Jars of Clay: Disability in Intentional Christian Community

BY S. KAY TOOMBS

Living in an intentional Christian community offers a nurturing context in which it is possible to fully embrace the vulnerability that accompanies disability, to concretely enact our Christian beliefs with respect to the intrinsic worth of all human beings, and to affirm the value of all members of the community.

As a person who has lived with incurable neurological disease (multiple sclerosis) for more than half my life, and with permanent disability for many years,[1] I have been very aware of the many ways in which contemporary cultural values with respect to such things as independence, productivity, physical fitness, health, youth, beauty, and so forth, inevitably deepen the sense of vulnerability that accompanies debilitating illness and disability.[2] We live in a world that places inordinate value on autonomy and that soundly repudiates any signs of weakness and vulnerability. Thus the sick, aging, and those with disabilities find themselves isolated and marginalized, uncertain of their personal and social worth.

In these reflections, I will contrast contemporary social values with the countercultural perspective of intentional Christian community.[3] I will suggest that authentic Christian community offers an alternative culture with a radically different value system, thus offering a nurturing context in which it is possible to fully embrace the vulnerability that accompanies disability, to concretely enact our Christian beliefs with respect to the intrinsic worth of all human beings, and to affirm the value of all members of the community.

DISABILITY AND CONTEMPORARY VALUES

One of the most important barriers to retaining a sense of self-worth in the face of physical or mental disability is the overriding cultural emphasis on radical autonomy and self-reliance. There is a strong cultural message that we should be able to look after ourselves, make our own decisions, "stand on our own two feet." While personal responsibility is, of course, important, when radical independence is considered to be the ultimate value, dependence on others is negatively perceived as a form of weakness. As a consequence, those with disabilities (who include, of course, all those living with the limitations of debilitating illness or injury) are reluctant to admit their vulnerabilities, fearing they will be considered a "burden" on others. Paradoxically, this cultural emphasis on self-reliance may also engender reluctance on the part of others to offer assistance when the opportunity arises. My students have shared that, if they see a person in a wheelchair approaching a door, they are uncertain whether they should offer to hold the door, since they are afraid such an offer (and overt recognition of the other's limitations) may be considered offensive and "politically incorrect."

Indeed, when society places inordinate value on independence and self-determination, the act of serving another is often negatively conceived as a constraint that robs the caregiver of the radical freedom imagined necessary to achieve self-fulfillment. When caregiving is conceived in these terms, feelings of resentment inevitably arise on the part of the caregiver and incalculable feelings of guilt and self-recrimination on the part of the person receiving care. Thus, in our culture, those with debilitating illness sense they expect "too much" of others, elderly parents constantly worry that they will end up being a "burden" to their children who "have their own lives to live," and there is a widespread presumption that persons with disabilities are a drain on the lives of their able-bodied partners.

For those living with disability the loss of autonomy is also profoundly disturbing because of the cultural emphasis on "doing" as opposed to "being." In our society a person's worth is judged according to the capacity to produce (to be useful) or the ability to achieve a certain professional status. When we say to our children, "You can *be* anything you want to be," what we mean is that you can achieve worth through *doing*. Given this cultural attitude, a person who is unable "to do" not only feels diminished by the inability to engage in projects that are judged meaningful according to societal markers of "success," but he or she also feels unable to contribute anything of worth to others.

Recognizing that the assessment of personal worth has as much to do with "being" (or character) as it does with "doing" is a vital step in maintaining personal integrity and countering negative attitudes with respect to disability. As a woman with Parkinson's disease told me, "I always imagined that when I became a grandmother, I would *do* a lot with my grandchildren. Then I got Parkinson's." "However," she added, "now I realize that I can *be* for my

grandchildren." This was a very empowering realization for her. Similarly, a young woman with a severe congenital physical disability recently told me that she had graduated from law school two years previously and had not been able to get a job. Because of this circumstance, she felt she was not worth anything. Recognizing the importance of "being" versus "doing" was an epiphany for her. "Now," she told me, "I can see that I have personal worth apart from what I can do."

Cultural attitudes with respect to "health" also shape the meaning of disability. In our society we equate "health" with the complete absence of disease and freedom from *any* physical or mental limitation. Moreover, certain ideal standards of beauty, physique, physical strength, fitness, and vigor are often subsumed into this cultural concept of "health." This cultural perspective on "health" makes it difficult for people to accept many unavoidable aspects of being human. Thus, any form of disability is considered an affront—an unnatural and unacceptable state of brokenness—a view that intensifies the experience of loss of control, social alienation, and vulnerability.

Indeed, this perception of "health" and "brokenness" makes it difficult for people to even see beyond the physical manifestation of disfigurement or disability. In the eyes of the "able-bodied" there is the clear assumption that disability is incompatible with living a meaningful life. This prevailing attitude is well reflected in the experience of our friend Perry—a young father of four who died from Lou Gehrig's disease at the age of thirty-five. Emaciated and strapped into his wheelchair, Perry did not meet the worldly ideal of physical beauty and strength. One day a saleswoman, eyeing his physical condition, said to his wife, "I can't believe you've stuck with him!" In judging Perry's worth solely on the basis of outward appearance, this woman completely missed the fact that Perry was a loving father and husband who instilled lifelong values in his children and who is still remembered by all who knew him for his intelligence, humor, thoughtfulness, and steadfast faith even in his difficult circumstances.

I have experienced similar negative attitudes with respect to my disability. When strangers observe I am in a wheelchair, they make the immediate assumption that my situation is an essentially negative one, that I am unable to engage in professional activities, and that I am wholly dependent on others. On many occasions people have said to me, "Aren't you *lucky* to have your husband!" This statement was not so much a comment about my husband's character as it was a perception that my relationship with him was wholly one of burdensome dependence. Furthermore, people overtly treat me as dependent. When I am in a manual wheelchair, people invariably address remarks to my companion and refer to me in the third person, "Would *she* like us to move this chair?" This invariably occurs when we travel through airports. We roll up to the security barrier and the person at the barrier turns to my companion and says, "Can *she* walk at all?" My husband developed a standard response. He would say, "No, but *she* can talk!" These common

responses on the part of others reinforce the perception that disability reduces one's personal and social worth.

VULNERABILITY AND CHRISTIAN COMMUNITY

The experience of illness and disability (a circumstance that strikes all of us at one time or another without regard to worldly status or position) concretely and irrevocably shatters the cultural myth that we are self-sufficient, invulnerable, and in complete control of our lives. In disrupting all our involvements in the world, a problem with the body (or the mind) demonstrates our radical dependence upon our bodies, confronts us with our vulnerability and our limitations, forces us to recognize the fragility of mortality, and reveals to us our need for others. In those moments of vulnerability (even if they are short-lived), we come face-to-face with reality and comprehend in a profound way that the individualistic endeavor, so lauded in our society, is based on an illusion—a false perspective that shapes our views on independence and relationship, on death and dying, on disability and vulnerability, and, ultimately, on our understanding of the transcendent meaning of our existence.

In deliberately rejecting this illusory perspective, a Christian community embraces a radically contrasting paradigm that is grounded in the centrality of covenantal relationship. Rather than pursuing the societal goal of autonomy and self-reliance, we are called to live out our lives in relationship: relationship with God and with each other. This paradigm shift turns the cultural perspective on individualism versus relationship upside down and transforms the meaning of dependence and independence. In imitating the example of Jesus, the suffering servant, we are called to continually lay down our lives for one another: "No one has greater love than this, to lay down one's life for one's friends" (John 15:13). Since selfless

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love, rather than self-determination, is the cardinal value, caregiving (care of and for another) is not considered a burdensome obligation. Rather, it is a form of communion in which both caregiver and care-receiver affirm their mutual need for one another and participate in sharing the love of God. Furthermore, since we are committed to cooperation rather than competition and to setting aside selfish ambition, envy, and worldly success in favor of

love, humility, and service to others, our lives in community are built upon a basis of trust that enables us to share our vulnerabilities and needs without fear of condemnation from others. As a result, the vulnerability that accompanies the reductions of illness and disability is less a negative life circumstance than it is an opportunity to share in the miracle of relationship.

Living in community permits us to serve one another in very concrete ways: whether it be providing several days of after-birth care for young mothers, caring for elderly parents, assisting with the education of an autistic child, doing housework and garden chores for those who cannot do these things themselves, constructing a wheelchair ramp to make home access easier for a wheelchair user, providing twenty-four-hour care for a friend with Alzheimer's, or working together to give round-the-clock care to those suffering from terminal illness. We have found that these acts of service are not just valuable in and of themselves (although they are surely that), but they are of inestimable worth in bringing us into ever-deepening relationships of love for one another. When my husband was dying from oral cancer, fifteen ladies in our community volunteered to assist me in providing him with round-the-clock care for the last three months of his life. Others prepared our meals, families visited daily, young people came and sang for him, and friends prayed with us at the bedside. The deep relational bonds we formed during this time will never be broken.

Indeed, we have found that one of the fruits of Christian community and the rejection of self-centered values is the breaking down of artificial social barriers that separate on the basis of age, economic status, education, ethnicity, culture, appearance, or physical condition. Furthermore, since we live our lives in close relationship, it is only natural to come together to serve those who have a special need. When an elderly lady in our community was unable to sleep at night due to a terminal illness, young people volunteered to go regularly to her house and sing for her through the night and into the early hours of the morning. They have shared that this experience has impacted their lives in a profound way.

In serving one another on a daily basis, we recognize the undeniable fact that we all need one another. Rather than viewing ourselves as either dependent or independent, we affirm our *inter*dependence and celebrate the unique place that each member of the Christian community occupies in the living organism that is the body of Christ. As the Apostle Paul noted:

> Even so the body is not made up of one part but of many.
> Now if the foot should say, "Because I am not a hand, I do not belong to the body," it would not for that reason stop being part of the body. … But in fact God has placed the parts in the body, every one of them, just as he wanted them to be. …
> The eye cannot say to the hand, "I don't need you!" And the head cannot say to the feet, "I don't need you!" On the contrary, those

parts of the body that seem to be weaker are indispensable…. If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it.

1 Corinthians 12:14-15, 18, 22, 26 (NIV)[4]

In this context, rather than being marginalized as they are in the wider culture, those "with disabilities" are simply absorbed into community life and find a place of participation where their particular gifts are appreciated. Indeed, so powerful is this shift in perspective that, while writing these reflections, I have actually found myself hard-pressed to identify people in our community under the category of "persons with disabilities." I simply never think of these individuals as "disabled." Rather, I think of them only in terms of the irreplaceable part each plays in the relational context of our community life: the young man, paralyzed after breaking his neck, who has a pivotal role in the young people's outreach ministry in nursing homes; the child with Down's syndrome who joyfully participates in our children's choir; the young woman with a congenital physical anomaly who weaves, spins, and cultivates beautiful flowers using one hand; the extraordinary farmer who works with the horses and who, in other contexts, would likely be discounted as a "person with an intellectual disability"; and the autistic child who comes to all meetings and gatherings and who is gradually beginning to reach out to others.[5] I also realize that, since becoming a part of this community, I have not thought of *myself* as a person with a disability. It is not simply that no one here treats me in that way but also, in sharing my life, all are sensitive to any barriers that prevent my full participation in community activities. As an example, if there is no ramp providing wheelchair access into a person's house, arrangements will always be made for people to meet me there and carry me in and out of the premises.

A central tenet of Christianity is that, since we are made in the image of God, all human beings have intrinsic worth, regardless of any contingent circumstances. This shift in focus from *extrinsic* to *intrinsic* worth turns the cultural perspective on the importance of "doing" versus "being" on its head. The emphasis for the Christian is not so much, "How do I define myself by my role?" but, "How do I live out whatever role God has provided for me?" "What kind of a person am I?" Believers are called to be imitators of Christ, to develop Christ-like character. In stressing that the most important question is, "What kind of a person am I?" we affirm that qualities of character such as compassion, kindness, patience, humility, and courage relate to a way of being in the world that is not dependent on physical or mental abilities and that does not look to the world's criteria of success. This means, among other things, that it is possible to retain personal integrity no matter how severe the reductions of illness and disability are.

Furthermore, we are reminded that in the kingdom of God (as opposed to the "kingdom of the world") personal control, physical strength, beauty,

and human capability are not the criteria with which to measure a meaning-ful life. Rather, "we have this treasure in jars of clay to show that this all-surpassing power is from God and not from us" (2 Corinthians 4:7, NIV). Speaking of his own intractable disability, Paul also reminds us that in the radically distinct economy of the Christian life, God's power is made perfect in human weakness (2 Corinthians 12:9), for it is in weakness that we con-cretely feel our need for God and for each other.

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When I think of the val-ue of "being" reflected in these "jars of clay," I am re-minded of the many people I have known who, in the eyes of the world, would be considered profoundly dis-abled but who, by virtue of their character, had a power-ful impact on the lives of others. As one example, I think of Robert, a forty-nine-year-old father of five who became totally incapacitated due to a brain tumor. Yet, throughout his illness and dying, Robert continued to minister, not only to those who came under his pastoral care, but to his caregivers and to all who came in contact with him. Indeed, dozens of young people have testified that Robert's example of grace and fortitude has been a guiding influence in their lives.

In focusing on the centrality of relationship and sharing the daily chal-lenges of life, we see clearly that disease, suffering, disability, and death are givens and an integral aspect of our humanity. In accepting these givens in our lives, we affirm that central to the Christian message is the reality of the cross. The reality of the cross is at odds with the cultural understanding of autonomy. In imitating Christ, believers are called to relinquish absolute con-trol over their lives. Jesus' admonition is to "pick up your cross and follow me" every single day. Along the way we may well have to face the reductions of illness, suffering, and disability, and inevitably we will face the realities of aging and death. These reductions do not diminish one's worth as a human being. Consequently, those living with incapacitating illness and disability are not marginalized and separated from the community of the living, but rather they remain at the center of a web of intimate and supportive relation-ships that continue to affirm the value of their existence. Indeed, it has been our experience that those who are the most vulnerable among us—the dying—have been an incredible gift to all members of our community. In every case these individuals have pressed forward in faith and demonstrated that, no

matter how burdensome the physical circumstances, God's grace is sufficient for every need. We thus have a "cloud of witnesses" who have testified to the truth that one can die in dignity and in tremendous victory, even in the direst circumstances. They have helped all of us to overcome the fear of death that is so deeply rooted in the human psyche.

In speaking of the Christian community's response to the vulnerability of illness, Therese Lysaught contrasts two radically distinct ways of thinking and acting that are identified as either being a "friend of the world" (James 4:1-10) or being a "friend of God" (James 2:23).[6] To be a friend of the world means "to have the same mind, the same outlook, the same view of reality" as the world does.[7] It is, therefore, to buy into the contemporary values that guide actions and shape perceptions—including the emphasis on radical autonomy, productivity, health, youth, and beauty that causes us to marginalize and devalue those who do not meet these cultural ideals. To be a friend of God, on the other hand, is to share "God's mindset" and God's "way of being and acting in the world."[8] It is to live in such a way that we "proclaim this marvelous truth—that God exists, that God is true, and that, consequently, the fundamental context of existence is gift—open, abundant, for-the-other rather than against-the-other."[9]

In living a life based on the foundation stone of self-sacrificing love, and in affirming the centrality of relationship with God and with one another, the Christian community—the *ekklesia*—concretely witnesses to the world that it embodies those values and practices that characterize friendship with God. Responding positively to the vulnerability occasioned by disability, then, represents a particular opportunity for the community to proclaim "the marvelous truth" that God exists, that all human beings have inestimable worth, and that there is a larger wisdom that places disease, disability, suffering, and death within the context of a cosmic narrative of the power of love overcoming even the power of death.

NOTES

1 I was diagnosed with multiple sclerosis at the age of twenty-nine. Over the years my illness has affected my ability to see, to sense, to move, to maintain my balance, to sit up, to stand up, to walk, and to control my bowels and bladder. With regard to mobility, my disease has progressed through various stages necessitating the use of a cane, then forearm crutches, then a walker, and finally the full-time use of a manual or a motorized wheelchair, since I can no longer walk.

2 S. Kay Toombs, "Vulnerability and the Meaning of Illness: Reflections on Lived Experience" in Carol R. Taylor and Roberto Dell'Oro, eds., *Health and Human Flourishing: Religion, Medicine and Moral Anthropology* (Washington, DC: Georgetown University Press, 2006), 119-140.

3 I have been a member of Heritage Ministries for fourteen years. Our community has found its roots in the 500-year-old nonviolent Anabaptist tradition and has embraced a simple, agrarian lifestyle. This is a tradition that has best served our values and goals and that continues to guide our way of life. While, of course, we do not expect everyone to embrace our religious perspective, we have found that our intentional community provides a context in which all members of the community can live meaningful lives that maintain

a sense of integrity and wholeness. For more information about this community, see *www. homesteadheritage.com*.

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5 The parents of this child have been told by a professional who works with autistic children that the loving, caring, communal environment in which he is growing up is the perfect environment for an autistic child. In other circumstances parents pay many thousands of dollars to send their children to different professionals to work on particular problems, and even to camps where children can interact with animals. As helpful as these interventions may be, an autistic child is thus constantly being thrown into unfamiliar environments and different worlds. In the context of our community life, however, the child is always surrounded by brothers and sisters, adults and children with whom he is familiar, who relate to him and work with him as a part of the wholeness that characterizes our daily life. Nor is he marginalized and set aside with other autistic children.

6 M. Therese Lysaught, "Vulnerability within the Body of Christ: Anointing of the Sick and Theological Anthropology," in Carol R. Taylor and Roberto Dell'Oro, eds., *Health and Human Flourishing: Religion, Medicine and Moral Anthropology* (Washington, DC: Georgetown University Press, 2006), 159-182.

7 Luke Timothy Johnson, *The Letter of James: A New Translation with Introduction and Commentary* (New York: Doubleday/The Anchor Bible, 1995), 85, cited in Lysaught, "Vulnerability within the Body of Christ," 168.

8 Lysaught, "Vulnerability within the Body of Christ," 169.

9 Ibid.

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