FROM WHERE I SIT: “THAT WE MAY UNDERSTAND”  By Jo D’Archangelis

(On October 22, 2006, Fallbrook (Calif.) United Methodist Church observed Disability Awareness Sunday. Military chaplain Rev. Van Dickens, who counsels Marines returning from Iraq with disabilities, and yours truly were each asked to speak on the theme, “That We May Understand.” The following is a slightly revised version of the message I gave.)

What is it that I would like people to understand about me on this Disability Awareness Sunday? Three things come to mind.

First, I would like people to understand that I have a disability. Well, you might say, that’s pretty obvious. But what perhaps is not so obvious is how I feel about my disability. Disability in our society often carries with it the stigma of helplessness, incompetence, uselessness, etc. Disability can be regarded as the worst thing that could happen to a person. I am not ashamed of my disability either and never have been. Perhaps that’s because I’ve been disabled since I was a very young child and my family never made me feel I was anything less than capable simply because I had a disability.

This is not to say that having a disability, especially a severe one, is not hard. Many times I have wished I weren’t disabled. If God had given me a choice, I would have opted to be non-disabled. But he didn’t. So the best thing for me to do was to choose to live with my disability as full a life as I could with God’s help. And with the help of countless others—among them my family, my friends, and my personal care assistants.

My disability does not define me. It is not the whole of my being. But it is a significant part of what I am; it has helped to shape the kind of person I have become over the years, for good and for bad. So I am comfortable with the fact that I have a disability, and I would hope that those people who come into contact with me would be comfortable with it also.

The second thing I would like people to understand is that I am a human being. Again, this may seem obvious. But you’d be surprised at the number of people who pat me on the head as though I were a cocker spaniel puppy or who look around and over me as though I were a potted plant.

And, all rumors to the contrary, I am not a saint on wheels. Anyone who knows me well will be the first to tell you that. One time several years ago someone asked my mother if I were always smiling (please note that I was sitting right there at the time), and she answered, "No, she’s just like everyone else." And in that sense I am just like everyone else. I can be cranky and sometimes I get depressed. I laugh, I cry, I get embarrassed, I make major mistakes. I don’t always do what’s good for me, and I don’t always act like a Christian should.

People often tell me how courageous they think I am as though I were some kind of hero. But I am not a hero. Heroes overcome fear to do what they have to do in spite of great risk. I do not overcome fear to do what I have to do to get through each day, I overcome inertia. Each day requires not courage and heroism but a determination and...
(FWIS continued from page 1)

effort on my part to resist the temptation to just sit in my room and not get involved with life. Yes, it can be a struggle, but it is not a superhuman struggle. It is a struggle that many people at one time or another go through when they encounter great difficulties.

So I’d like people to understand that I am not comfortable being placed on a pedestal. Pedestals should be reserved for true saints and heroes. It’s much too easy for a person like myself to fall off and land on her tush.

The third thing I would like people to understand about me is that I am a child of God. I feel that I have been made in God’s image as much as anybody else has. God does not look upon me as a mistake, as something he carelessly put together on one of his “off days.” Nor do I need to be “healed” as a sign that God fully accepts me. I am not a punishment for anyone’s sins, my own or my parents’. And I do not believe it was God’s will that I be disabled just so that I might become a better person or serve as an inspiring life lesson for others.

Actually, I don’t know why, theologically speaking, I am disabled and someone else isn’t—or why bad things happen to good people or good things happen to terrible people or good and bad things happen to all of us alike. What I do know is that, as Paul says in Romans 8:28, “all things work together for good for those who love God, who are called according to his purpose.” God can bring love out of hate, light out of darkness, life out of death, and wholeness out of brokenness.

I would like people to understand that I am not just an object of Christian charity, that I am not one of the “least of these” here only to be “done unto.” I believe that God calls each of us—whatever our age, race, nationality, economic status, or physical and mental condition—to serve him and to serve others.

God blesses each of us with our own special gifts. Here in the Fallbrook United Methodist Church, I am grateful that I have been given the opportunity to use the gifts God has given me to promote church accessibility for people with all types of disabilities and to bring to everyone’s attention what people with disabilities have to offer.

I’d like to close with a poem by Patricia Knock. Pat was a member of this church for several years before leaving Fallbrook to return to her home state of Texas to be with her family. She died this past spring. Although she herself was not disabled, Pat wrote this poem in the voice of someone in a wheelchair:

TO THOSE LESS FORTUNATE

As I roll down the aisle...
Past the pews...
You see my frailties
I see your imperfections
I do not envy you
We all have our problems
But we come to this place
In love and faith
Accepting God’s will
Lift me up
Pray for me
As I want to lift you up
Pray for you
We all need God’s love
We are all transformed in Christ
Can I help you?

This in a nutshell is what I would like people to understand: whether or not we can be said to “have a disability,” all of us have our limitations; all of us are human; and all of us are here to learn from each other, to inspire each other, and to bring each other closer to God.
HOW A BOY NAMED POWELL CHANGED CHURCH LAW
By Mary Ellis and Steve Richardson

Our son Powell experienced a severe stroke at his birth on July 20, 1984. Over the next few years, very dark ones in our journey with Powell, we would learn the realities of this catastrophic event: our son would be profoundly mentally retarded and would have numerous physical limitations, including the inability to talk or walk.

As we were learning how to face and accept Powell's limitations, we had many, many questions of what kind of life he would have and how he would fit in. One area of importance to us was the church. We were both active, life-long members of the United Methodist denomination….We wondered whether he could attend a Sunday School class and whether he had a chance to become a member of our church—all the things we churchgoers take for granted.

In the United Methodist tradition (and according to specific rules at that time about church membership), an individual was required to communicate for himself or herself certain vows indicating a full covenant relationship with God, before becoming a member. Even though Powell's spirit may have been in full covenant relationship with God, obviously he would never be able to speak the prerequisite vows either audibly or through sign language.

We talked with several ministers to learn if Powell could be made a member, based on the requirements. Mixed opinions were offered. One minister said "No."...Others said, "Yes" (yet with varying degrees of assurance that it would be truly acceptable). One opined that he could be a member, but he would be classified under a special category of membership—a category that another minister described as "the dog pound of church members."

One minister opined that Powell could be a member but he would be classified under a special category of membership—a category that another minister described as "the dog pound of church members."

We finally concluded that receiving an individual like Powell into full membership was subject to interpretation.

Rev. Ken Carder, then Senior Minister at our church, Church Street United Methodist Church, Knoxville, Tenn., was the only minister who not only said he could be a full member but who also expressed a strong willingness and desire to receive Powell into membership. However, we wanted our son's membership to be a matter of right, not subject to the discretion of an individual minister. Moreover, on behalf of other families with family members unable to assume the church vows, we wanted to ensure that they, too, would not face the uncertainties and inconsistencies we experienced.

To do this, we sought to change the church law as contained in the United Methodist Church's Book of Discipline. Such a change would have to be approved by the denomination's General Conference, the legislative body for the United Methodist Church. This body meets only once every four years. Fortunately at that point in time for us, the next General Conference was only a year away.

With the assistance of Powell's grandmother, Dorothy Bedwell, Rev. Carder, and the congregation of Church Street United Methodist Church, we submitted a petition to the 1992 General Conference. We specifically sought to include the language: "In the case of persons whose disabilities prevent them from..." (CHURCH LAW continued on page 4)

“AARON’S ROD”: INSPIRING ALL OF GOD’S CHILDREN TO BLOSSOM

Aaron’s Rod is a new quarterly newsletter aimed at families with disabled family members of any age. Christ-centered but non-denominational, the newsletter features devotions, brief biographies, poems, inspirational quotes, listings of books and other resources for parents, as well as a forum where parents and family members can express thoughts and ideas.

Lori Ciccanti, the founder/editor of Aaron’s Rod, is the wife of a Baptist minister and has a son with autism and a sister with both multiple sclerosis and schizophrenia. Ciccanti says that a hospice counselor who is also a United Methodist minister got her to thinking about putting out a newsletter. "I see the newsletter as a support and communication tool for families sharing and encouraging each other through difficult times," she says.

The name, Aaron’s Rod, comes from Numbers 17:8 (KJV): Behold, the rod of Aaron…was budded, and brought forth buds, and bloomed blossoms, and yielded almonds. Underneath the name on the first page of the newsletter are the words: “Inspiring Children of God With Disabilities To Blossom Using The Gifts God Has Given Them.”

Published by The Bread Of Life Ministries Association, Aaron's Rod is free to anyone interested in receiving it. Contact Lori Ciccanti at e-mail DLAlsina@mchsi.com or BreadOfLife@mchsi.com; telephone 302-541-4303; mailing address 501 Lake Court, Ocean View, Del. 19970.
assuming the vows, their legal guardian(s), themselves in full covenant relationship with God and the Church, the community of faith, may recite the appropriate vows on their behalf." In a few simple words, this language would allow a parent or guardian—along with the support of the full congregation—to assume the vows of membership on behalf of a person with no visible or audible means to communicate.

We were fortunate that Rev. Carder was a delegate to the General Conference that year. He was in a position to articulate among other delegates both the pragmatic and theological bases for the petition. Further, he made sure the committee members who dealt with the petition also heard “Powell’s story.” Only a few days into the Conference, Rev. Carder reported to us that the petition had been enthusiastically endorsed by the major committee and would be presented for a vote before the delegation. Upon the final vote, it became the law of the United Methodist Church worldwide.

We believe that Powell, on August 9, 1992, was the first member of the United Methodist denomination to be received into full church membership under this new provision. On that Sunday, Steve and I stood with Powell, and we as his parents, along with hundreds of church members in the congregation, assumed the vows of membership on his behalf. After the service, members warmly greeted Powell and us with comments such as, “This was the most meaningful service I’ve ever intended” and “Thank you for sharing this event with us.” Even now, years later, we hear stories of others with severe disabilities who have become members of the United Methodist Church, thanks to Powell’s provision that is now a part of the denomination’s Discipline.

Through this process and the years that have followed, we (and many others) have come to recognize Powell in a new way. We have always been proud of him, for despite his many limitations he has advanced further than anyone thought was possible. In unexpected ways, he continues to inspire and motivate others who know him to do their best, too, particularly in spiritual matters. Powell, a regular, faithful member of the congregation, sitting in the back of the church, lets his presence be known by his occasional “Powell sounds” during the service and “dancing” to the sacred music.

Simply by being who he is—more than just a person in a wheelchair who cannot talk—he has made a significant impact on United Methodism by challenging and changing what was an obstacle to inclusiveness. He is a parable to all of us of the profound meaning of God’s unconditional love, of the unconditional inclusiveness of God’s kingdom, and of the reality that God’s grace and acceptance of each of us as His children transcend all obstacles—especially cognitive and physical limitations.

Slightly abridged from the DISC (United Methodist Church Disability Concerns) website (Oct. 25, 2005); originally published under the title “Profoundly Retarded Child Changes United Methodist Church Law.” DISC may be accessed at new.gbgm-umc.org/umcor/work/health/disc/.

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**MY FRIEND CHARLIE**

By Nate Hajdu

He is my friend; I am his friend. I help him out; he helps me to learn. I help him to learn; he helps me to grow. I help him to grow; he teaches me to accept. His struggle is my struggle. His vulnerability leads to my respect. My respect leads him to trust. His trust leads to my devotion. His availability feeds my desire to be needed. I keep his secrets; he keeps mine.

We have an arrangement. His lack of self-consciousness leads to my tolerance. His constant need for stimulation leads to my patience. His discomfort sharpens my sensitivity. His unhappiness is my challenge. His presence eases my isolation. His loyalty leads to my loyalty. Which leads to mutual appreciation. His brokenness makes me accept my own brokenness. Which leads to healing. His humanity leads to personal connection. His steadfastness centers me. His smile is my reward. His joy lifts my spirits. His happiness gives me a sense of purpose. His struggles expose my anxieties. Which tests me. Then strengthens me. And in turn bolsters my faith.

In guiding I am guided. In helping I am helped. In teaching I am taught. In his laughter there is joy. In that joy there is energy. In that energy there is spirit. In that spirit there is grace. In his eyes there is a glow. In that glow is his soul. In his soul there is God. And in God there is peace.

From Extras, the newsletter of Friendship Ministries (Jan. 2006), and originally given at the Interfaith Disability Pre-Summit to the Alliance for Full Participation held in Washington, D.C., on Sept. 22, 2005. Hajdu is a direct support professional from the Jubilee Association of Maryland in ministry with Charlie Swenson, a person with a cognitive disability.
A POWERFUL UNION
By Ginny Thornburgh

(This article first appeared in 1997, but its message still rings true today. With Americans with disabilities and older Americans forming an ever larger percentage of the nation’s population, both groups need to be aware of their common needs and concerns, and work together toward a more accessible and inclusive society for all.)

A recurring dream comes to me in the early mornings—that of people with disabilities and older adults advocating for each other and for a welcoming America. Just imagine millions of us with disabilities joined with our colleagues, setting common goals for America’s communities and congregations—dignity, respect, opportunity, and full participation. Now, that’s an exciting prospect!

Since the needs of these two groups are so similar, why have they not banded together before? Possibly people with disabilities, many of whom are under 65, don’t want to face the fact that they, too, will age and die. Possibly older Americans are uncomfortable with folks who remind them of their own limitations. An 85-year-old friend of mine stated recently: “I may use a walker and two hearing aids, but at least I’m not disabled.”

For the past seven years, I have worked at the National Organization on Disability (N.O.D.) to help make churches and synagogues more welcoming to people with all types of disabilities. In the course of these efforts, I have learned that many of the accommodations which people with disabilities look for in a congregation—ramps, railings, elevators, accessible rest rooms, pew cuts, designated parking places, improved lighting and sound systems, large print, Braille and taped materials as well as sign language interpreters—can also serve the community’s older members.

Unfortunately, seniors who have supported their congregations over the years—with time, talent and money—are often relegated to the “shut in” list or a once-a-month visit by the clergy. Their isolation from the congregational mainstream becomes more complete when mainstream ministries are sporadic or rushed and congregational responsibilities are assigned to other members. When supportive community is needed most, it is often no longer available.

It is the sense of being removed and burdensome, as well as the inability to use their gifts, which people with disabilities and older adults often feel. When I recently asked my 95-year-old mother which among her many disabilities was the most troublesome, she answered sadly, “I no longer feel useful.”

What can we do to address this longing to contribute, this desire to “feel useful”? First, we need to ask people with disabilities and older adults how they would like to contribute. And then we need to listen to their answers. The accommodation needed here is the willingness to listen and be fully present to the person.

Second, we need to use our problem-solving abilities. For example, why can’t an adult Bible Study class be moved to the home of a person for whom transportation is difficult? Why can’t churches or synagogues offer valet parking to those who need it? Why can’t the committee chosen to consider the installation of an audio loop be chaired by an older member who has poor hearing? Why can’t the scripture lesson be taped ahead of time by a lay reader confined to home and then played back at the appropriate time during the worship service? The possibilities are limited only by our resolve to use the gifts and talents of all of us in the House of God.

Those of us who have disabilities and those of us who are older need to band together and create a wider, deeper and more caring advocacy movement. Those involved in such a powerful union will be blessed in amazing ways.

Reprinted from Access Press (Jan. 10, 1997). Thornburgh is the Director of the Religion and Disability Program at N.O.D. (National Organization On Disability). Please contact N.O.D. at 910 16th St. NW, Ste. 600, Washington, DC 90006, telephone: 202-293-5960, fax: 202-293-7999, website: www.nod.org, e-mail: religion@nod.org, if you would like information about its interfaith publications or about sponsorship of

GRATITUDE
By Henri Nouwen

To be grateful for the good things that happen in our lives is easy, but to be grateful for all of our lives—the good as well as the bad, the moments of joy as well as the moments of sorrow, the successes as well as the failures, the rewards as well as the rejections—that requires hard spiritual work. Still, we are truly grateful people when we can say thank you to all that has brought us to the present moment. As long as we keep dividing our lives between events and people we would like to remember and those we would rather forget, we cannot claim the fullness of our being as a gift of God to be grateful for. Let’s not be afraid to look at everything that brought us to where we are now and trust that we will soon see in it the guiding hand of a loving God.

From Bread For The Journey, Harper (San Francisco:1997).
Honor Roll Of Appreciation

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

- Jill Halley
- Margery Chapman
- Allen & Virginia Clark
- Nell Hong
- Mary Klein
- Bill & Ruth Bevil
- Bill & Wilma Chain
- Pat Donehoo
- Gerry & Bobbi Carne
- Rev. Ed Hoffman
- Rev. Diane Mettam
- Ed & Carol Stika
- Lila Lanham
- Loyce McWee

A SLOWER PACE  By Kim Covey

...[W]e also boast in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope, and hope does not disappoint us, because God's love has been poured into our hearts through the Holy Spirit that has been given to us. — Romans 5:3-5 (NRSV)

Slow down! "Rest!" "Let someone else do that!" Loved ones constantly tell me to be still. I am a 40-year-old, working mother of three. Chronic lung problems have forced me to change my lifestyle. Gone is the demanding career, but I've also lost the volunteer work and the bike rides with my kids. Long-term illness can bring a myriad of emotions, from denial to depression. I've experienced them all.

I had a prayer list, but I had failed to pray for myself. When I finally put myself on my prayer list and asked close friends to pray for me, I began to experience spiritual healing.

Each day, I strive to give my illness to God. God has comforted me and given me peace; God has strengthened my faith. God has given me new opportunities for spiritual growth that could come only if I slowed down my pace. Now I spend time with God in prayer. I have cultivated new friendships. I have learned the joy of taking time for quiet conversations with my children. I have many beautiful blessings that have come from learning to be still.

From The Upper Room (Nov./Dec. 2001)