



Beyond SUFFERING

Wolfensberger's 18 Wounds of Disability

By Jeff and Kathi McNair

The following is a presentation and discussion of the “18 wounds” that persons with disabilities may experience as a result of the actions and attitudes of society. This material is drawn from the work of Dr. Wolf Wolfensberger in his training on “Social Role Valorization,” and has been adapted for this curriculum by Dr. Jeff McNair and Kathi McNair.¹

Wound 1: Bodily or intellectual impairment

A person is born with or develops an impairment. It could, for example, be a physical (bodily) impairment, such as cerebral palsy or an intellectual impairment.

Wound 2: Functional limitation

As a result of the bodily or intellectual impairment, there are functional limitations. So, due to cerebral palsy I may not be able to walk. Due to intellectual disability, I may not be able to balance a checkbook.

Wound 3: Relegation to low social status/deviancy

Because of my bodily/intellectual impairment and/or functional limitation, society relegates me to a low social status, such that I am considered deviant. Society defines the normal range so tightly, that the slightest variation outside of that normal range is considered deviant and I experience ostracism.

The church can respond by seeing people as individuals and by viewing them in terms of their gifts. By allowing people to express their gifts, there is a greater likelihood that they will be seen as contributing to the larger fellowship. However, even with the most disabled of persons, their presence is indispensable to the life of the larger body (1 Cor. 12:22).

Wound 4: Disproportionate and relentless attitude of rejection

Because of my bodily/intellectual impairment and/or functional limitation I experience rejection by society and the rejection is relentless in that it occurs all the time in most social environments. Even in the context of a faith system, harmful rejection may occur: “you sinned” may be expressed unconsciously (unconscious rejection is still very harmful) and may be couched in terms of “positive” motives, “we need quiet so we can worship.”

The church should counter this wound with “relentless acceptance.” We should tell people that there is almost nothing that you could do that would cause us to reject you. This relentless acceptance would cause significant changes in the way we do things at church, as at the moment our traditions have contributed to the relentless and disproportionate rejection experienced by people with disabilities.

Wound 5: Cast into one or more historic deviancy roles; devalued social status causes devalued roles or vice versa.

Thus, people can be considered as:

1. Non-human
 - a. Pre-human
 - b. No longer human
 - c. Sub-human (animal, vegetative/vegetable, insensate object)
 - d. other “alien” (non-human but not sub-human)
2. A menace/object of dread
3. Waste material, garbage, offal, excrement
4. Trivium
 - a. Not to be taken seriously
 - b. Object of ridicule
 - c. Joculator, jester, clown, etc.
5. An object of pity—accompanied by a desire to bestow happiness on people and associated with the victim role. The person is “suffering.”
6. A recipient of charity
 - a. Ambiguous/borderline object-of-charity role; “nobility” in helping
 - b. Burden of dutiful caring; “cold charity”; entitled to only the minimum; should be grateful “takers,” not “givers”
7. A child
 - a. Eternally
 - b. Once again
8. A sick/disease organism (leads to handicap); “Medicalization of everyday life”; psychiatrization of deviance
9. In death-related roles: dying, already dead, as good as dead, should be dead, should never have lived²

Each of the deviant role perceptions described above have been or are now present in the church. For example, people will refer to adults with intellectual disabilities as “kids” (number 7 above), independent of their chronological age. In each of these cases, the church should seek to do the counter—that is, the opposite—or at least make the effort not to contribute to the kind of negative stereotyping described above.

Wound 6: Symbolic stigmatizing, “marking, deviancy imaging, branding”

Because of my bodily/intellectual impairment and/or functional limitation, I am given a label—e.g., “retard” or “mental age of a child”—and interactions with me cascade out of that characterization. The church ought to be careful not to reflect society in the manner in which it deviancy-images people. Unfortunately, however, we are often guilty of this. For example, in California, about a tenth of one percent

of Christian schools have programs for children with disabilities. How are the children of Christian families who have a disability being imaged? They are imaged as either unworthy/unable to benefit or as not a priority for a Christian education. That people with disabilities are not present in churches indicates that they are imaged as not a priority for ministry or unable to respond to the Gospel, which in turn causes the church itself to be deviancy-imaged by society as being self-serving.

The church can do a great deal to remove the stigma of deviancy imaging by simply seeking out people with disabilities and bringing them into the church. People are often stereotyped when they are not known. The presence of people with disabilities in the church would dispel stereotypes and the deviancy imaging would be destroyed by personal experience. Church members would then work to correct their own symbolic stigmatizing and also work to correct those perceptions that they run across in the community.

Wound 7: Being multiply jeopardized/scapegoated

Because of my bodily/intellectual impairment and/or functional limitation, I am thought to be the reason for many negative things that occur in the environments I find myself in. In the early 1900s “feble-mindedness” was thought to be the cause of crime, degeneracy and disease in America, which led to mandatory sterilization laws. In our society, people with disabilities are also often scapegoated as the reason for divorce.

When a person with a disability arrives at a church, the response should be to ask, “What is the value added by the inclusion of this person in our congregation?” “What is God doing by bringing this person to us?” Typically, when a person with autism (for example) comes, our response is, “Now what are we supposed to do with this person?” Instead, our response should be, “What can we gain by this person being in our fellowship that we would not gain if they were not here, and how can we contribute to the life of this person God has brought to us?”

Wound 8: Distanciation: usually via segregation and also congregation

Because of my bodily/intellectual impairment and/or functional limitation, I am distanced from the rest of society via physical or social segregation. One only needs to make an attempt to get involved with people living in group homes to experience the degree they have been distanciated from the rest of society. Minimally, one must get fingerprinted even to develop a *friendship* with such people.

On the other hand, because of my bodily/intellectual impairment and/or functional limitation I am always grouped with people who have disabilities because we are easier to manage that way. The overwhelming presentation of difference in a large, congregated group is itself a contributor to people being segregated.

People should only be segregated for really good reasons—e.g., because they are a danger to themselves or others. However, when a person with a disability arrives at a church, often our initial response is to develop a separate group for people like him or her. There can be reasons for such groups. However, if the only involvement in church by persons with disabilities is in the context of a separate group, we are contributing to the wounding of that person. Integration of persons with disabilities into the typical life of the church will indeed cause the typical life of the church to change; however, it is the right thing to do and that change moves the church in the right direction.

Wound 9: Absence or loss of natural, freely given relationships and substitution with artificial/bought ones

Because of my bodily/intellectual impairment and/or functional limitation my life is filled with people who are paid to be with me, whether they be social workers, group home staff or day/vocational program workers. Research indicates that the average individual living in a group home is visited by someone not paid to be with him only once every 20-30 months. Here again, this can be at least partially attributed to the manner in which human service agencies provide their services. There are many alternative ways in which services could be provided that would increase the likelihood of the development of freely given relationships.

The church offers great potential for the development of many freely given relationships with persons with disabilities. These can occur at the church itself; however, they should also occur in the community. Community relationships can revolve around going to ball games or bowling or just a periodic visit to the group home. Churches also typically offer myriad opportunities for participation in social activities. To have a friend call and ask you to do something with him is something that far too many people with disabilities have not experienced.

Wound 10: Loss of control, perhaps even loss of autonomy and freedom

Because of my bodily/intellectual impairment and/or functional limitation, I am placed in settings that, although they are described as being for my benefit, are largely designed on the basis of administrative convenience. So, for example, adults living in a group home all go to bed at the same time, take showers on the same evening and watch the same program on the television. Simple things such as taking a walk in the community are often not possible because of the way in which staffing arrangements are made. Additionally, those who would attempt to offer freedom are stifled because of the changes that these freedoms cause in the lives of persons with disabilities. This includes aspects of religious freedom.

Autonomy and freedom are important aspects of life that the church can contribute to the lives of people with disabilities. They are provided the opportunity to eat too much, to talk too much, to walk around and just to experience life with less regulation. The first step in this is for the church to advocate for religious freedom in the lives of persons with various disabilities who might not experience such freedom because of the constraints their care providers place upon them in not allowing them to attend church.

Wound 11: Discontinuity with the physical environment and objects, (“physical discontinuation”)

Because of my bodily/intellectual impairment and/or functional limitation, I may not have access to the physical environment in ways that those without impairments do. These restrictions are blamed on my disability; however, they are more often due once again to issues of administrative convenience.

The church can provide people with disabilities with access to valued things in the environment, such as a personal Bible, a crucifix that one wears or displays on a wall and materials about upcoming programs. During worship services, people with disabilities may have access to participation in communion, with all that that entails in a given context. These types of access validate the person as being like everyone else, thereby giving them value.

Wound 12: Social and relational discontinuity, even abandonment

Because of my bodily/intellectual impairment and/or functional limitation, I may be abandoned by my family or by the larger society. Research indicates that nonreligious families are significantly

more likely to view the care of their family member as being the responsibility of the state and not their personal responsibility. Thus, people with disabilities end up having relationships only with people who are paid to be with them. At the same time, research also indicates that religious parents of children with disabilities feel supported by their personal faith, but not by their corporate faith (the church), which indicates that parents also experience relationship discontinuity and distancing.

The church offers great potential for participation in ongoing relationships and prevention of abandonment. When a person with a disability comes, he is greeted and welcomed and his name is called. Perhaps he has a nickname that causes laughter in those around him. People bring him a cup of coffee the way he likes it. These things may seem small, but they are proof of a relationship, proof of inclusion in the group.

Wound 13: Deindividualization, “mortification,” reducing humanness

Because of my bodily/intellectual impairment and/or functional limitation, I am viewed as less than fully human, because of my degree of dependence upon others, my functional limitations and the “drain” I am on society, among other things. Abortion is disdained by most in the Christian world, but even among Christians, exceptions may be made for disability. Because people with disabilities are not perceived as being fully human, they experience some of the deindividualization that has been described above. There are those in society who would ask the question, “What does it matter that someone who is not fully a person has no freely-given relationships or limited freedom or has his life restricted and managed?”

The church puts teeth in its pro-life position when people with all types of disabilities are present in the church. Even apart from a relationship with such people, they are recognized as valued simply by their presence. As church members develop relationships, they find that people with disabilities are people just like them. Growing up with people with Down syndrome around cannot help but take the fear of Down syndrome from you. It can't help but cause you to second guess the recommendations of physicians pushing for prenatal diagnosis and abortion. The church also needs to be active in speaking out against the deindividualization of people with disabilities in whatever form it is seen. This advocacy begins with the actual presence of people with disabilities in the church.

Wound 14: Involuntary material poverty, material/financial exploitation

Because of my bodily/intellectual impairment and/or functional limitation, I can expect people to strip me of what I have and prevent me from acquiring things. After all, what does it imply if I am a “ward of the state” and I own a TV or stereo or nice clothes? The state is required only to maintain a subsistence level of existence for me. This is “cold charity.” If I am victimized by staff that steal my possessions—well, that is just too bad because staff are hard to find. The question might be asked whether I would miss the stolen things anyway.

Although I myself may be poor, because I am a member of a church, I have access to the resources of the church. These resources evidence themselves in a variety of ways. Research indicates that churches provide money, food, clothing and education, among many other things. The church therefore has tremendous potential to minimize the wound of poverty. Additionally, presence in the lives of people with disabilities can assist in the prevention of financial exploitation. An extra set of eyes can work wonders.

Wound 15: Impoverishment of experience, especially that of the typical valued world

Because of my bodily/intellectual impairment and/or functional limitation, I may never have been to a restaurant or a ball game or a movie. If I do participate in these things, they are “special” events, not typical events. Because care providers are held to minimal standards, group home outings can literally be a once-a-month trip to the grocery store to get milk.

The kinds of typical experiences most people have can be provided via participation in churches. These include dinners out, social outings, service projects and so on. Typically, people will be involved in nonreligious service projects and assist only if they are asked. No wonder the range of experiences of those who participate in a church versus those who don't are significantly different!

Wound 16: Exclusion from knowledge and participation in higher-order value systems (e.g., religion) that give meaning and direction to life and provide community

Because of my bodily/intellectual impairment and/or characteristic functional limitations, I am excluded from religious groups. As a result of my lack of participation in such groups, I may lack moral guidance, am not privy to the solace and comfort faith in God might bring and as a result am excluded from participation in community and in society, as religious groups are the vehicle that many use to receive these benefits.

Through church participation, I learn that God loves me as I am, that I am not a mistake and that those who tell me that I am a mistake are wrong. I learn about Jesus— who he is, what he did and what that means to me. I learn about how to live. I learn about how God uses people like me to accomplish his purposes. I learn that if people are unkind to me, particularly in a church situation, that I am not wrong—they are wrong for rejecting me. I come to a place where I learn what it is to be loved and accepted by God through the love and acceptance I receive from those in the church.

Wound 17: Having one's life “wasted”; mindsets contributing to life-wasting

Because of my bodily/intellectual impairment and/or functional limitation, my life is wasted by those who are my care takers. I spend useless hours in day care or “vocational” settings, often due to the lack of imagination of my care providers. That these settings exist as they do provides insight into the minds of those who develop such programs, in terms of how they perceive people with disabilities.

When I come to church, I first learn that my life has value. I then learn that I have the potential to be of service to the church. Churches need to be wise in how they assign the “low hanging fruit” of service. People who have the ability to work with the children should be working with the children, not ushering. But for those to whom ushering is a challenge, challenge them with ushering or greeting or handing out programs. I may spend my week in adult day care, but on Sunday, I am an usher. I may make no money at all in my workshop all week, but on Sunday, I police the grounds to be sure that the grounds are looking beautiful. Other opportunities might also be imagined such that people see themselves as having responsibility that gives their life meaning.

Wound 18: Being the object of brutalization, killing thoughts and death making

Because of my bodily/intellectual impairment and/or functional limitation, society is increasingly seeking to end the “burden” of my life. Abortions occur to prevent “suffering” of those with congenital dis-

abilities, when in reality most of any suffering may be largely due to the way in which people are treated by society rather than from the disability itself. Authors write about how the future may lead to the limitation of health care access by those with disabilities.

As stated, the church can do tremendous good to reverse the trend toward eliminating persons with disabilities through abortion and other means by having such people present in numbers that minimally reflect their numbers in the community. The church also holds responsibility to speak up in defense of the lives of persons with disabilities and to teach regularly from the pulpit about the value of all life and the Christian's responsibility in affirming that value. Unfortunately, leadership is typically silent on these issues.

NOTES

1. Wolfensberger, W. (2000). "A Brief Overview of Social Role Valorization." *Mental Retardation*, 38(2), 105-123.
2. Wolfensberger, W. (1972). *Normalization: The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation.



Jeff and Kathi McNair are career special educators, and professors of special education. They have been involved in ministry to adults with intellectual disabilities for over 30 years. Kathi's area of expertise is students with learning disabilities. Jeff is the Director of the Public Policy Center for Joni and Friends, and also directs the Disability Studies Program at California Baptist University, one of the few graduate programs in disability ministry. He also directs the university's program in severe disabilities.