

Perspectives

Presidential Address 2005: Peace-Making Is the Answer: Spiritual Valorization and the Future of Our Field

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The address given by each president of the American Association on Mental Retardation (AAMR) is an opportunity to summarize the most important things one has learned in a career that culminated in the presidency of AAMR. It is also an opportunity to offer some advice about how to deal with the challenges of the present and future. My focus here is not on my professional journey as a physician and a child neurologist, nor will I review my research on carnitine deficiency and the treatment of epilepsy in persons with disabilities. I focus instead on my spiritual journey as a caregiver for individuals with disabilities and their families and share what I have learned so far from them and from others in our field. The great joy one gets from being in this multidisciplinary professional association (AAMR) is the chance to transcend one's own field (in my case, medicine) and to learn from people in many other diverse fields. Thus, I now know a little bit about a lot of things that I have learned from sharing with others in AAMR for the past 23 years. My intent here is to synthesize a variety of themes (some of which I know more about than others) into a coherent message that can be useful to us now and to those who will come after us.

The Spiritual Journey Begins

I was fortunate to begin my adult life as an undergraduate at the University of Notre Dame in the 1960s. As a biology major, I enjoyed every minute I spent in every biology class and lab, learning to love bugs and worms and acquiring the scientific background I would need in medical school. Notre Dame, however, also provided a nurturing spiritual environment in which to confront the great questions of life and to begin to work out personal solutions. I had already pretty much given up the immature faith of my childhood, and I was looking for something more meaningful to which I could com-

mit my adult life. I devoured readings and classes in philosophy, theology, and the humanities and hung out with a diverse group of students and teachers. One could not avoid confronting the fact of the Vietnam War, which was raging during this time. So it was that as a senior in 1969, I committed myself to pacifism and opposition to all war. I had found my inspiration in a Biblical text that became the guiding text for all of my life thereafter.

John wrote in his first letter to the new Christian communities of the time (1 John 4:16, using inclusive language): "God is love, and all who live in love, live in God, and God in them." This was a God I could believe in. The pastor of the church I attend wrote recently, "Faith is an activity because God is more of a verb than a noun." Thus, if God is *love*, this suggests that God lives in us through our acts of loving. We tend to think of God as pure transcendence, the ultimate infinite Being, a God in heaven to whom we pray, a distant and remote Other. This reading of "God is love," however, also means that transcendence exists through the act of transcending: God exists in us when we transcend our love for ourselves to love others as God has loved them. *Love*, like faith, is a verb that calls for action.

What kind of action? Christ taught that there are two commandments: first, to love God and second, to love your neighbor as yourself (Matt. 22: 37–40). In terms of action, Christ taught us to treat others as we would like them to treat us (Matt. 7: 12). This is, of course, the Christian expression of the Golden Rule, which can be found in all of the world's major religions (see, e.g., Teaching Values, 2005). We also know it as the secular moral requirement to "do unto others as you would have them do unto you." The Golden Rule provides the foundation for the related concepts of nonviolence and peace-making, which are the issues highlighted here.

Commitment to the Golden Rule means that we cannot inflict violence on others, because we would not wish to have violence inflicted upon us. This commitment to nonviolence is somewhat passive because it identifies what we will not do, but it is necessary for a moral life founded on the Golden Rule. The sixth commandment (Exodus 20:13) does not have an asterisk (“Thou shalt not kill, except when the government tells you to”), and the Golden Rule does not have an asterisk (“Do unto others as you would have them do unto you, except when you have more power than the other guy”). This is the reason I became a pacifist at the age of 21 and published my refusal to serve in the military in any capacity.

Peace-making is the active commitment based on the Golden Rule, because it describes what we should do to live a moral life. (I prefer the term *peace-making* because it is a word that calls for action.) Active peace-making includes initiatives to love others, treat others lovingly, and care for and heal those who are suffering. This is the reason I became a doctor. It also means we must oppose violence in all of its forms (including war, racism, and discrimination) and act to prevent them. I wore a white armband as a first-year medical student in 1970, when we student medics stood between the National Guard troops and the demonstrators protesting racism and war on New Haven Green and urged both sides to remain peaceful. When the National Guard fired tear gas at the demonstrators, we student medics retreated with the protesters and took care of those who were injured in the demonstration. The white armband I wore that night was as important to me as the white coat I wore in the hospital, and that experience as a peace-maker showed me why I wanted to be a doctor and what kind of doctor I wanted to be.

Attending AAMR annual meetings over the years, I witnessed numerous opening sessions with the usual military color guard presenting the flags. I vowed that if I were ever elected president and had the opportunity to plan the opening session, there would be no guns in my opening session. My opportunity came when I planned the 128th annual meeting in 2004 in Philadelphia, the City of Brotherly (and Sisterly) Love. Those of you who were there may recall that there were no guns and no military color guard in my opening session. Instead of the Star-Spangled Banner, we sang, “Let There be Peace on Earth, and Let it Begin With Me.”

Also in Philadelphia in 2004, I had the oppor-

tunity to share a panel on peace-making and non-violence with Wolf Wolfensberger, perhaps the only time he has ever (almost) agreed with a medical doctor about anything. He has rightly criticized doctors for their capacity for death-making, and in my presentation (summarized below), I showed how peace-making is the answer to death-making. Wolfensberger preferred to talk about nonviolence, which he argued was not the same as peace-making. He pointed out that not all peace-makers are non-violent, but I would counter that violent peace-making cannot be based on God’s love. Wolfensberger said that nonviolence means a willingness to suffer violence from others, a promise not to inflict it on others, and a commitment to value and care for those who have been wounded by violence. He said further that healing for wounded persons with disabilities begins with three messages: (a) you are valuable, (b) you are as valuable as any other person, and (c) you are loved by those around you. Wolfensberger and I both agreed that these messages are the foundation of peace-making.

To say that someone with disabilities is valuable is a radical notion. A young doctor who had practiced in Guatemala told me that her colleagues there referred to children with disabilities as *minos validos*, which could be interpreted to mean *children of minimal value*. Do we really mean that everyone is as valuable as everyone else? Is Oliver, the brother with profound disabilities whom Christopher de Vinck (1998) wrote about, really as valuable as Albert Einstein? Is a child with Down syndrome really as valuable as the Pope? The answer is yes, in a spiritual sense. This is the essence of the concept of spiritual valorization.

Spiritual Valorization

To understand how peace-making is the answer, we need to learn how to value other people. We can certainly value people on a religious basis. Many texts can be found in the Judeo-Christian Bible, the Talmud, and other sources to support this view. I am most familiar with Roman Catholic teaching and the papal elucidation of a “consistent ethic of life” that extends from conception to natural death. I am less familiar with similar teachings found in other religions, but even a cursory web-based search reveals ample material to support a universal religious basis for valuing people. Wolfensberger has shown that there is an empirical basis for valuing people based on their roles in society,

what he calls social role valorization. Many professionals in our field have taken his social role valorization training courses and accept this basis for valuing people. I have argued that there is an experiential basis for valuing people, which I have called “the three ways of looking” (Coulter, 2001). Because it demonstrates how to value people based on sharing the experience of their spirituality, I call it *spiritual valorization*.

Spiritual valorization is the fruit of the spiritual journey that began during my days at Notre Dame and Yale Medical School. It comes from my day-to-day attempt to live out a commitment to peace-making through 32 years of clinical practice as a physician. Only gradually did I begin to see that what I was doing during those innumerable doctor-patient encounters could be systematized into the “three ways of looking.” I learned some of it from a few of my medical teachers, who showed me how to connect with children who have neurological disabilities, but I learned most of this from the patients and their families whom I have had the privilege to care for over the years. Thus, it is experiential because it is based on my own experience as well as being grounded in the experience of understanding and sharing spiritual meaning with another person.

Spirituality is the essence of subjective self-hood and is expressed through individual, personal beliefs and statements of faith about the nature of one’s identity, the impact of one’s culture (including ethnicity, religious beliefs, and healing practices), one’s relationships of love (who we love and who loves us), and one’s sense of meaning and purpose in life. It can be religious, but it does not have to be. These three ways of looking at individuals demonstrate how people can share this sense of their spirituality. Obviously, one needs to have a sense of one’s own spirituality (as I have defined it) in order to be able to share it with another person.

The Three Ways of Looking at Individuals

The first look is to see the other person as a unique individual and try to understand their subjective sense of their own self-hood. As Gaventa (2001) has shown, it is the attempt to learn how the other person answers the spiritual questions, “Who am I? Whose am I? Where do I come from? What do I value in life?” It is more than compassion or empathy that require objectivity and distance, because this first look requires closeness and a willingness to embrace the other person’s subjectivity.

It is the attempt to look into the other person’s heart and soul. This first look, however, is necessary but not sufficient for the experience of spiritual valorization.

The key to spiritual valorization comes with the second look, which is *the attempt to see the other person as a human being just like myself*. Knowing what it means to me to be alive (from experiencing my own spirituality), I can try to understand what it means to the other person to be alive (from learning the other person’s experience of spirituality). I can then see how to value in the other person that which I value most for myself. As Crocker has pointed out (Rubin & Crocker, 2005), with this look we do not focus on the objective differences between us (such as differential abilities or exceptionality) but, rather, on the subjective essence and values that we all share. We then see that we must desire for others what we desire for ourselves, and we must protect for others what we would protect for ourselves, including the desire for life (which we protect through peace-making), the desire for liberty (which we protect through tolerance), and the desire for happiness (which we protect through advocacy). This second look conveys Wolfensberger’s message that “you are loved, you are valuable, and you are as valuable as any other person.” The key to valorization in this second look, however, is the understanding that we are all equal in the spirituality we share.

The third look is a special experience that comes when we least expect it and does not happen when we go looking for it. It is *the sense of universal spirituality that lives in every human being*. It can be considered a blessing or God’s grace that comes when we have made ourselves open to receive it through the first two looks. With the third look, we see in the other person the ground of all being and all existence, the transcendence that we may recognize as God Who is Love. It may be presumptuous to think that we can see the face of God with this look, but perhaps like Moses (Exodus 18:33), we can hope to see God’s splendor reflected in the eyes of another person—and that is enough for a lifetime.

Spiritual valorization and the three ways of looking are the fruit of the spiritual journey that sustained my professional career and brought me to the presidency of AAMR and provided me with the opportunity to publish this address. Now it is time to show how what I have learned from this life-long commitment to peace-making can help us respond

to the challenges we face today and will likely face in the future.

What Is The Question?

If peace-making is the answer, what is the question? In a broad sense, the question is the foundation of human society and ethics: “How should we act as moral agents in a diverse community of other people?” In a narrower sense, consistent with our roles as professionals in the field of disability, the question becomes: “How should we act today so that our actions will be viewed as moral by others, now and in the future?” Given the changing answers offered throughout human history, are there eternal truths that could provide an answer that would stand the test of time? Stated another way, we can ask: “How can we act so that professionals in the future will not feel the need to apologize for what we did in our time?”

Death-Making

In many historical reviews, authors have described how people with intellectual and other disabilities were not valued by society and how their devaluation led to actions that jeopardized their life, liberty, and happiness (Trent, 1994). These attitudes and actions persist, and we owe a debt to Wolfensberger for calling our attention to the impact of devaluation in modern society (Wolfensberger, 1994). He coined the term *death-making* to describe what society can do when it does not value persons with disabilities as I have shown above. There are at least four aspects of death-making that can be identified, and in the following discussion, I show how peace-making provides the only true answer to all of them.

Aspects of Death-Making

First, the medical model of disability viewed individuals with disabilities as inherently defective. The defect was within them, so they were less valuable than others in society who did not have disabilities. If the defect could not be fixed through education, training, or medical treatment, then the medical model allowed society to isolate defective individuals and prevent the spread of defective traits. Institutions that had been developed as centers for humane treatment sometimes became mere warehouses to remove persons with disabilities from society. Physicians and scientists used the theories

of eugenics to promote widespread sterilization of people with disabilities in order to prevent the birth of more supposedly defective individuals. Because people with disabilities were less valuable to society, health care providers were justified in restricting or denying them the medical resources they needed to live and to flourish.

The medical model of disability was replaced by the functional model in which disability is now viewed as a problem in functioning that reflects the interaction between personal impairments in structure and function, limitations in the ability to perform desired activities, and restrictions on the individual's opportunity to participate in society (World Health Organization, 2001). In 2004, I developed the community health supports model to show how this functional approach leads to health care that values and supports the community inclusion and participation of all persons with disabilities (Coulter, 2004). The core elements of peace-making—valuing and protecting everyone equally—can be found in this approach.

Second, people with disabilities were viewed in the past as being a social burden imposed on society. The costs of their care were a drain on society and consumed resources that could be better applied in other ways. Because they were less valuable, policymakers could justify denying them these resources. Indeed, their value was often measured by the cost of their care to taxpayers as a line-item in the public budget. This view of people with disabilities as a social burden is challenged by the concept of social role valorization, in which their true value to society is recognized. Indeed, the peace-making approach recognizes the gifts and contributions to society of all persons, including those with disabilities, who are valued equally as members of society. Proponents of a Rawlsian approach to justice would argue further that social resources should be directed particularly to people with disabilities in order to help them function more successfully. In this approach individuals with disabilities are viewed as opportunities for social betterment rather than a social burden.

Third, death-making is based on the idea that the very humanity of people with disabilities is limited or nonexistent. It sets up criteria to determine who is a human person and devalues those who fail to meet these criteria. According to this view (advocated by Singer and others, e.g., Kuhse & Singer, 1985), infants born with disabilities do not meet these criteria and, therefore, are not per-

sons who should receive life-sustaining medical treatment. This may be the starkest manifestation of death-making, because it leads to actions that truly result in death. Those who believe in peace-making reject the idea that anyone is less of a human person than another and recognize that everyone's personhood is equally valuable. In Swinton (2005), Hauerwas argued that the question of developing criteria for human personhood is fundamentally wrong-headed, because "We are all human creatures, created by God to be here and to be dependent on one another. No one's existence needs to be justified." He argued further that instead of seeing the presence of a disability, we should accept the disability of presence: "We are all here by God's grace and the task is to rejoice in our existence."

Fourth, those who support death-making accept the marginalization and objectification of people with disabilities as social facts rather than as problems to be solved. When we do not value the presence of people with disabilities in society, we allow them to exist at the margins of society. When we emphasize the ways in which they are different from us, we treat them as objects to be managed through public policies that are largely bureaucratic in nature. Peace-making is a rejection of the marginalization of people with disabilities and an argument for their full social inclusion as valued members of society who have important social roles. Spiritual valorization and application of the three ways of looking allows us to see this population subjectively as people just like ourselves and just as valuable. Social policy can then be based on recognition of our shared humanity instead of on bureaucratic strategies to manage problems. Crocker's theory of exceptional bioethics (Rubin & Crocker, 2005) is based in part on this subjective recognition of shared humanity and is an example of how peace-making can provide the answer to death-making in facing the issues confronting medicine today.

Peace-Making in Modern Society

A commitment to peace-making calls for action to respond to diverse problems that are present in modern society. The corollary commitment to nonviolence means that the peacemaker must oppose war in all of its forms. There is no such thing as a "just war." Even the Catholic Church has become squeamish about its "just war doc-

trine." In 1968, Pope Paul VI told the United Nations, "Never again war! War never again!" More recently, Pope Benedict XVI clarified that the church no longer supports the idea of nuclear deterrence. I am a long-time member of Pax Christi, the Catholic peace-making organization, which is an excellent resource for up-to-date information on this topic.

Peace-making is based on the commandment to love others as we love ourselves and on the Golden Rule. Peace-makers must, therefore, promote justice because, as Pope John Paul II said, "There can be no peace without justice." By justice we mean a world in which all people are valued and in which social resources are provided "to the maximal extent feasible" to help them flourish. Those of us who were blessed with resources through no merit of our own should help those who were denied those resources through no fault of their own, which is the essence of Rawlsian justice. We cannot all be Mother Teresa or Paul Farmer, but we can strive to emulate them and support public policies that assist other countries in need. The hundreds of billions of dollars being spent currently to fight the war in Iraq could be spent more effectively to promote justice around the world.

Indeed, a personal commitment to peace-making is probably more important than is political action, which ended the Vietnam War but did not change the hearts and minds of those in this country who choose to wage pre-emptive war today. I think we could accomplish more long-lasting positive change if we could encourage everyone to practice spiritual valorization on a daily basis.

Because peace-making celebrates the value inherent in all persons, it opposes all forms of racism and discrimination. Peace-makers argue that those whose social status benefits from society's discrimination against others must accept responsibility for what society has done on their behalf. As a white male, I am paid more than a woman who is doing the same work, and I do not have to worry about being pulled over for "driving while white." This is not by my choice but because I benefit from the racism and discrimination that is present in society. Accepting this responsibility could mean apologizing to those who are harmed by society's racism and discrimination, but any such apology would be empty unless it was accompanied by

peace-making actions to promote equality and justice for all.

As a peace-maker who was president of AAMR, I committed myself to help AAMR value and support people with intellectual and developmental disabilities. In January 2005, we officially endorsed the Universal Declaration of Human Rights for Persons With Intellectual Disabilities. In June 2005, we adopted our new policy on caring at the end of life, which conveys these values. As a long-time member of AAMR's Religion and Spirituality Division, I support their work to help all of us recognize and celebrate the gifts all people bring to the human community, especially those with disabilities. Some years ago AAMR officially endorsed the Community Imperative, which states that: "All people, regardless of the severity of their disabilities, are entitled to community living." Although my time as president is over, these AAMR policies and practices must continue to inform and guide our efforts to value and support all people with disabilities. I am well aware of my weaknesses, imperfections, and limitations, but I did everything I was capable of during my time as president to help AAMR succeed in these efforts.

Peace-Making in the Future

Looking back, we have seen how inhumanely society treated people with disabilities. Many of those who did so were physicians, exemplified by those who implemented the medical model to promote eugenics, sterilization, and euthanasia. We saw how peace-makers accept responsibility for things they oppose personally if they have benefited from the results of those actions. As a peace-maker and a physician who benefits from the advances of modern science and medicine, I accept responsibility for the inhumane actions of physicians in the past. In particular, as a physician in the field of disability, I acknowledge, accept responsibility, and express my regret for what physicians in the past did to people with intellectual and other developmental disabilities. It is, thus, entirely appropriate that I should apologize to those who were harmed by physicians in the past, which I have done and reiterate today. My apology is personal and does not reflect my past leadership within AAMR. It is based solely on my professional role as a physician and my commitment to peace-making action that promotes equality, jus-

tice, and spiritual valorization. This apology would be empty if I did not work to change things for the better, which I hope I have done during my time in AAMR leadership and which I will continue to do as long as I am able.

As I noted earlier, the question before us today can be stated thus: "How can we act so that professionals in the future will not feel the need to apologize for what we did in our time?" I believe that peace-making and spiritual valorization provide the only true answers to this question. Peace-making is based on the Golden Rule, which has existed for more than two thousand years and has stood the test of time. Spiritual valorization conveys the message that all people are valuable because they exist, and all are valued equally. The three ways of looking demonstrate how we can make this message a reality and how by doing so we commit ourselves to peace-making actions that promote the life, liberty, and happiness of all people with disabilities. If we love all people with disabilities as much as we love ourselves, and if we seek to do for them as we would have them do for us, then the actions we take based on these beliefs should be judged moral now and in the future. Looking back, we can see that the actions of our predecessors, which we deplore and regret, were not based on these beliefs. Looking to the future, we can promote and teach these beliefs to our students and to those who will come after us. Working together as peace-makers, we can help to build a more moral and just society in which all people are valued and supported to participate fully in human society throughout the world.

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