM

Worship became more meaningful for hard-of-hearing people at Christ United Methodist Church in Albuquerque, N.M., when a new audio loop system was installed in the sanctuary last year. "The system reduces background noise, enabling the user to hear as if someone is speaking directly in the ear," said Virginia Carr, a church member with hearing loss.

A wire installed along the baseboard surrounding the sanctuary is connected at both ends to the public address system....A hearing aid equipped with a telecoil—a device used to pick up sound from telephones—can pick up sound from the audio loop system. A portable receiver with headphones or ear buds can also provide access....

Christ Church's audio loop system cost approximately \$1,200, including three receivers....

Christ Church can be reached at (505) 255-1669. For more information..., visit the website of the Hearing Loss Association of America, [www.hearingloss.org](http://www.hearingloss.org).

*Abridged from Interpreter Magazine (May-June 2006).*

### LEADERSHIP CONFERENCE

The Lift Disabilities Network of the Christian Council On Persons With Disabilities (CCPD) is sponsoring a Leadership Conference on November 3–5, 2006, at Wyndham Resort in Orlando, Florida.

This conference provides a restful and renewing environment for networking opportunities, advancement in training, and personal growth for Christian leaders serving in the disability community.

Go to the CCPD website <[www.ccpd.org](http://www.ccpd.org)> for more information.

### HIDDEN DISABILITIES

Some tips for congregations in welcoming people with hidden disabilities, such as heart disease or allergies, that may not be easily noticeable but can severely limit everyday activities:

1. Become aware of the presence of hidden disabilities through education and training.
2. Support those learning to live with a hidden disability with affirmation and encouragement.
3. Be watchful and mindful of special needs such as the need to avoid wheat.
4. Start a parish nurse program to help the congregation feel safe to reveal its hidden disabilities.

*Adapted from DAMI NEWS, the newsletter of Disability Awareness Ministries, Inc.*

(FWIS continued from page 1)

 other reason than that I'd be able to live my life with a lot less dependence on others.

However, under the above definition of "difference" I am also—*different*. I move around in a low chair with wheels instead of on two legs. I have ankles that turn inward and a torso compressed into a C-shape. With my low wheelchair and compressed torso, I "stand" at about the same height as some Little People, having as they do the same easy access to public telephones and items on grocery store shelves.

Now whether we consider ourselves different, disabled, or both, we all have to deal with a world predominantly designed for people of average height and weight, capable of speaking, hearing, seeing, thinking, walking, etc., in accordance with some hypothetical norm. In other words, we have to deal with a world full of unnecessary obstacles and barriers. Just like every other human being, we want respect for who we are and acceptance of what we are. This respect and acceptance will be most truly shown to us in a world that is made more and more accessible to us—and thus accessible to everyone.



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## GROWING IN FAITH

### By Alfonso Roman

Sunday morning finds members of the United Evangelical Church of Puerto Rico Arzuaga Street in Río Piedras ready to participate in the intercession prayer. Suddenly Edgardo brings forward Sorimer. His smiling, healthy-looking eight-year-old daughter goes into the praying circle. From her walking chair [wheelchair], in a firm but slightly unclear voice she tells the pastor, "Quiero que oremos por la paz (I want us to pray for peace)." The congregation bursts into a joyful ovation.

Sorimer states love for her Tata's (maternal grandmother's) church where the congregation's poet has celebrated her in a poem. She participates in special celebrations. She is seen not as an invalid or disabled child but an angel sent to transform the member's perception of the value of a human life. She is respected with dignity as a human being growing with them as a member of the family of God in Arzuaga Street.

They consider this fourth generation member God's gift to them. Mirla, Sorimer's mother, said, "Since she was in my womb they have been praying for her, sharing her development with apprehension and joy." After her premature birth Sorimer developed severe cerebral palsy. She has to always be in her chair. Even with movement and communications difficulties, her normal, impressive intellect flourishes. To her parents, relatives, and congregation, Sorimer is "God's power manifested."

While in the hospital during her first two months, her parents, both music teachers, played the flute and sang hymns to stimulate her still-developing sensations and body functions. The local pastor and church members remained with them praying and singing in hope, as they did two years later during another lengthy hospitalization. Once again the faith of the parents and congregation grew. Sorimer left the hospital to participate as the Virgin Mary in the Christmas pageant.

In Puerto Rico, where persons with

disabilities comprise one-third of the population, Sorimer's special education programs are limited and costly. Sometimes their perceptive child becomes impatient as she waits while the active intellectual section of her brain tries to use her speech muscles.

Sorimer prayed for a little sister, asking God that she could walk. She then challenged Yarimer, asking her to walk and to do things that she, from her walking chair, cannot do. Seeing her sister as God's response to her prayers, Sorimer states, "Yo voy a caminar (I am going to walk)!" She tells her parents, "Pídanle a Dios que pueda andar (ask God that I can walk)!"

Knowing that her development will be

slow, her parents trust that God's spirit will be manifested and that with Sorimer's determination, their loving care, and the congregation's prayers, she will succeed. Her development in God's hand, they select her training with care to guarantee that it is according to her potential and abilities. Their goal is to have a happy, loving, and creative daughter who loves God and her church, and who functions at the peak of her potential by sharing what God has given her.

With her father at the piano, she shares the "corito" learned in Sunday school: "Hay una unción aquí cayendo sobre mi (there is a blessing around me) sanando todo mi ser (giving health to my whole life)."

*From That All May Worship And Serve, the newsletter of the United Church of Christ Disabilities Ministries (Jan.-Feb. 2005). Roman is a retired UCC minister.*

## A PRAYER FOR HEALING

- Holy God, we pray that you would heal us of our vision impairments... that we might look beyond outward appearance and see—as you do—the heart inside each person.
  - Heal us of our speech impairments... that words of peace and encouragement might come more readily from our lips than hostile and degrading words.
  - Heal us of our hearing impairments... that we might hear the cries of the poor, the oppressed, and the marginalized and listen attentively to your still small voice calling us out of ourselves.
  - Heal us of our emotional impairments... that we might love even those who wound us and accept those who are different from us even as we love and accept ourselves as we are.
  - Heal us of our mental impairments... that we might gain wisdom in your Truth, develop understanding in your Spirit, and find freedom from those worldly distractions and distortions that keep us from focusing on your will for us.
  - Heal us of our mobility impairments... that we might walk in your ways without stumbling, reach out our hands to others in love and support, and dance our lives in time to the movement of your Spirit.
  - God, come to each of us in our manifold disabilities... that you might be glorified in our limitations and weaknesses and that your power might flow through us to bring healing and wholeness to a broken world.
- We pray in the name of Jesus Christ, the Great Healer...Amen!

— Mariposa Ministry (June, 2006) —



## ENCOUNTER IN THE DESERT By Linda Douty

I had been in desert country for three weeks alone—not roughing it, for sure, thanks to a friend who had loaned me her house in Scottsdale, but truly and positively alone. Plenty of time to work out all my issues, listen to God, get some clarity and answers, I thought. But here I was packing for departure and wondering what had really been settled.

I had enjoyed the adventure of being in a strange place, the hikes in the desert, the feeling of independence and competence, but I couldn't say that my questions of relationship and vocation were answered. Still, somehow I knew that time hadn't been wasted—it had been a unique experience for a middle-aged woman.

As I placed the clothes neatly in the suitcase, I began experiencing an overwhelming urge, as if an inner voice were demanding my attention. "Return to

Squaw Peak," kept entering my mind. Why Squaw Peak? I thought. It made no sense, it wasn't one of the scenic desert parks—too crowded, hot, totally uninspiring. Was I going nuts? But some urgency made me stop in the midst of packing, get in the car, and drive thirty minutes to the park.

I found it almost deserted, and I headed to a trail at the back of the parking lot, one that I had never walked. For the next hour, I encountered not a single person to distract me. My only companions were the hundreds of saguaro cacti that dotted the Sonoran Desert. As I rounded a bend in the path, I was suddenly face-to-face with an old beaten-up cactus about fifty feet tall. Up close and personal, these stately plants were anything but beautiful. There were ragged holes where birds had nested, ugly gashes cut by years of weather and wear. Unexpectedly, I burst into tears. My silent thoughts said clearly, "Look

how tall she stands. See how proudly she wears her scars? She is unashamed."

As I gathered my emotions, the gentle inner voice directed me again: "Go to the large boulder over there, sit on it and turn around." As I did, I faced the open desert, dotted with hundreds of saguaro cactus plants, looking like fingers pointing to the sky. After a long silence, the voice urged, "Just be a 'pointer'...I have scores of them....You don't have to be the smartest, the prettiest, the best educated, or the most engaging. Just BE ONE. Just point UP."

I continued to amble along the trail, second-guessing myself. I must have been out in the desert sun too long. Better get back to the parking lot and go home. But after a few moments, I again felt the prompting to turn and sit on a boulder. Astoundingly, I find myself face-to-face with the same cactus over which I had cried, this time viewing her from a different angle. The gigantic plant was situated in the center of a very small rise, surrounded by smaller cacti and desert plants. The thought emerged, "Just be a pointer in your smaller area of influence; don't try to do everything; just point the way ahead to those on your little hill." And then the most surprising suggestion of all arose: "Allow people to build nests in your wounds."

I was stunned—confused—full of doubts. Of course, by the time I had returned to my car, I had resumed my inner critique, chastising myself for having such a vivid imagination. But the experience would not fade. As the days turned into weeks and into years, not a single feeling, word, or impulse as been dimmed by time. Often when I see the picture of a saguaro cactus on my desk, I cry for her; I remember her pain and vulnerability; but most of all, I remember her purpose—to stand tall in the dry, desolate landscapes of life and allow people to build nests in her wounds. I'm only beginning to know what that means.

## OFFERING By Roberta Porter

Suffering clutched to a wounded heart  
bound by blame and bitterness  
often leads to more isolation, rigidity,  
and deeper suffering.

Suffering poured from a broken-open heart  
and taken to the cross as offering  
to the overcoming Christ  
leads toward trust in God's presence,  
God's promise of comfort  
in things not understood.

And the heart—scarred, but healing—  
becomes available  
to be used by the Spirit  
for another's wound.

**From *Alive Now* (Mar/Apr 2006). Roberta Porter is a retired teacher who lives on the Oregon Coast with her husband. She is the mother of three and the grandmother of nine.**

**From *Alive Now* (May/June 2004). Linda Douty is a United Methodist laywoman, spiritual director, and retreat leader in Memphis, Tenn. She is writing a book on the spiritual issues of letting go.**



## DISABLED PEOPLE CHALLENGE WCC INCLUSIVITY

People with disabilities seek to affirm the church as an inclusive community, but the struggle for recognition at the decision-making levels of the World Council of Churches has been a long and difficult struggle. It was only at the 1998 Harare Assembly that the Ecumenical Disability Advocates Network (EDAN) was established as a full program of the WCC.

During meetings prior to the Ninth Assembly held in February, General Secretary Samuel Kobia met with disabled participants and committed himself and the Geneva headquarters to full inclusion in all programs. In a classroom packed with people living with a wide variety of disabilities from almost all regions of the church, Kobia presented his vision of inclusion and challenged the EDAN leadership to make their impact heard and felt at the Assembly in Porto Alegre, Brazil, "because it has been a major omission at previous assemblies."

Kobia engaged in a lively discussion with more than 100 EDAN representatives, especially in regard to their small representation among the 691 delegates. Of that number, Kobia noted, only one percent were from EDAN. Men represented 67 percent, women 37 percent, but only three delegates were disabled, along with five advisors. "You will have to be a very visible presence," he said. "You have performed exceptionally well since Harare and are already a world-wide network that has been faithful to the vision of an inclusive ecumenical movement."

EDAN has its headquarters in Nairobi under the full-time co-ordination of Samuel Kabue, a blind Kenyan, who stressed, however, that EDAN is not an African program but a full part of the WCC although based outside Geneva. It has a well-deserved reputation for action and efficiency in its short WCC life, Kobia said, noting that "in a world that is not enabling to disabled people, EDAN presents a different attitude to the 9th Assembly, and you must come up with a strong statement of what trans-

formation means. Your perspective brings a critical view for transforming the world."

The pre-Assembly group confronted the General Secretary about their lack of official representation. "Who," they asked, "in these able-bodied, male-dominated churches are going to give up one of their delegates to the disabled? How do we get on program and policy committees let alone the central and executive committees so that our concerns are taken seriously and the WCC's vaunted inclusion becomes a reality?"

Another contradiction that EDAN participants noted was the use of "we-they" language in WCC material, indicating that disabled people were outside the overall ecumenical movement because of their situation. Kobia was urged to educate staff and other mem-

bers of the ecumenical movement "to practice inclusion as well as talk about it." It was pointed out, for example, that the blind cannot read WCC material.

A participant from Asia added, "We were often told not to talk. Now we will talk, and we also talk about our poor disabled—those who are hidden, those who have the least of limited resources like water and housing and food. We are frustrated at this continuing marginalization...."

Kobia acknowledged their frustration, but urged them to work with him to overcome cultural barriers and get things done in the political process. "There is no doubt the institutional culture of the WCC must be changed," he said. He was especially critical of the attitude of many African churches towards ministry to people with disabilities. As Kobia left, he was gently reminded by Kabue that "we will be watching you carefully."

Adapted from a World Council of Churches news release (February, 2006).

### OVER 51-MILLION AMERICANS REPORT HAVING DISABILITIES

About 51.2-million Americans, or 18% of the total population in 2002, said they had disabilities, and 32.5 million, or 12% of those with disabilities, had severe disabilities, according to a report released by the U.S. Census Bureau. 4-million children ages 6 to 14, or 11%, had disabilities, while 72% of people age 80 and older had disabilities.

People ages 21 to 64 with severe disabilities reported an employment rate of 42%. The employment rate of people with non-severe disabilities was 82% and those with no reported disabilities 88%. 32% of people ages 25 to 64 with non-severe disabilities and 22% with severe disabilities were college graduates. The graduation rate for those without disabilities was 43%.

People with severe disabilities had an increased likelihood of having Medicare or Medicaid coverage, living below the poverty level, reporting their health status to be "fair or poor," receiving public assistance, and having a household income below \$20,000. For instance, the poverty rate for people ages 25 to 64 with severe disabilities is 26% and with non-severe disabilities 11%, compared with 8% for those with no disabilities.

The report defines a person as having a disability if they have difficulty performing an activity such as seeing, hearing, bathing, or doing light housework, or have a specified condition such as Alzheimer's disease or autism. People are considered to be severely disabled if they are completely unable to perform one or more of these activities, need personal assistance, or have one of the severe conditions described in the report.

Based on a U.S. Census Bureau press release (May 12, 2006).

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to the front pew. Communion was one of those holy, special times. He found God in the spirit and actions of his minister. One Sunday, he quietly stood with her as she offered the bread and juice to the people. Some were bothered, of course, but others discerned that God had come to the small country church in the form of an unexpected, uneasy but unique gift called Jon and found him no trouble.

From *That All May Worship And Serve*, the newsletter of the United Church of Christ Disabilities Ministries (Jan.-Feb. 2005).

**ABOUT JON by Mary Beth Nicholson**

There was a child named "Jon" in a small country church. He spoke little as he was autistic. However, he watched what went on during worship. Jon was not a "regular kid," but he had regular feelings. He listened and knew how it feels to be in a loving place. Jon was little trouble although he was restless and needed to wander around the sanctuary sometimes. His church friends understood. They were not bothered.

Some people in the church were bothered, though, when Jon whistled. His whistle jumped into their hearing aids. [But] they came to understand that this was a bit of joy bursting out from a little boy who seldom felt accepted enough to feel comfortable anywhere [and] his occasional whistle no longer bothered these people as much. In fact, it told them he was in touch with something far deeper than they had noted.

On Communion Sunday, Jon moved

*I Am Disabled And...*

like all my brothers and sisters, disabled and non-disabled, I am your workmanship, LORD, created in Jesus Christ to do those good works you prepared beforehand to be my way of life.

**Affirmation #17 based on Ephesians 2:10(NRSV) by Ken Tittle, Mariposa Ministry, and Mariposa On-Line.**

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